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Healthcare gaps and inequities following hospitalisation for COVID-19 in Brazil's universal healthcare system: a patient-engaged survey of Long COVID healthcare needs, use and barriers

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Abstract

Background Long COVID (LC) is an infection-associated chronic condition (IACC) that tends to be neglected by healthcare systems. Studies of post-COVID healthcare utilisation find elevated levels of use but have mainly been conducted in high-income settings. In the context of Brazil's universal health system (SUS), our patient-engaged study aimed to map healthcare needs, use, and access barriers related to LC up to 24 months following COVID-19 hospitalisation, in the interest of informing health system planning for an equitable LC response.

Methods A cohort survey included a probabilistic sample of hospitalised COVID-19-confirmed individuals aged ≥ 18 , who had been discharged from public hospitals in Rio de Janeiro between December 2020 and November 2022. Socio-demographic and clinical data were collected, including self-reported LC symptoms, self-reported LC, healthcare needs, use, and access barriers.

Results In a sample of 556 participants, corresponding to an estimated population of 11,328 individuals, 50.0% (95%CI 44.3–55.6%) reported healthcare needs in the six months prior, due to new-onset or worsened conditions after COVID-19. Almost 45.0% did not complete high school, while 26.5% lived below the poverty line (~US\$6.85 per day), indicating a high proportion of socially vulnerable individuals. High prevalence of LC symptoms, self-reported LC, and new diagnoses were observed. Healthcare needs were associated with acute disease severity, number of LC symptoms, and new post-COVID diagnoses, including cardiovascular and kidney diseases, and endocrine and musculoskeletal disorders. Significant gaps existed between need and access to services, and part of the access to

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services involved substantial out-of-pocket expenditure. These gaps were particularly pronounced for specialised medical services, scans/imaging, post-COVID rehabilitation services, and mental healthcare. Despite a universal health system, those with higher monthly incomes (above R\$1,500 or ~US\$250) were more likely to have accessed specialised medical care.

Conclusions The SUS is not meeting the high need for LC healthcare, raising concerns about deepening health inequities. In Brazil, as elsewhere, LC joins other IACCs in becoming an invisibilised epidemic, with LC patients, especially those unable to pay for care, neglected amid general healthcare backlogs. A comprehensive pandemic response must include dedicated efforts to surveil and treat the long-term impacts of infection.

Keywords Post-COVID condition, Long COVID, Healthcare needs, Healthcare use, Access barriers, Healthcare inequities, SUS, Disparities

Background

Long COVID (LC), also known as post-COVID-19 condition, or post-COVID-19 syndrome, is an infection-associated chronic condition (IACC) comprising a wide range of symptoms that persist or develop after a SARS-CoV-2 infection and last at least three months [1, 2]. Despite the World Health Organization (WHO)'s estimation that LC affects 10–20% of people infected by SARS-CoV-2 [3], and high incidences of LC symptomatology in high-, and low- and middle-income countries (LMIC) [4–8], LC tends to be neglected by healthcare systems [9–12]. Globally, access to high-quality LC healthcare has been limited, with scepticism and stigma from medical professionals, limited medical training on IACCs, diagnostic difficulties, and limited specialist capacity amongst the many barriers patients face [1, 9, 12–15].

Yet many countries suffer from nil to limited surveillance of LC and little knowledge of the healthcare needs of COVID-19 patients after acute disease. Without knowledge of LC patients' healthcare needs, public healthcare systems are unable to allocate resources appropriately. In the interest of informing health system planning within Brazil's Unified Health System (*Sistema Único de Saúde* – SUS), this study examines healthcare needs and use related to LC, and barriers to healthcare access, for Brazilian patients up to 24 months after discharge from hospitalisation due to acute COVID-19. In doing so, over a follow-up period longer than most studies to date, we aim to equip public healthcare systems to better address LC patients' needs, support the quality of life of individuals, and mitigate the intensification of health inequities.

Long COVID in Brazil

Brazil has been significantly affected by the COVID-19 pandemic, and, consequently, by LC [8, 16–21], with a disproportionate impact on marginalised populations already facing challenges accessing quality healthcare [22, 23]. A 2023 national household survey indicated one in four Brazilian adults who had had COVID-19 developed LC [24], while a study tracking a socially vulnerable

population in the city of Rio de Janeiro for three months to two years post infection showed that only 20% fully recovered, and 26% and 32% experienced deterioration in functional status and quality of life, respectively [20].

LC emerged in Brazil while the universal and public SUS was still overwhelmed by the COVID-19 pandemic and accumulating unmet demands for routine healthcare [25, 26]. This context contributed to a delayed and limited response to LC. Between 2021 and 2023, LC-specialised SUS clinics were established in a few major cities, and guidelines for “post-COVID conditions” were issued [27–29], which underlined the ‘gateway’ role of primary healthcare [1, 30–32]. Over time, some LC-specialised clinics were closed while, paradoxically, LC patients' need for care continued to be invisibilised within the SUS [9]. In Brazil, challenges common globally (scepticism, lack of IACC training, diagnostic difficulties, limited specialist capacity) are compounded by an overburdened health system, inadequate LC detection and surveillance to inform resource allocation, poor care coordination including unclear referral processes to specialist LC services, and professionals' lack of knowledge of LC and its severity [9].

Public, accessible healthcare for LC is essential to combating socioeconomic and health inequities – hence our focus on SUS patients in this study. Without appropriate care, LC patients' health will deteriorate, negatively impacting their quality of life and capacity to work [33, 34]. Moreover, *early* identification and management of LC could play a critical role in alleviating the disease burden for both patients and the healthcare system [35].

An urgent need for knowledge about LC healthcare needs and access gaps

Studies in high-income countries extending into 2023 found increases in healthcare use up to 22 months after acute infection [35–40]. Evidence from these settings indicates increased healthcare utilization amongst people with LC compared to other adults [31, 32] (49% greater utilization in one UK study [40]) and that patients with LC are more likely to report financial and non-financial

barriers to care [14]. However, research into the healthcare needs of people with LC is still in its early stages, particularly in LMICs and low-resource settings, where support systems are already heavily burdened [41].

In this study, we aimed to address the research question: what are the healthcare needs, uses, and barriers to healthcare access for people with LC who were formerly hospitalised for COVID-19 in the city of Rio de Janeiro? Secondly, we also aimed to address questions on factors associated with healthcare needs and utilization identified. Low public and professional LC awareness, challenges gaining LC diagnoses in the local context, and recognition that post-COVID new diagnoses, such as cardiovascular disease, could also be related to COVID-19 [36], led us to a comprehensive approach to data collection to identify LC, including presence/number of LC symptoms, self-reported LC, new diagnoses potentially related to COVID-19, as well as LC diagnosis by a professional. Distinguishing healthcare *need* from healthcare *use* was also important, as people may not be able to access all the healthcare they need; thus our study includes patients' self-reported health service needs as well as the actual use of those services, and we consider the discrepancy between the two to indicate a healthcare access gap. Recognising the multi-level factors shaping healthcare utilisation [42], we also examine associations between individual socio-demographics and healthcare need and use, aiming to contribute to a deeper understanding of the disparities in access and the challenges in obtaining appropriate care faced by people living with LC.

Methods

This study is part of a comprehensive mixed-methods project involving a patient-engaged, interdisciplinary, and international collaboration [43]. Our patient-engaged study design benefits from the LC patient researchers' scientific and experiential insights in this rapidly changing field [43]. The quantitative component surveyed patients after discharge from COVID-19 hospitalisation in the SUS in Rio de Janeiro City, Brazil, to estimate LC prevalence, impacts on patients, and related healthcare needs, use, and access barriers. This paper reports on the survey findings concerning healthcare needs, use, and access. The survey design [43] and protocol [44] were previously published. We followed the STROBE guidelines for reporting observational studies [45].

Study design and population

We developed a cohort survey study with patients aged at least 18 years who were discharged from SUS hospitals following acute COVID-19 (confirmed by PCR test or clinical diagnosis) from December 2020 to November 2022. The study population was stratified into four

discharge cohorts: those recruited and surveyed at six, 12, 18, and 24 months post-discharge.

Sampling

The study relies on a two-step probability sample in which municipality, state, and federal public hospitals were selected in the first stage and COVID-19 hospitalised patients in the second stage. Fifteen hospitals participated in the study.

The total sample size was defined to estimate a minimum proportion of 3% ($P_{\min}=0.03$), with a relative error of no more than 0.5% at a significance level of 5%, implying a 95% confidence interval ranging from 1.5% to 4.5%. Sample size was allocated among the participating hospitals proportionally to their size (i.e., the number of patients surviving hospitalisation), ensuring a minimum of five patients per hospital. The hospital patient sample size was then allocated among its four cohorts proportionally to the number of survivors in each cohort.

The patients were selected using a simple inverse sample procedure from a non-anonymised Influenza Epidemiological Surveillance Information System database (*Sistema de Informação da Vigilância Epidemiológica da Gripe – SIVEP-Gripe*) within each hospital and the four post-discharge cohort strata. Patients were sorted in a random order for sequential recruitment.

Data collection

We employed a structured questionnaire [44] specifically designed for the study through a patient-centred, collaborative process oriented to comprehensively capture the long-term impacts of COVID-19, enabling the participation of a racially and economically diverse sample and those with severe disabilities [43, 44].

Participants were recruited via telephone from November 2022 to August 2023 using the available SIVEP-Gripe contact information. If patients appeared in multiple cohorts due to reinfection, the oldest cohort was utilised. Patients transferred between hospitals during a COVID-19 hospitalisation event remained in the sample from the hospital where they were selected; however, the entire hospitalisation period was considered in the study.

The selected patients (or their proxies) were informed about the research's nature and objectives and invited to participate. Where participants had difficulties responding to the survey directly (e.g., due to disabilities), we invited people close to them (e.g., spouse, daughter/son, or caregiver) who could answer the questions on their behalf. Surveys were conducted via telephone or video call and scheduled at the respondents' convenience. The interviewers registered the answers on the RedCap® Platform.

Although the study also involved collecting data from participants who had died between the discharge and

recruitment, this paper includes only living participants. Some analyses were further restricted to those who reported needing healthcare in the six months preceding the interview for conditions that emerged or worsened following COVID-19.

Variables of interest

As baseline data before the COVID-19 event, we collected demographic, socioeconomic, and lifestyle variables in addition to comorbidities, work status, and vaccination status. The questionnaire also included measures of clinical progress since discharge, such as persistent symptoms, self-reported LC, new onset or worsened comorbidities, and SARS-CoV-2 reinfections, in addition to current employment situation, income, and vaccination status. The questionnaire also included questions assessing perceived healthcare needs, care received, whether in the SUS or private sector, and barriers to accessing health services—the central object of this study.

Questions about healthcare needs and usage were worded to account for the low levels of LC awareness and limited access to formal diagnoses of LC; thus, we asked patients if, in the last six months, they had experienced a need for a health service due to a ‘condition that appeared or worsened after COVID-19’. Reflecting our theoretical framework and patient-centred design, only participants who perceived a need for a service were asked questions about its use and barriers to accessing it.

Regarding the need for and use of health services, access to 10 types of health services (i.e., primary health care appointments, hospitalisation/emergency, post-COVID clinic/rehabilitation service, specialist appointments, mental health care, alternative medicine, pharmacy, home healthcare/aid, laboratory tests, and imaging exams) was assessed. Participants were first asked if they needed a given service. If the answer was positive, follow-up questions assessed their actual use, whether in the private sector or SUS, and barriers to accessing the needed service via SUS. Out-of-pocket expenses by patients or their families for tests, medicines, or clinical visits in the previous month were also registered. Additionally, we asked whether participants had received assistance from a healthcare professional for care coordination (called ‘care management’ in the SUS context) and, separately, about the need and access to support from social workers.

Through a patient-engaged approach, survey testing, interviewer training, and regular meetings, the interviewer team ensured patient-centredness, alignment, and consistency in the questionnaire application. In addition to data from the questionnaire, we collected indicators of the severity of the hospitalisation from the SIVEP-Gripe database (e.g., use of ventilatory support and admission to an intensive care unit (ICU)).

Analyses

Considering the complex survey design, we accounted for the sample variables – selection cohort strata, primary sampling units, and sample weights – in all analyses, employing procedures of the SAS® statistical package oriented toward complex survey data. Population estimates are provided.

Descriptive statistics included absolute and relative frequencies for categorical variables and mean, standard deviation, and quartiles for numerical variables. We show the characteristics of the estimated population alive in the study recruitment and with post-COVID healthcare needs in the previous six months for a condition that appeared or worsened after COVID-19. We also provide population estimates for patients requiring specific types of health services and, amongst those expressing needs, the use of those services and the distribution of service use in the SUS versus the private sector. Descriptive statistics also focus on the access barriers to specific services and out-of-pocket expenses for tests, medicines, and clinical visits in the previous month.

We used logistic regression models to identify factors associated with healthcare needs and utilisation in the six previous months for conditions that appeared or worsened after COVID-19.

We first hypothesised that reported needs for healthcare in general, and for eight specific services (out-patient primary healthcare, hospital/emergency care, post-COVID clinic/rehabilitation services, specialised medical care, mental healthcare, pharmacy, laboratory exams, and scan/image exams), would be associated with clinical variables, such as hospitalisation severity and the presence of post-COVID conditions (operationalised as persistent symptoms, LC self-report, LC formal diagnosis by a professional or other new diagnoses) as well as age, gender, race, and education. We ran nine separate logistic regression models to assess the association between these clinical and demographic variables and each healthcare service need.

Then, we narrowed our analysis to two specific services, specialised medical care and scans/imaging, selected because of high demand and anticipated access difficulties, to identify factors associated with utilisation and utilisation in the private sector (vs. SUS), among those who needed and used them, respectively.

Our hypotheses were informed by Andersen’s behavioural model of healthcare utilisation, in which predisposing characteristics (i.e., demographic and social factors), enabling resources (i.e., economic factors), and individual perceptions or professional evaluations of need shape individual healthcare utilisation [42].

Missing data were explicitly presented in the descriptive results and included in the reference categories for the multivariable analyses.

Results

The final study sample comprised 651 individuals. The response rate was 53.2% of patients (or their proxy) whom we could contact. Among the 651 individuals, 95 had died between discharge from the hospital and the study recruitment/interview (Figure 1). Accounting for sample weights, the sample of 651 individuals corresponded to 12,936 persons discharged from hospitalisations for COVID-19 in public hospitals in Rio de Janeiro from December 2020 to November 2022 [44], predominantly distributed in the 24 and 18-month cohorts.

The sample of 556 individuals alive at the interview corresponded to an estimated population of 11,328 persons, 54.8 years old on average, of which about 54.0% were men and 46.0% were women. Regarding racial identity, 47.7% were estimated to be pardo (mixed race), 35.2% were white, and 14.7% were black (Table 1). Almost 45% had not completed high school, and approximately 26.5% were living below the poverty line (approximately US\$6.85 per day) (Table 1), indicating a significant level of socio-economic vulnerability.

Reported healthcare needs and symptoms

Data show a substantial need for healthcare services. About half the individuals in the study population (5,662 individuals, 50.0% (95% CI 44.3–55.6%)) were estimated to have needed healthcare for health conditions that appeared or worsened after COVID-19; the majority, about 18 or 24 months after COVID-19 hospitalisation discharge. This figure is lower than the percentage of people estimated to have at least one persistent LC symptom (71.3% (66.3–76.2%)) and higher than that of people estimated to self-report LC (39.3% (34.2–44.4%)) (Table 2).

Among those with healthcare needs, compared to the overall population of COVID-19 discharged patients still alive in the study recruitment, a higher proportion of individuals were estimated to self-report LC or new diagnoses of health problems such as cardiovascular diseases and endocrine disorders (Table 2). Those who needed healthcare were also estimated to present a higher relative frequency of LC symptoms than the overall population, with fatigue, post-exertional malaise, joint pain, sleep disturbance, and cognitive disturbances most prevalent in both groups (Table 2). Additionally, they were estimated to be more likely to report feeling anxious and little interest/feeling down.

Healthcare use and healthcare access gaps

Table 3 presents absolute and relative frequency estimates of the need for, use of, and use of services in the SUS vs private sectors among individuals requiring healthcare for a condition that emerged or worsened after COVID-19 ($N=5,662$).

The services estimated to be the most needed were specialised medical services (76.5% (69.7–83.3%)), pharmacy (76.5% (69.4–83.6%)), laboratory exams (73.3% (65.7–81.0%)), outpatient primary care (72.6% (65.1–80.1%)), and scans/imaging (61.6% (53.6–69.7%)). Examining the utilisation estimates of these services among those needing them, 81.7% (75.4–88.0%) used specialised medical services, and among them, 44.7% (34.5–54.9%) in the SUS; 90.4% (85.0–95.7%) used pharmacy, among whom 61.5% (52.3–70.6%) exclusively in the SUS. Among persons needing laboratory exams, 92.1% (87.4–96.8%) were estimated to use the service, with 68.9% (59.7–78.1%) in the SUS. Most individuals in the population who needed outpatient primary care (89.2%; 84.2–94.2%) were estimated to access it, 95.1% (91.0–99.2%) of whom accessed it via the SUS. Regarding scan/image exams, 84.1% (77.9–90.4%) of those with their need were estimated to use, and, among them, 61.8% (50.1–73.5%) in the SUS.

The need for hospital/emergency services was estimated to be lower (33.4%; 26.0–40.8%), but of people who needed this service, 95.8% (91.4–100.0%) were able to access it, mainly in the SUS (94.6%; 88.9–100.0%). Complementarily, Table 2 shows that 10.1% (5.3–14.8%) of the population needing healthcare were estimated to have used inpatient care for possible COVID-19 complications in the previous six months.

Mental healthcare and post-COVID rehabilitation services were estimated to be needed by 22.8% (16.2–29.4%) and 17.4% (11.3–23.5%) of those needing healthcare, respectively. Access to mental healthcare was estimated to be reached by 56.9% (40.1–73.6%) of the population needing it, most of whom through the private sector (70.9%; 51.9–89.8%), while access to post-COVID rehabilitation services was reached by only 52.3% (33.3–71.3%) in need, predominantly in the SUS (69.8%; 38.7–100.0%). At the same time, our findings point out low awareness of the existence of post-COVID clinics in the SUS, as participants were surprised in the interview about it.

Seven of the 10 types of health services considered were accessed mainly in the SUS, particularly for outpatient primary care and hospital/emergency services. The use of services in the private sector was especially relevant for necessary specialised medical care and mental healthcare.

Only 14.0% (8.7–19.3%) of those needing healthcare were estimated to receive clinical care management support from healthcare units. Regarding support from social workers, estimates suggest that 11.6% (6.6–16.5%) needed and accessed it, and 6.4% (2.7–10.0%) needed but did not access it.

Out-of-pocket expenses were estimated to be made by 50.1% (42.3–57.9%) of those in the population who needed healthcare: 83.7% bought medicines/pharmacy products not delivered/available in the SUS, with a mean

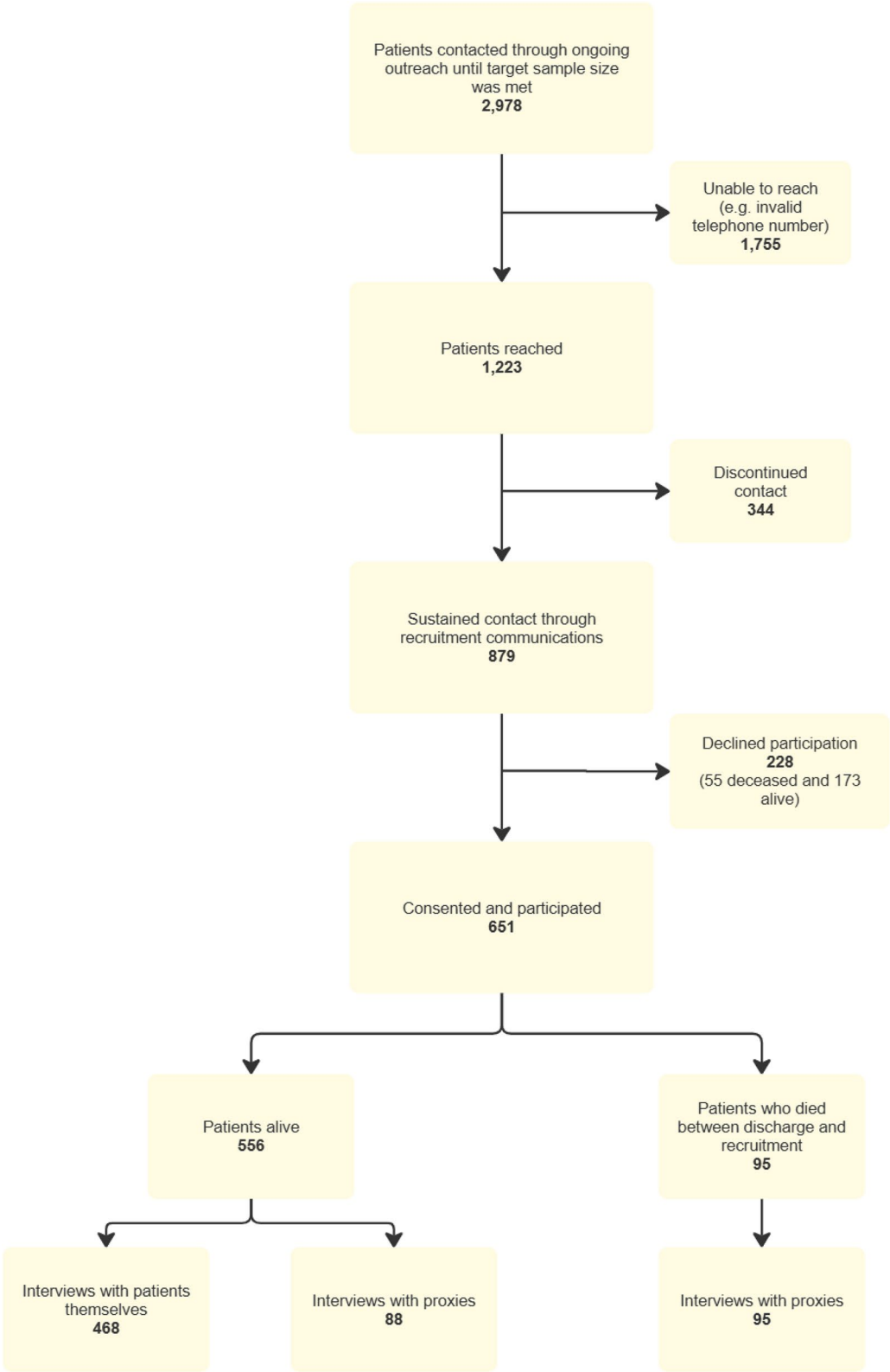


Fig. 1 Flowchart concerning contact attempts in the recruitment process for the study

Table 1 Estimated characteristics of the population alive in the study recruitment, and with post-COVID healthcare needs

Variable	Population alive at study recruitment (N = 11,328)			Population with healthcare needs (N = 5,662)		
	N	%	95% CI	N	%	95% CI
Age at hospital admission						
18–29	583	5.1	2.7;7.6	104	1.8	0.0;3.7
30–39	1,489	13.1	8.7;17.5	773	13.6	6.7;20.6
40–49	2,168	19.1	14.8;23.5	1,221	21.6	15.0;28.2
50–59	2,681	23.7	19.3;28.1	1,490	26.3	19.6;33.0
60–69	2,306	20.4	16.3;24.4	1,038	18.3	12.9;23.8
70 +	2,101	18.5	14.0;23.1	1,037	18.3	11.1;25.5
Gender						
Cis woman	5,187	45.8	40.3;51.3	2,921	51.6	43.0;60.1
Cis man	6,082	53.7	48.2;59.2	2,697	47.6	39.1;56.2
Not listed	14	0.1	0.0;0.4	-	-	-
Preferred not to answer	45	0.4	0.0;1.1	45	0.8	0.0;2.1
Race/color						
White	3,989	35.2	30.0;40.4	1,909	33.7	26.3;41.1
Black	1,670	14.7	11.1;18.4	965	17.0	11.4;22.6
Mixed race	5,406	47.7	42.3;53.1	2,609	46.1	38.2;54.0
Asian	73	0.6	0.0;1.5	46	0.8	0.0;2.4
Indigenous	103	0.9	0.7;1.2	88	1.6	1.4;1.7
Preferred not to answer	87	0.8	0.0;1.7	45	0.8	0.0;2.1
Marital status						
Single	2,485	21.9	17.2;26.6	1,285	22.7	15.5;29.9
Married/Civil partnership	6,244	55.1	49.8;60.5	3,089	54.6	46.4;62.7
Separated/Divorced	1,309	11.6	8.3;14.8	609	10.8	6.0;15.5
Widow	1,244	11.0	7.7;14.3	680	12.0	6.9;17.1
Unknown	46	0.4	0.0;1.0	-	-	-
Education						
No school	388	3.4	1.6;5.2	247	4.4	1.2;7.5
Middle school uncompleted	2,885	25.5	20.5;30.4	1,619	28.6	20.3;36.9
Middle school	1,613	14.2	10.9;17.6	627	11.1	6.8;15.3
Graduated from High School or equivalent	5,058	44.7	39.3;50.1	2,471	43.6	35.4;51.9
Bachelor's degree	1,109	9.8	6.1;13.4	556	9.8	4.4;15.2
Postgraduate degree	161	1.4	0.1;2.8	85	1.5	0.0;3.5
Unknown	114	1.0	0.1;1.9	58	1.0	0.0;2.4
Occupation at interview						
UNPAID Domestic/caregiving worker	748	6.6	4.1;9.1	395	7.0	3.2;10.8
PAID Domestic/caregiving worker	245	2.2	0.8;3.6	117	2.1	0.0;4.2
Private sector employee	2,051	18.1	13.6;22.6	1,035	18.3	11.4;25.2
Public sector employee	311	2.7	1.1;4.4	199	3.5	0.6;6.4
Self-employee	2,447	21.6	17.1;26.1	895	15.8	10.2;21.4
Informal worker	260	2.3	0.6;4.0	141	2.5	0.1;4.9
Student	225	2.0	0.0;4.2	179	3.2	0.0;7.2
Retired/Receiving a pension	3,550	31.3	26.4;36.3	1,851	32.7	24.7;40.7
Unemployed	1,490	13.2	9.7;16.6	850	15.0	9.5;20.5
Monthly family per capita income (R\$) at the interview						
< 200	358	3.2	1.2;5.1	206	3.6	0.8;6.5
200–637	2,635	23.3	18.9;27.6	1,423	25.1	18.5;31.8
638–999	1,484	13.1	9.7;16.5	795	14.0	8.5;19.6
1000–1499	2,421	21.3	16.6;26.0	1,340	23.7	16.1;31.2
1500–1999	1,341	11.8	8.2;15.5	818	14.4	8.8;20.1
2000–2999	1,229	10.8	7.3;14.4	397	7.0	2.2;11.9
≥ 3000	464	4.2	1.8;6.5	142	2.5	0.6;4.4

Table 1 (continued)

Variable	Population alive at study recruitment (N = 11,328)			Population with healthcare needs (N = 5,662)		
	N	%	95% CI	N	%	95% CI
Not informed	1,395	12.3	9.5;15.2	541	9.6	6.1;13.0
Tobacco smoking						
Smoker	579	5.1	2.7;7.5	281	5.0	1.6;8.3
Former smoker	2,252	19.9	16.2;23.6	1,090	19.3	14.4;24.1
Not smoker	8,447	74.6	70.3;78.8	4,253	75.1	69.4;80.8
Preferred not to answer	50	0.4	0.0;1.1	37	0.7	0.0;2.0
Physical Activity						
Yes	5,012	44.2	38.9;49.6	2,896	51.2	43.3;59.0
No	6,278	55.4	50.1;60.7	2,728	48.2	40.4;56.0
Unknown	38	0.3	0.0;1.0	37	0.7	0.0;2.0
COVID-19 vaccination status before hospitalisation						
Not vaccinated	6,829	60.3	55.4;65.1	3,748	66.2	59.3;73.1
Only one dose (AstraZeneca, Pfizer, Sinovac)	1,432	12.6	9.5;15.8	583	10.3	6.0;14.6
Two doses (AstraZeneca, Pfizer, Sinovac) or one dose Janssen	996	8.8	5.9;11.6	490	8.7	5.1;12.2
1 Booster	584	5.2	2.5;7.8	233	4.1	0.0;8.2
2 Boosters +	1,240	10.9	7.6;14.3	536	9.5	4.8;14.1
Preferred not to answer	43	0.4	0.0;1.0	-	-	-
Unknown	204	1.8	0.6;3.0	72	1.3	0.0;2.7
COVID-19 vaccination status at the interview						
Not vaccinated	313	2.8	1.1;4.4	221	3.9	0.9;6.9
Only one dose (AstraZeneca, Pfizer, Sinovac)	274	2.4	1.3;3.6	151	2.7	1.4;4.0
Two doses (AstraZeneca, Pfizer, Sinovac) or one dose Janssen	1305	11.5	7.7;15.3	755	13.3	7.5;19.2
1 Booster	1774	15.7	11.4;19.9	861	15.2	8.7;21.8
2 Boosters +	7493	66.2	60.8;71.5	3,548	62.7	54.8;70.6
Preferred not to answer	134	1.2	0;2.8	91	1.6	0.0;4.5
Unknown	35	0.3	0;0.9	35	0.6	0.0;1.9
Comorbidities prior to COVID-19						
Arterial hypertension	5,847	51.6	46.3;56.9	3,219	56.9	48.9;64.8
Obesity	2,912	25.7	20.7;30.7	1,645	29.1	21.6;36.6
Diabetes	2,779	24.5	20.2;28.8	1,426	25.2	18.4;32.0
Heart disease	1,499	13.2	9.1;17.4	922	16.3	9.3;23.3
Neurologic disease (epilepsy, migraine, etc.)	1,236	10.9	7.6;14.2	615	10.9	6.1;15.6
Mental health conditions	1,142	10.1	6.9;13.3	733	12.9	7.4;18.5
Sequelae from other viral infections	1,033	9.1	5.9;12.3	450	7.9	3.4;12.5
Rheumatologic disease	899	7.9	5.2;10.6	447	7.9	4.0;11.8
Kidney disease	794	7.0	4.7;9.4	421	7.4	3.8;11.0
Asthma/bronchitis	872	7.7	4.8;10.6	592	10.5	5.5;15.4
Pulmonary disease (COPD, emphysema)	535	4.7	2.8;6.7	363	6.4	3.0;9.8
Immunodepression/immunodeficiency	531	4.7	2.2;7.1	292	5.2	1.8;8.5
Cancer	499	4.4	2.2;6.6	205	3.6	0.5;6.8
Chronic liver disease	412	3.6	1.3;6.0	264	4.7	0.3;9.0
Osteoporosis	311	2.7	1.3;4.2	202	3.6	0.0;3.6
Hematological disease	287	2.5	0.8;4.2	220	3.9	0.7;7.1
Tuberculosis	136	1.2	0.2;2.2	100	1.8	0.0;3.6
Asplenia (absence of spleen)	28	0.2	0.0;0.5	8	0.1	0.0;0.4
Number of comorbidities previous to COVID-19						
0	2,560	22.6	18.0;27.2	1,103	19.5	12.9;26.1
1	3,029	26.7	22.1;31.3	1,438	25.4	18.6;32.2
2	2,509	22.2	17.9;26.4	1,191	21.0	15.0;27.1
3	1,602	14.1	10.5;17.8	875	15.4	9.6;21.3

Table 1 (continued)

Variable	Population alive at study recruitment (N = 11,328)			Population with healthcare needs (N = 5,662)		
	N	%	95% CI	N	%	95% CI
4	893	7.9	5.1;10.7	549	9.7	5.3;14.1
≥ 5	733	6.5	3.7;9.3	506	8.9	4.2;13.7
ICU use during COVID-19 hospitalisation						
Yes	3,529	31.2	25.7;36.6	2,060	36.4	28.3;44.5
No	7,707	68.0	62.6;73.5	3,579	63.2	55.1;71.3
Unknown	92	0.8	0.1;1.5	23	0.4	0.1;0.8
Ventilatory support use during COVID-19 hospitalisation						
Yes, invasive	585	5.2	2.3;8.1	328	5.8	1.7;9.8
Yes, non-invasive	8,982	79.3	74.7;83.9	4,670	82.5	76.3;88.6
No	1,539	13.6	9.4;17.8	615	10.9	5.6;16.1
Unknown	222	1.9	0.8;3.1	49	0.9	0.0;1.8

of R\$380 (Brazilian *reais*) and median expense of R\$247 (corresponding to 28.8% and 18.7% of the minimum wage, respectively); 46.4% paid for clinical visits, corresponding grossly to a mean of R\$414 and median of R\$194 (31.4% and 14.7% of the minimum wage); and 31.6% paid for exams, with a mean of R\$487 and median of R\$202 (36.9% and 15.3% of the minimum wage) (Supplementary material 1).

Barriers to healthcare access

The most frequently reported barriers to accessing SUS services were the long waiting time to be seen and the difficulty of scheduling an appointment (Table 4). Long waiting times were especially noted for imaging diagnoses, specialised medical services, and outpatient primary care visits. Not being able to make an appointment was reported mainly for mental healthcare and specialised medical services, with the non-availability of medicines in pharmacy services also frequently mentioned. Financial costs were indicated as an access barrier, mainly for rehabilitation services.

Factors associated with post-COVID-19 hospitalisation healthcare needs

Table 5 shows the estimated parameters from the logistic regression models explaining needs for health services in general, outpatient primary care, hospital/emergency care, post-COVID/rehabilitation service, specialised medical services, mental healthcare, pharmacy, laboratory, and imaging services.

Regarding severity of COVID-19 hospitalisation, those requiring ICU use were more likely to report needing specialised medical care (OR=2.27; 1.28-4.05) and laboratory exams (OR=2.45; 1.37-4.36). Those who needed ventilatory support during hospitalisation were more likely to report needing laboratory exams (OR=2.32; 1.15-4.67) and mental healthcare (OR=2.99; 1.09- 8.18).

In all models presented, the higher the number of reported LC symptoms, the higher the odds of reporting healthcare needs. Self-reported LC (i.e., participants said they believed they had LC) was associated with increased odds of needing hospital/emergency care (OR=2.60; 95%CI 1.14-5.94) and specialised medical care (OR=2.14; 1.17-3.92).

Also, Table 5 shows the higher odds of healthcare needs associated with the presence of new-onset conditions (cardiovascular disease, endocrine disorder, kidney disease, and musculoskeletal disorder) diagnosed after the COVID-19 event. The need for post-COVID rehabilitation services was significantly associated with the diagnosis of LC/post-COVID condition. Similarly, the reported need for mental healthcare was significantly associated with the diagnosis of a mental health condition by a healthcare professional.

Generally, healthcare needs among adults are expected to increase with age. However, the odds of needing overall healthcare and specialised medical care were highest among those between 30 and 59 years and 30 and 49 years, respectively. Age was still associated with outpatient primary care and pharmacy needs, with the first more likely to be reported by persons 40-49 and 60-69 years old and the second by persons 50-59 years old. Persons 70+ years old were more likely to report the need for post-COVID rehabilitation services. Individuals who graduated at the bachelor's level (i.e., a higher education) showed lower odds of needing emergency/hospital care and post-COVID rehabilitation services. Our data did not allow for identifying differences related to gender and race/colour.

Factors associated with the use and sector of use of specialised medical care and scan/image exams

Table 6 presents the factors associated with using specialised medical care and scan/image exams among those

Table 2 Estimated post-COVID-19 clinical characteristics of the population alive in the recruitment and with healthcare needs

Variable	Population alive at study recruitment (N = 11,328)		Population with healthcare needs (N = 5,662)	
	%	95% CI	%	95% CI
Reinfection with SARS-CoV-2				
Yes, once	9.6	6.4;12.9	12.0	6.4;17.6
Yes, more than once	2.8	1.2;4.5	2.6	0.3;4.9
No	82.2	78.1;86.3	80.4	73.7;87.1
Unknown	5.3	3.0;7.6	4.9	1.7;8.2
Hospitalisation because of a COVID-19 complication in the previous six months				
Yes, at least once	5.3	2.9;7.7	10.1	5.3;14.8
No	94.3	91.8;96.7	89.5	84.8;94.3
Unknown	0.4	0.0;0.8	0.4	0.0;1.0
Self-reported Long COVID symptoms (16 most observed frequent symptoms of 29 considered)				
Fatigue	34.0	28.9; 39.1	48.7	40.9; 56.5
Post-exertional malaise (PEM)	32.3	27.3; 37.3	45.5	38.0; 53.1
Joint pain	30.1	25.1; 35.0	43.3	35.6; 51.0
Sleep disturbance	28.4	23.8; 33.0	39.6	32.4; 46.8
Cognitive impairment	27.5	22.7; 32.3	39.0	31.4; 46.5
Numbness or tingling	27.4	22.0; 32.7	41.4	32.9; 49.9
Symptoms of anxiety	27.3	22.6; 32.0	39.0	31.5; 46.4
Little interest, feeling down	25.3	21.0; 29.7	37.8	30.7; 44.9
Muscle pain	22.7	18.3; 27.1	32.2	25.2; 39.1
Problems with vision	19.2	15.1; 23.2	26.8	20.1; 33.4
Difficulty walking or moving about	16.7	13.0; 20.4	25.5	19.1; 31.9
Post-traumatic stress disorder (PTSD)	14.9	11.0; 18.7	20.3	14.2; 26.5
Hair loss	14.2	10.7; 17.7	19.7	14.2; 25.3
Breathlessness	13.2	9.9; 16.6	20.1	14.2; 26.0
Dizziness	10.6	7.3; 13.9	16.2	10.6; 21.8
Headaches or migraines	10.6	7.4; 13.7	15.8	10.4; 21.2
At least one frequent Long COVID symptom	71.3	66.3; 76.2	85.4	79.7; 91.2
Number of Long COVID self-reported frequent symptoms (mean)	4.3	3.8; 4.9	6.3	5.5; 7.1
Self-reported Long COVID				
No	38.9	33.7;44.1	23.8	16.5;31.1
Had, but not anymore	7.2	4.6;9.9	9.8	5.3;14.2
Yes	39.3	34.2;44.4	54.8	47.7;62.7
Not sure	14.1	10.4;17.8	11.6	5.1;18.1
No answer	0.5	0.0;1.1	-	-
Diagnoses received from healthcare professionals after COVID-19				
Cardiovascular disease	15.3	11.3;19.3	25.3	18.6;32.1
Endocrine disorder	10.5	7.2;13.7	19.2	13.2;25.2
Mental health conditions	8.4	5.5;11.3	12.6	7.6;17.6
Long COVID, post-COVID syndrome	8.4	5.3;11.3	14.2	8.7;19.7
Musculoskeletal disorder	7.8	4.7;10.8	13.5	7.8;19.3
Pulmonary disease	7.2	4.5;10.0	8.4	4.4;12.4
Kidney disease	6.3	3.5;9.1	11.2	6.1;16.3
Neurologic disease (epilepsy, migraine, etc.)	3.3	1.4;5.2	4.6	1.5;7.7
Dermatologic disease	2.2	0.9;3.5	2.7	0.3;5.1
Sequelae from viral infections (e.g. chikungunya, dengue, yellow fever, and Zika)	1.2	0.0;2.4	2.1	0.0;4.5
Reproductive disorder	1.2	0.1;2.3	1.7	0.0;3.8
Myalgic encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS)	1.1	0.0;2.4	2.3	0.0;4.6
Autoimmune disease	1.1	0.0;2.3	2.3	0.0;4.7
Hematological disease	1.1	0.0;2.2	2.2	0.1;4.4

Table 3 Population estimates for healthcare services need and use up to 24 months after COVID-19 discharge

Service	Service required by those who declared a need for healthcare (estimated <i>N</i> = 5,662)			Use of the service among those who needed it			Use of SUS or private systems among those who used the services			
	<i>N</i>	%	95%CI	<i>N</i>	%	95%CI	Where	<i>N</i>	%	95%CI
Outpatient primary healthcare unit	4,110	72.6	65.1;80.1	3,665	89.2	84.2;94.2	SUS	3,484	95.1	91.0;99.2
							Private	181	4.9	0.8;9.0
Hospital/Emergency care	1,893	33.4	26.0;40.8	1,813	95.8	91.4;100.0	SUS	1,715	94.6	88.9;100.0
							Private	98	5.4	0.0;11.1
Post-COVID rehabilitation service	984	17.4	11.3;23.5	515	52.3	33.3;71.3	SUS	360	69.8	38.7;100.0
							Private	101	19.7	0.0;46.6
							Unknown	54	10.5	0.0;34.2
Other specialist/specialty medical care	4,330	76.5	69.7;83.3	3,540	81.7	75.4;88.0	SUS	1,582	44.7	34.5;54.9
							Private	1,958	55.3	45.1;65.5
Mental health care	1,291	22.8	16.2;29.4	734	56.9	40.1;73.6	SUS	214	29.1	10.2;48.1
							Private	520	70.9	51.9;89.8
Alternative medicine (herbalist, acupuncturist, etc.)	690	12.2	5.5;18.9	557	80.7	61.9;99.5	SUS	206	36.9	12.3;61.6
							Private	351	63.1	38.4;87.7
Pharmacy	4,332	76.5	69.4;83.6	3,914	90.4	85.0;95.7	SUS	2,406	61.5	52.3;70.6
							Private	1,508	38.5	29.4;47.7
Home healthcare/aid	881	15.6	10.0;21.1	617	70.0	52.2;87.8	SUS	340	55.1	30.0;80.3
							Private	277	44.9	19.7;70.0
Laboratory/specimen collection	4,151	73.3	65.7;81.0	3,823	92.1	87.4;96.8	SUS	2,634	68.9	59.7;78.1
							Private	1,189	31.1	21.9;40.3
Scans or imaging	3,489	61.6	53.6;69.7	2,935	84.1	77.9;90.4	SUS	1,814	61.8	50.1;73.5
							Private	1,121	38.2	26.5;49.9

In each case, the percentages for the use of services are referred to for those needing them

who declared needing them and using them in the private sector (vs. SUS).

Regarding specialised medical services, the odds of their use among those with family per capita income equal to or greater than R\$1,500 were 3.56 times higher than those with a lower income, conditional on other variables in the model. Despite the borderline statistical significance ($p=0.067$), the result is substantive and not negligible, especially considering the sample loss of power incurred by restricting analysis to those who reported needing the services. A borderline statistically positive association of use of specialised services was also observed with the presence of a post-COVID diagnosis of endocrine disorder ($p=0.059$). In contrast, lower odds of specialised medical care utilisation were observed among women ($p=0.066$), and, with statistical significance, for those who faced barriers to schedule an appointment in the SUS or for personal limitations. The conditional odds of specialised care utilisation in the private sector (vs. SUS) were higher among persons aged 30–39 years old and among those with a post-COVID diagnosis of cardiovascular disease; odds were lower among the unemployed and those with a post-COVID diagnosis of kidney disease.

The odds of using scan/image exams were significantly higher among those aged 70 years or older and among

private-sector employees, and lower among the unemployed and those who reported long wait times as an access barrier. Private sector use of these services was negatively associated with a neurological post-COVID hospitalisation diagnosis.

Discussion

Our analysis offers the most comprehensive mapping of LC healthcare needs and use in the SUS to date. Consistent with international evidence, our findings indicate significant pressure of post-COVID conditions on the health system. At the same time, they highlight substantial access gaps and reliance on the private sector for certain services, despite a universal public healthcare system. Importantly, our patient-engaged approach facilitated participation of a diverse sample [43], countering the over-representation of white, more affluent individuals in LC research. Given the disproportionate impact of COVID-19 on communities made vulnerable by racial and economic inequalities [20, 23] and increased likelihood of their reliance on public healthcare, our results indicating inequities in access to care raise significant concerns about deepening inequalities.

Table 4 Estimates of population proportions reporting barriers to accessing healthcare, among those needing specific services

Barriers	Outpatient primary care unit (N=4110)		Hospital/ Emergency (N=1893)		Post-COVID rehabilitation service (N=984)		Specialised medical service (N=4330)		Mental health care (N=1291)		Alternative medicine (N=690)		Pharmacy (N=4332)		Home healthcare/ aid (N=881)		Laboratory/ specimen collection (N=4151)		Scans or imaging (N=3489)	
	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI	%	95%CI
<i>Explicitly asked</i>																				
The participant did not seek the service in the SUS	1.4	0.0;2.7	6.0	0.4;11.6	1.1	1.0;1.2	27.6	19.5;35.6	37.7	22.5;52.9	37.1	23.4;50.8	16.5	10.0;23.0	20.4	5.6;35.1	19.6	11.9;27.4	25.7	16.3;35.1
Not able to schedule*	13.1	8.2;18.0	3.8	0.0;8.2	13.1	0.0;27.3	25.4	17.8;33.1	38.6	22.5;54.8	12.6	0.0;28.2	39.9	31.4;48.3	20.3	4.4;36.2	8.7	4.1;13.2	14.1	7.9;20.3
Physical/emotional personal limitations	5.4	1.1;9.6	5.9	0.0;12.6	20.1	2.7;37.5	4.0	0.6;7.4	6.9	0.0;16.8	-	-	1.3	0.0;3.6	1.2	1.1;1.4	1.7	0.0;4.3	1.2	0.0;2.6
Location or service opening hours	7.3	2.9;11.7	0.7	0.0;1.3	5.0	0.0;15.4	7.1	1.9;12.4	1.9	0.0;4.3	-	-	0.1	0.0;0.3	3.6	0.6;6.5	2.7	0.0;5.8	1.9	0.1;3.7
Financial costs	0.9	0.0;1.9	0.4	0.0;1.3	13.0	0.7;25.3	3.0	0.6;5.5	1.3	0.0;3.2	1.7	0.0;5.4	4.8	0.8;8.8	8.3	0.0;20.0	3.3	0.0;6.8	0.4	0.0;0.9
Long waiting time	25.2	18.2;32.3	19.5	8.5;30.4	19.8	4.4;35.2	26.6	18.7;34.4	13.8	1.9;25.7	6.5	0.0;16.0	2.5	0.0;5.6	18.6	3.7;33.5	18.4	12.2;24.5	33.5	24.1;42.8
<i>Spontaneously mentioned as other barriers</i>																				
Shortage of doctors	7.1	2.6;11.5	-	-	0.3	0.0;1.0	2.9	0.0;6.3	2.9	0.0;8.7	-	-	0.1	0.0;0.2	0.6	0.0;1.8	0.5	0.0;1.1	0.2	0.0;0.7
Lack of responsiveness of the healthcare system	0.1	0.0;0.3	2.8	0.0;8.5	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
Concerns on healthcare quality	7.9	3.2;12.7	5.9	0.0;12.4	-	-	1.0	0.0;2.7	-	-	-	-	0.3	0.0;0.8	8.0	0.0;20.5	0.2	0.0;0.5	1.3	0.0;4.0
Care continuity difficulties	4.1	0.7;7.4	0.5	0.0;1.6	12.4	0.0;25.6	6.1	1.9;10.2	-	-	-	-	-	-	-	-	0.5	0.0;1.5	2.3	0.0;5.1
Lack of resource	0.2	0.0;0.7	-	-	-	-	-	-	2.9	0.0;8.7	1.9	0.9;2.8	-	-	2.4	0.0;7.4	0.3	0.0;0.8	1.0	0.0;2.5
Unaware of the service	-	-	-	-	13.0	0.0;27.9	-	-	-	-	-	-	-	-	-	-	-	-	-	-

*In the case of pharmacy, the question was reframed to address "medicine not available"

Table 5 Logistic regression models' estimates for explanatory variables of post-COVID-19 healthcare needs

Variable	Healthcare generally	Outpatient primary healthcare	Hospital/emergency care	Post-COVID rehabilitation service	Specialised medical care	Mental healthcare	Pharmacy	Laboratory exams	Scan/image exams
	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)	OR(95% CI)
Age at COVID-19 admission (ref.: 18–29 years + omitted categories)									
30–39	6.65* (1.37;32.31)	3.08 (0.45;21.01)	-	-	4.01 (0.95;16.96)	-	5.61 (0.72;43.94)	-	-
40–49	4.20* (1.04;16.95)	5.84* (1.11;30.65)	-	-	3.22 (0.86;11.98)	-	4.55 (0.67;30.71)	-	-
50–59	4.66* (1.13;19.27)	4.52 (0.86;23.61)	-	-	1.75 (0.48;6.44)	-	8.13* (1.19;55.53)	-	-
60–69	3.36 (0.83;13.64)	6.63* (1.29;34.18)	-	-	2.72 (0.69;10.71)	-	6.45 (0.95;43.71)	-	-
70+	3.67 (0.91;14.72)	4.45 (0.84;23.65)	-	3.37* (1.27;8.94)	2.86 (0.75;10.89)	-	4.55 (0.65;31.70)	-	-
Bachelor's degree (ref.: lower education level)			0.23* (0.06;0.86)	0.23 (0.05;1.20)		-		-	-
ICU use during COVID-19 hospitalisation	1.85 (1.00;3.42)	1.67 (0.91;3.06)	-	-	2.27** (1.28;4.05)	-	-	2.45** (1.37;4.36)	-
Ventilatory support during COVID-19 hospitalisation	-	-	-	-	-	2.99* (1.09;8.18)	-	2.32* (1.15;4.67)	-
Number of Long COVID symptoms	1.22*** (1.15;1.30)	1.19*** (1.12;1.26)	1.17*** (1.09;1.25)	1.19*** (1.10;1.29)	1.14*** (1.08;1.20)	1.25*** (1.17;1.34)	1.15*** (1.09;1.21)	1.17*** (1.11;1.23)	1.14*** (1.09;1.20)
Long COVID self-report	-	-	2.60* (1.14;5.94)	-	2.14* (1.17;3.92)	-	-	-	-
New diagnosis post-COVID-19 hospital discharge									
Cardiovascular disease	6.25*** (2.77;14.08)	2.06* (1.04;4.08)	2.05 (0.91;4.61)	-	5.00*** (2.25;11.11)	-	3.74*** (1.72;8.15)	3.80*** (1.87;7.70)	4.54*** (2.13;9.68)
Endocrine disorders	10.81*** (2.67;43.80)	-	2.75* (1.11;6.83)	-	5.49*** (1.99;15.12)	-	5.47*** (2.30;12.98)	4.87** (1.79;13.24)	2.96* (1.18;7.41)
Kidney disease	12.20** (2.35;63.41)	3.54* (1.18;10.62)	5.83* (1.52;22.28)	3.91 (0.78;19.58)	-	-	6.54** (1.60;26.69)	24.67*** (5.05;120.65)	7.61*** (2.49;23.27)
Musculoskeletal disorder	3.96* (1.27;12.34)	2.35 (0.88;6.29)	-	-	2.57 (0.86;7.67)	-	4.73** (1.66;13.51)	-	-
Post-COVID condition/Long COVID	-	-	-	4.41** (1.51;12.89)	-	-	-	-	-
Mental condition	-	-	-	-	-	8.16*** (3.04;21.90)	-	-	-
C Statistic	0.82	0.78	0.83	0.81	0.80	0.88	0.79	0.81	0.80

Variables related to p -values ≤ 0.10 were kept in the models* $p \leq 0.05$, ** $p \leq 0.01$, *** $p \leq 0.001$ **Demand for Long COVID healthcare**

Half of the participants reported healthcare needs due to conditions that emerged or worsened after COVID-19, with the majority accessing needed services. This is consistent with international research showing increased healthcare utilisation and costs over a prolonged period following COVID-19 diagnosis [46, 47], and specifically increased (re)admission rates [14, 39, 48–50], high use of outpatient primary care [14, 36, 37, 48, 51], specialised medical care [37], medicines, and diagnostic tests [52] among people with LC. Our findings also demonstrate that increased demand on the health system is sustained

well beyond the six or 12-month study period of much prior LC research.

Factors associated with Long COVID healthcare needs

Of those reporting healthcare needs, more than 60% mentioned requiring specialised medical care, pharmacy, laboratory exams, outpatient primary care, and scan/image exams. These needs were consistently associated with the number of LC symptoms reported and the incidence of conditions with increased risk after COVID-19 [53, 54]. Self-reported LC was found to be associated with needing hospital/emergency and specialised medical care.

Table 6 Logistic regression models' estimates for factors explaining healthcare use and sector of use

Variable	Use of specialised medical care among those who needed it (N=4,330) OR(95% CI)	Sector in which specialised medical care was used (N=3,540) (Private vs. SUS) OR(95% CI)	Use of scan/image exams among those who needed them (N=3,489) OR(95% CI)	Sector in which scan/image exams were used (N=2,935) (Private vs. SUS) OR(95% CI)
Age at COVID-19 hospitalisation admission (ref.: 18–29 years + omitted categories)				
30–39	-	8.32** (2.34;29.65)	22.53 (0.68;748.62)	-
40–49	-	-	5.78 (0.71;47.01)	-
50–59	-	-	5.71 (0.72;45.25)	-
60–69	-	-	8.36 (0.93;75.36)	-
70+	-	-	13.93* (1.41;137.43)	-
Cis women	0.41 (0.15;1.06)	-	-	-
Occupation at interview (ref.: retired)				
Private sector employee	-	-	6.54* (1.35;31.70)	-
Self-employee	-	-	-	2.59 (0.82;8.14)
Unemployed	-	0.11** (0.02;0.51)	0.24* (0.06;0.88)	-
Monthly family per capita income (R\$) (ref.: < 1,500)				
≥ 1,500	3.56 (0.92;13.87)	-	-	-
New diagnosis after COVID-19				
Cardiovascular disease	-	3.87** (1.44;10.35)	-	-
Endocrine disorders	2.82 (0.96;8.26)	-	-	-
Kidney disease	-	0.08** (0.02;0.42)	-	-
Neurological disorder	-	-	-	0.06* (0.01;0.60)
SUS access barriers declared				
Not able to schedule	0.27** (0.11;0.65)	-	-	-
Personal physical or emotional limitations	0.06** (0.01;0.34)	-	-	-
Long waiting time	-	-	0.22** (0.09;0.58)	-
C Statistic	0.68	0.66	0.72	0.59

Variables related to p -values ≤ 0.10 were kept in the models* $p \leq 0.05$, ** $p \leq 0.01$

Echoing evidence suggesting a higher prevalence of LC among working-age adults [55], our study identified higher odds of requiring some healthcare or specialised medical care for those aged 30–59 years, who were also more likely to report fatigue, PEM, and joint pain. However, the need for post-COVID rehabilitation services was higher among the oldest (70+ years) – possibly reflecting age-associated patient and provider perception service availability and suitability.

Our findings align with previous studies suggesting that increased severity of COVID-19 is associated with increased odds of developing LC and/or subsequent healthcare needs [36, 47, 56, 57], specifically an increased need for specialised medical care and laboratory exams among those who used the ICU. Patients who received ventilatory care also reported higher need for mental healthcare, which may be associated with the mental health impacts of a traumatic experience during the acute disease, involving the use of life support devices in the ICU – ‘Post Intensive Care Unit Syndrome’ [58–60], *in addition to* the mental health impacts of living with a chronic condition that diminishes functional capacity

and quality of life, and the consequences of reduced income [34, 61, 62].

Gaps in access to healthcare and SUS services

Our study also highlights concerning gaps in access to LC healthcare, defined as a discrepancy between reporting need and reporting use of services.

Access gaps in care for LC are not unique to Brazil, and have been reported in other health systems, including in high-income countries [12, 13, 63]. In our study, long waiting times, difficulties scheduling appointments, and personal physical and emotional limitations in accessing services were important barriers to SUS services, with financial barriers (e.g., transportation costs) reported especially for rehabilitation services. Bottlenecks in access to specialists and poor care coordination are well-documented problems in the SUS [57, 64]. At the same time, the high level of needs and use we found demonstrates *additional* strain on an already overburdened public healthcare system.

Another factor likely contributing to access gaps is the poor understanding of LC and the lack of confidence in

recognising, diagnosing, and treating it amongst clinicians. This is the case in Brazil [9] and internationally [13]. For people living with LC, having to overcome such barriers not only delays care but also risks exacerbating symptoms and mental health impacts [65], and depleting the limited social and financial capital of patients reliant on public healthcare [9, 61].

Despite the establishment of two post-COVID rehabilitation clinics in Rio de Janeiro City, only 52.3% of those needing rehabilitation services were able to access them, and, of those, almost 40% did so in the private sector. Low public and professional awareness of these clinics [9] likely contributed to this gap. Rehabilitation services have been overburdened in the SUS, historically and especially during the pandemic [66], and private sector services are cost-prohibitive for most of the population.

A second major access gap concerned mental healthcare, where, again, only about half of participants who reported needing these services accessed them, with the majority doing so via the private sector. These findings underscore a pattern of increased demand on an under-resourced and overburdened sector of SUS [67]. Also concerning is the limited receipt of social work support, given the diverse care needs of people with LC (e.g., related to employment or home-based care needs).

Gaps in access to SUS services – with patients relying more on private sector services – were significant for specialised medical services and scan/imaging, especially given the high demand for these services. At a more granular level, among those using specialised care, a new diagnosis of cardiovascular disease was associated with increased use in the private sector. By contrast, new diagnoses of kidney disease and neurological disorders were associated with higher odds of using specialised medical care and scan/imaging (respectively) within the SUS, perhaps reflecting higher costs of these services in the private sector vs. relative affordability of private cardiovascular services. Neurological symptoms are highly prevalent (amongst other LC symptoms) [68], underscoring additional demand placed on the public health system.

Inequalities in healthcare access

Links between income and employment status indicate that socioeconomic inequalities play a major role in enabling healthcare use, highlighting how marginalised populations are falling through the cracks of a universal healthcare system meant to serve them. For example, family per capita income equal to or higher than R\$1,500 (approximately the minimum monthly wage in 2025) more than tripled the odds of using specialised care. The decreased need for emergency/hospital care and post-COVID rehabilitation services amongst those with

higher education may be explained by better access to regular follow-up of health problems.

Use of private sector services and out-of-pocket expenses perpetuates inequalities in access, with our findings particularly concerning given the level of socioeconomic vulnerability in our sample. For instance, compared to being employed or retired, being unemployed was associated with substantially lower odds of using specialised medical care in the private sector. Significantly, about ¼ of participants reported out-of-pocket expenses, despite a universal public health system. These costs represent a large portion of income for an already vulnerable population whose ability to engage in paid work may also be diminished by LC. Tracking items more likely to incur out-of-pocket expenses and establishing SUS coverage policies or strategies oriented towards mitigating the problem is crucial.

Though no significant differences in self-reported healthcare needs were observed, the lower odds of cis women's use of specialised medical care, compared to cis men, demonstrate a relevant gender inequality given that LC is more likely to affect females [4, 6, 7].

Implications for the SUS

Lack of awareness about the SUS's specialist post-COVID clinics and confusion regarding referral pathways leading to their closure due to underutilisation despite the huge need for LC care [9] underscores the importance of accompanying such innovations with education about their existence and referral pathways, particularly within primary care. Additionally, while critical to avoid 'psychologization' [69], integrated mental healthcare to help patients cope with the mental health consequences of living with a chronic, often debilitating condition, is essential.

SUS clinicians need better training about LC symptoms, diagnosis, and management, including that it is just one of many vector-borne viral diseases prevalent in Brazil linked to IACCs [10]. Though the science of LC is rapidly evolving, with multiple pathophysiological mechanisms, potential biomarkers, and treatments under investigation [3], currently, effective therapeutic treatments for LC are lacking [70]. Nonetheless, evidence-based recommendations to support rehabilitation and management of LC and patient-centered, holistic care do exist [30]. Sustained investment in updating training and international collaboration, including with patient-led movements to translate scientific developments into routine care, will be crucial.

LC healthcare needs add pressure to address longstanding challenges in the SUS, notably, weaknesses in the coordination of care across specialists for complex and chronic conditions [71], and severe shortages in the availability of mental healthcare [67]. Tackling these

established structural issues would ensure that the WHO recommendations for LC care, involving multidisciplinary teams, rehabilitation services, care coordination, shared decision-making, and workforce planning, can be met [51, 72]. A crucial opportunity exists to leverage SUS' established social participation practices to harness LC patients' input in implementing these structural changes [10].

Two recent initiatives from the Brazilian Ministry of Health may mitigate healthcare access gaps and inequalities identified: a program aimed at expanding access to visits with specialists and specialised exams [73], and the expansion of the Brazilian Popular Pharmacy Program [74], which has expanded free access to certain medications. However, such initiatives need to encompass the specific needs of LC patients to address the significant increase in demand for such services due to this condition and avoid deepening inequities due to out-of-pocket expenses; currently, for example, pain medications commonly prescribed for patients with LC are not included.

Study limitations

Our data are mainly from patients hospitalised for COVID-19 before vaccination rollout (which lowered hospitalisation rates) and when COVID-19 incidence and case lethality were very high. Thus, while representative of patients hospitalised for COVID-19 during that period, estimates may not be valid for more recent COVID-19 patients, nor for the broader population of people with LC, most of whom did not have severe COVID-19 and were not hospitalised. Although people hospitalised due to severe acute COVID-19 have a higher risk of LC than those with mild acute disease [75], most LC patients in the general population have not been hospitalised. Among non-hospitalised patients, COVID-19 has been associated with increased risk of 30 neurological disorders and 18 cardiovascular conditions for at least a year [76, 77]. It is also possible that, relative to non-hospitalised LC patients, those hospitalised have increased access to post-COVID care due to specific protocols of referral. Moreover, non-hospitalised patients and those without proof of a positive test or clinical diagnosis of COVID-19 may face additional challenges accessing care for LC. With vaccination rates plummeting and significant barriers to accessing updated vaccines [78]—at a time when reinfections are common and are associated with increased risk of developing LC [79]—our findings remain highly relevant for addressing the healthcare needs of people living with LC.

Our questionnaire design did not capture the common practice of simultaneous use of both private and SUS pharmacy services, which may have underestimated access to medications via SUS.

Our decision to phrase questions about healthcare needs and use for 'a condition that arose or worsened after COVID-19' rather than asking questions about seeking care 'for LC' (whether self-identified or diagnosed by a clinician) could be considered a limitation for a study aiming to inform the provision of care for LC. However, our data show that patient self-reports of LC and receipt of formal diagnoses of LC are not aligned, and both are much lower than the reported burden of LC symptoms and new diagnoses such as cardiovascular disease [53]. We do not report on a homogeneous group of 'those with LC', but rather use some different measures in considering the condition. Nevertheless, we suggest that the approach to examining LC healthcare needs and use taken in this study is warranted in a context of low awareness and understanding of LC amongst the general population and health professionals.

An important area for further research is the quality and appropriateness of LC care: our study did not assess this, but existing evidence makes clear that *access* to services is necessary but insufficient to ensure high-quality, patient-centred care for people with LC [12, 13].

Finally, limitations of our sample prevent discriminating differences across socioeconomic segments in a predominantly low-income population, or deeper explorations of factors associated with the use of healthcare services for which few participants declare need. Further research exploring differences by (non-cis) gender identities and race/ethnicity – inferences our sample did not allow for – is important to advance healthcare equity, given structural inequalities in vulnerability to COVID-19 and healthcare access more generally.

Conclusions – an urgent need to address an invisibilised epidemic

Our findings reinforce global evidence of high healthcare needs amongst LC patients, and contribute to a deeper understanding of the disparities in access and the challenges in obtaining appropriate care faced by people with LC in an LMIC, including up to two years after acute infection. This further confirms previous evidence of the invisibilisation of LC within the SUS in ways that undermine equitable access to appropriate care [9].

The disproportionate impact of LC on socially and economically vulnerable populations, exacerbating entrenched health and social inequalities, represents a major concern for any universal public healthcare service. Failure to allocate adequate resources results in devastating costs to individuals with LC (quality of life, mental health, social participation, etc) and those who care for them [61]. The economic costs of LC, in Brazil and globally, are enormous, whether measured in terms of impacts on GDP or household earnings, or in healthcare costs (for universal public health systems or patients

themselves) [80]. Failure to provide adequate, timely care will only result in increased costs in terms of long-term disability, loss of work, costs of chronic care, and the costs to society of worsened inequalities.

Being prepared to deal with the risk of epidemics requires the capacity to learn from previous experiences. Learning from LC highlights the lack of spare capacity within the healthcare system to accommodate the increased burden of chronic illness; the invisibilisation of LC; and the need for surveillance systems to be more proactive in seeking to identify IACCs. As is so often the case, the most socio-economically vulnerable are likely to face increased risk of illness and of the deleterious consequences of chronic illness, and will not have the resources to turn to private sector services when public healthcare is unresponsive. Addressing these challenges is not just a matter of preparedness for tomorrow's epidemics: the *current* epidemiological context is one of an invisibilised epidemic of IACCs, which demands an urgent health system response today.

Abbreviations

CI	Confidence interval
IACC	Infection-associated chronic condition
ICU	Intensive care unit
LC	Long COVID
LMIC	Low- and middle-income countries
PEM	Post-exertional malaise
SIVEP-Gripe	Sistema de Informação da Vigilância Epidemiológica da Gripe—Influenza Epidemiological Surveillance Information System
SUS	Sistema Único de Saúde—[Brazilian] Unified Health System
WHO	World Health Organization

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

MCP – conceptualisation, data curation, formal analysis, funding acquisition, investigation, methodology, project administration, supervision, writing – original draft, and writing – review & editing; CCE – conceptualisation, formal analysis, writing – original draft, and writing – review & editing; SMLL – conceptualisation, formal analysis, funding acquisition, investigation, methodology, writing – original draft, and writing – review & editing; MB – data curation, investigation, writing – original draft, and writing – review & editing; BNC – conceptualisation, funding acquisition, methodology, writing – original draft, and writing – review & editing; LS – conceptualisation, writing – original draft, and writing – review & editing; MTLV – methodology, writing – original draft, and writing – review & editing; MM – conceptualisation, writing – original draft, and writing – review & editing; CLTA – conceptualisation, analysis programming, writing – original draft, and writing – review & editing; NPB – investigation, writing – original draft, and writing – review & editing; GG – investigation, writing – original draft, and writing – review & editing; BS – investigation, writing – original draft, and writing – review & editing; MC – investigation, writing – original draft, and writing – review & editing;

DF – investigation, writing – original draft, and writing – review & editing; ES – conceptualisation, writing – original draft, and writing – review & editing; FC – conceptualisation, writing – original draft, and writing – review & editing; ELA – conceptualisation, funding acquisition, methodology, project administration, supervision, writing – original draft, and writing – review & editing.

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Data availability

The datasets generated and/or analysed during the current study are not publicly available due to analyses still in progress, but are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

The project was submitted to and approved by the Research Ethics Committees of ENSP/Fiocruz (CAAE 57680922.3.0000.5240), of Rio de Janeiro Municipal Health Secretariat/RJ (CAAE 57680922.3.3001.5279), and of one of the coparticipant hospitals (CAAE 57680922.3.3003.5257), as required by its Management. Given the international collaboration and funding, it was also submitted and approved by the National Research Ethics Commission (CONEP) (CAAE 57680922.3.0000.5240). All participants provided verbal informed consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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