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Barriers, facilitators, and the role of central coordination: understanding long COVID-19 healthcare access in a universal healthcare system

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Abstract

Background This study comprehensively analyses healthcare access barriers and facilitators encountered by long COVID-19 patients in a universal healthcare system, including the potential role of central coordination units in alleviating the patient burden.

Study design Retrospective cross-sectional long COVID-19 patient questionnaire survey.

Methods Data collection took place 10–12/2024 in Austria ($n = 433$). Conceptualized along the five steps of the 'access to care' framework, the questionnaire covered 47 barriers and 10 facilitators derived from a previous qualitative study. Descriptive statistics, Whitney-Mann-U and t-tests, as well as linear and ordered logistic regressions were used in the statistical analysis.

Results Barriers were encountered in all access steps with the mean number of barriers considered problematic being 31.9 (SD 8.4) out of 47. The most common barriers were lacking information and the burden of self-organising one's treatment (perceived as problematic by over 90%), followed by the need to consult private (non-contracted) doctors due to insufficient expertise in the public sector and difficulties in treating symptoms by GPs and specialists (85%). Participants living in federal states offering central coordination encountered statistically significantly fewer barriers, perceiving a mean of 17.4 barriers (SD 9.7) as very problematic compared to 21.0 (SD 9.2). Differences were particularly pronounced regarding the availability of services within the public sector and incurred costs although the overall burden remained high. Main facilitators included family and friends and the (information) exchange with other patients.

Conclusions Our findings have important policy and research implications beyond the Austrian context, supporting the establishment of central coordination units and research assessing the effectiveness and implementation of long COVID-19 pathways to improve patients' healthcare access.

Keywords Long COVID-19, Healthcare access, Barriers, Facilitators, Central coordination, Survey

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Text box 1. Contributions to literature

- Quantitative evidence on healthcare access barriers and facilitators for long COVID-19 (LC) patients remains limited internationally.
- This study provides new insights from Austria, a universal healthcare system, where LC patients face a wide range of healthcare access barriers and report a high overall barrier burden.
- Main barriers were lacking available expertise within the public healthcare sector and the need for patients to self-organize care. However, central coordination units were linked to fewer barriers.
- There is an urgent need for public health policies supporting the establishment of centralized LC coordination units, provided that suitable treatment structures are in place for coordination.

Background

Healthcare access is widely considered a key indicator to measure health system performance and consequently has long been a priority to policymakers [1]. However, factors such as cost, proximity to services, and waiting times can substantially impede healthcare access and thereby utilization. Unmet healthcare needs as a proxy for healthcare (in)accessibility overall are minimal across the European Union (EU) at 2.4% of the population. Yet vulnerable population groups such as patients with chronic conditions still encounter access barriers to a much larger extent – despite higher care needs and equal healthcare access for all being a policy priority [2–5]. This conversely implies that respective policies so far either did not receive sufficient priority/resources or were insufficiently implemented, emphasizing the public health relevance of further research in this area.

Long COVID-19 (LC) serves as an interesting example in this regard as not only the condition itself only has risen to prominence since 2020 (although wider post-acute infection syndromes have been known and researched far longer [6]) but also respective policies and clinical guidelines were developed comparatively recently. While LC prevalence estimates vary widely due to inconsistencies in study design, definition, and population, conservative estimates point to a cumulative global incidence of around 400 million by 2023, highlighting the disease's public health relevance [6]. LC strongly impacts the patients' health-related quality of life, often severely restricting their ability to participate in social and professional activities over an extended period of time [7, 8]. Moreover, the large number of patients requiring ongoing care to manage complex, changing symptoms puts pressure on health and social systems already stretched post-pandemic [6].

By 2024, most OECD countries issued clinical guidelines to inform decision-making and developed national plans to tackle LC or were in the process to do so [9]. While country-specific health system characteristics lead to differences between guidelines, there are multiple components that can be found irrespective of country and health system type. Most guidelines see the primary care sector as first and main point of contact for LC patients, responsible for initial assessment and coordination of further specialist treatment and rehabilitation as required. Emphasis is put on patient-centred inter- and multidisciplinary care, acknowledging the oftentimes heterogenous and changing LC symptoms. [10, 11] Moreover, most countries introduced specialised LC clinics, bundling multiple disciplines to improve care and facilitate research. Notable differences in foreseen care pathways can be observed with regards to specific coordination units as introduced, for example, in France and Belgium. [9]

In practice, however, those foreseen care pathways appear to be insufficiently implemented as a growing body of qualitative research across countries and health systems finds substantial difficulties by LC patients in accessing appropriate care [12–16]. The first – and to the best of our knowledge so far only – study to quantitatively investigate healthcare access barriers on a population level was recently published on the Netherlands [17]. Differences in approaches to LC care pathways, by contrast, were highlighted in prior research and reports [9, 11], however, there are so far no studies assessing different models and common pathway components such as central coordination of LC treatment.

This study contributes to this line of research by building on the findings of a recent qualitative study [14], which explored barriers and facilitators to LC patients as first part of a sequential mixed-methods research effort. In this second part, we aim to quantitatively assess healthcare access barriers and facilitators encountered by LC patients in a universal healthcare system, Austria. We leverage Levesque et al.'s [18] comprehensive access-to-care framework, conceptualizing healthcare access as a process spanning from the emergence of health care needs all the way to health care consequences. Investigating a multitude of barriers and facilitators along all process steps allows for detailed insights into potential issues and targeted policy recommendations. Moreover, we aim to provide initial insights on the association of central coordination units with healthcare access.

The Austrian context

Drawing on an Austrian patient sample, we ensure applicability of our findings to other countries as the Austrian patient pathway largely is in line with most other OECD countries in terms of a central role for primary care and specialised LC clinics. Moreover, two out of the nine Austrian federal states - Tyrol and Vorarlberg, which together account for approximately 13% of the population - introduced central coordination (CC) units in 2021 and 2022 [19–21]. By contrast, the Austrian LC guideline and clinical pathway published in 2021 and updated in

2023 foresee general practitioners (GPs) to take on this coordination task as practiced in the other seven federal states, allowing for an analysis of the two LC care models in an otherwise similar context [22–24]. The Austrian healthcare system is considered universal with 99.9% of the population covered by statutory health insurance, very low unmet healthcare needs in an international comparison, and no gatekeepers restricting access to specialist outpatient care [25–27]. There also is a sizeable and growing private healthcare sector, resulting in 38% of the Austrian population having complementary private health insurance to cover appointments with non-contracted (henceforth: private) GPs, specialists or additional services [28, 29]. Nonetheless, prior Austrian qualitative research [5, 14] finds a wide range of healthcare access barriers for LC and other chronic patients, particularly regarding experienced stigma, availability of expertise/services and incurred costs. Moreover, patients highlighted the burden of having to self-coordinate treatments. We consequently expect to quantitatively confirm those earlier findings and moreover gain insights on the potential role of CC, providing evidence for a critical reflection on the official Austrian LC patient pathway and its implementation as well as future research.

Methods

Underlying framework

The survey developed for this study builds on the framework developed by Levesque et al. [18], conceptualizing access to health care as a multi-step process. The framework proved fit for purpose in other empirical quantitative research [2, 30] including the qualitative exploratory study providing the basis for this study [14]. As visualized in Fig. 1, the framework covers five dimensions from health care need to health care consequences, each from a health system (upper part) and population (lower part) perspective [18].

Survey development

The survey used in this study builds on the barriers and facilitators identified in the abovementioned qualitative study drawing on patient focus groups and expert interviews [14]. Additionally, the questionnaire was designed drawing on literature research into available instruments

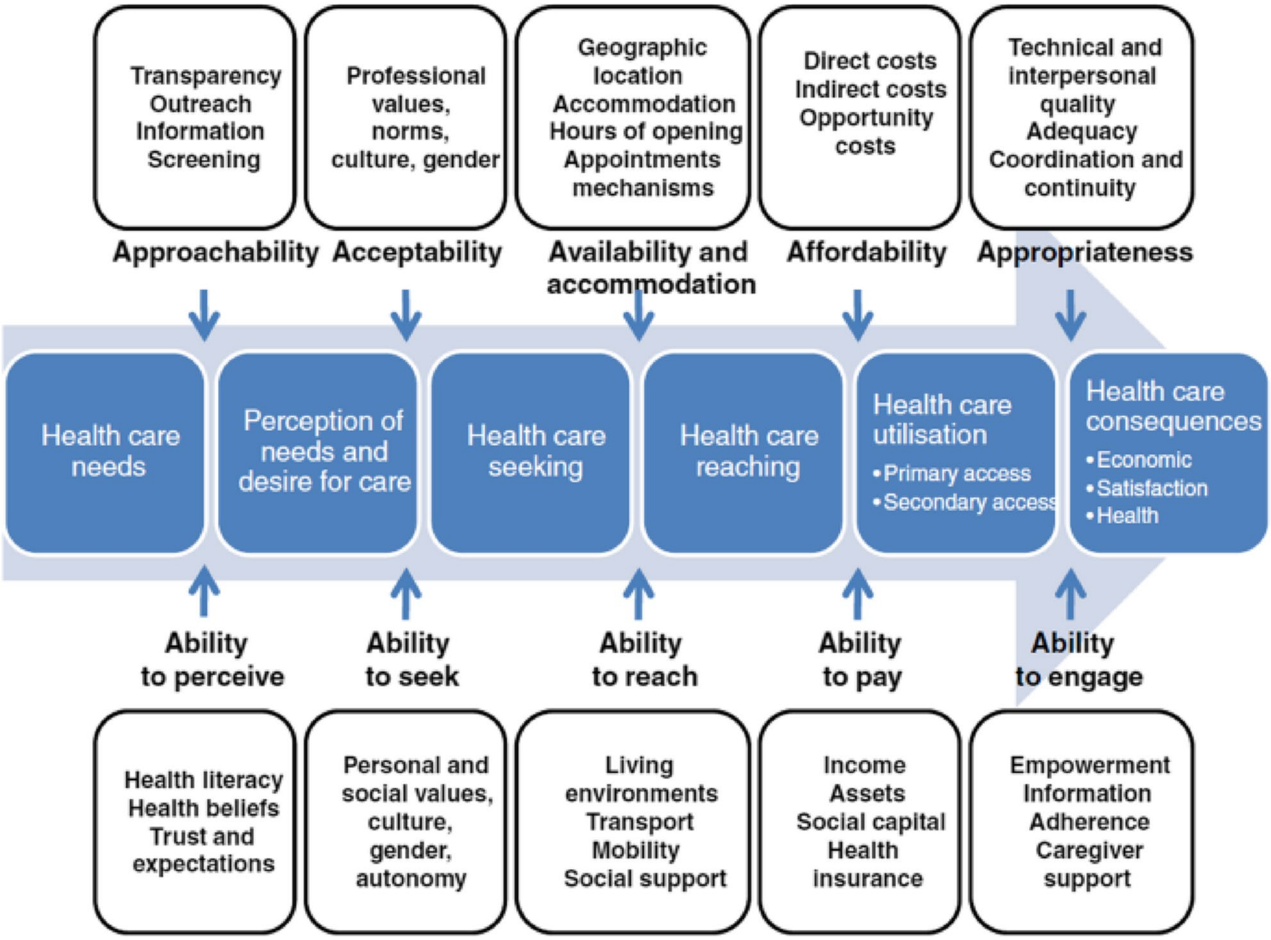

Fig. 1 Access to health care framework by Levesque et al. [18].Permission to use this conceptual visualization was obtained from Jean-Frederic Levesque.

such as the Barriers to Access to Care Evaluation scale (BACE) [31] and other survey studies assessing barriers using Levesque's framework [2, 3]. Questionnaire sections included socioeconomic and demographic characteristics, barrier assessment, and facilitator assessment. In total, 47 barriers across all five framework dimensions were assessed as well as 10 facilitators. For each barrier/facilitator, participants were asked to choose whether it (i) was not applicable to them (e.g., if the barrier was related to hospital stays but they never went to a hospital because of LC), (ii) posed no barrier/facilitator, (iii) presented a minor problem/was somewhat helpful, or (iv) presented a major problem/was very helpful. Moreover, a short section on symptoms was included based on the questionnaire used in one Austrian region for initial LC assessment [32], which was refined based on expert feedback collected from Medical University of Vienna internal LC experts.

The questionnaire was individually piloted with two patients, taking 15–20 min to complete the survey and receiving a compensation of €30 in vouchers. Only minor patient feedback – pertaining to the clarity of some response options – was received and incorporated.

Data collection

Data was collected in German both online via SoSci Survey and paper-based from October to December 2024. The survey was distributed via three main channels across Austria, (i) the Austrian patient support group *Long Covid Austria* and the regional groups *Long COVID und ME/CFS Tirol* (Tyrol), (ii) via 64 physicians (both GPs and specialists) and rehabilitation clinics recommended by LC patients to the *Long Covid Austria* support group [33] and (iii) via 59 primary care centres to additionally reach patients not engaged with the support groups. *Long Covid Austria* shared the study material and a reminder in its patient-only Facebook group and also via its public Instagram channel as did some doctors with social media presence. Groups ii) and iii) were asked to share the survey link with their patients and make information material as well as paper-based questionnaires available in their waiting areas. Data collection was fully anonymous and no tracing of online responses to the distribution channels was possible. Only one distribution channel returned paper-based surveys, however, no identifying participant data were collected to ensure anonymity.

Inclusion criteria were at least 18 years of age, sufficiently understanding German, acute or recovered long COVID-19, and reading, understanding, and agreeing to the patient information provided. LC status was self-reported and no proof of diagnosis required as obtaining a formal diagnosis could itself represent a barrier [14]. At the same time, the LC definition following the UK's National Institute for Health and Care Excellence (NICE) [34] was provided as an explanatory text. The survey could be paused at any time to reduce participant burden. Participants could opt to provide their email address to enter a lottery for one of three €50 vouchers and to allow the study team to contact them solely for the purpose of arranging voucher mailing in the event of a win.

Analysis

Sample characteristics were described using frequencies and percentages. Overall barrier burden/facilitator benefit was assessed by (i) counting the total number of barriers/facilitators perceived as problematic/helpful including both minor and major problems/somewhat and very helpful facilitators, (ii) only counting those perceived as major problems/very helpful, and (iii) calculating a burden/benefit score for each participant to account for differences in minor/major and somewhat/very. The barrier score was calculated counting minor problems as 1 and major problems as 2, with a corresponding possible score range of 0–94 based on 47 assessed barriers. The same procedure was applied for facilitators with the possible score range of 0–20 for 10 assessed facilitators.

As a sensitivity analysis, the percentage of encountered barriers/facilitators out of the respectively applicable ones for each respondent was calculated since not all investigated barriers/facilitators were applicable to all participants. For example, someone encountering eight barriers out of the 47 investigated while choosing "Not applicable to me" for seven of them would be attributed a percentage of $8/40 = 20\%$ in terms of experienced barriers. This was done (a) counting both minor/somewhat and major/very and (b) only major/very. Moreover, analyses were also conducted excluding responses with less than ten minutes completion time as additional sensitivity analyses to account for potentially hasty completions. The distribution of individual barriers and facilitators was visualized along the framework dimensions.

Mann-Whitney-U, chi-squared, and t-tests were applied to test for statistical differences between federal states with and without CC, considering a 95% significance level. Bonferroni-Holm corrections were conducted to counter a potential multiple testing problem [35]. Moreover, depending on the outcome, we additionally estimated linear or ordered logistic regressions, controlling for gender, age, migration background, education, urbanicity, household financial situation, private complementary health insurance, and self-reported LC onset year. Only participants who reported that an individual barrier/facilitator was applicable to them were included in the respective regression.

Statistical software Stata 18 (StataCorp LLC, Texas/US) was used for data analysis. Only participants completing the entire survey were included in the analyses. The study was conducted and reported following the STROBE (Strengthening the reporting of observational studies in epidemiology) checklist for cross-sectional studies [36], detailed in appendix Table A1.

Results

Sample characteristics

In total, 558 people started the survey. Of those, 70 did not fulfil the inclusion criteria checked in the initial three filter questions and consequently could not proceed with the survey. Out of the remaining 488 individuals, another 55 did not complete the entire survey, resulting in a final sample of 433 participants. The corresponding flow diagram is presented in appendix Figure A1. Participants not completing the survey did not differ from the final sample in terms of socioeconomic and demographic characteristics. Mean completion time was 18.2 min (SD 6.6) with 33 participants (7.6%) finishing in less than ten minutes.

Study sample and sub-sample characteristics for non-CC/CC states as well as group differences are presented in Table 1. Notably, the sample consisted of 400 (92%) active and 33 (8%) recovered LC patients, 84.1% women, and 57.4% patients with a completed level of education higher than A-levels. The mean age was 42.9 (SD 11.0) years. All Austrian federal states were covered with 111 (26%) participants living in a federal state with CC, namely Tyrol or Vorarlberg. We find statistically significant differences regarding age and education, with comparatively older and less educated participants living in CC states. No group differences were found in terms of gender, migration background, rural/urban residency, household financial situation, and private complementary health insurance.

Looking at the experienced LC symptoms, post exertional malaise (PEM) was most often perceived as very severe with 54% of participants reporting maximum severity on a five-point Likert scale and only 0.2% reporting no symptoms at all. This was followed by persistent fatigue (39%) and sleep disorders (31%). There were no statistically significant differences in perceived symptoms between non-CC/CC states. Full details on the assessed symptoms can be found in appendix Figure A2 and Table A2.

Barriers

The mean number of barriers perceived as minor or major problem was 31.9 (SD 8.4) and the mean number of major problems 20.0 (SD 9.5) out of 47 barriers. The mean barrier score was 52.0 (SD 17.1) out of 94. Looking at the sensitivity analysis and only taking into account applicable barriers, the mean percentage of barriers perceived as problematic was 79.2% (SD 16.6) and 49.3% (SD 21.6) when restricting analysis to major problems. Overall barrier burden was statistically significantly higher in non-CC states across all three aforementioned measures and in the sensitivity analyses. Details on overall barrier burden are summarized in Table 2 and appendix Figures A3-A8.

The highest shares of participants perceiving a barrier as a major problem were found for GPs having difficulties to treat symptoms and the necessity to resort to the private sector due to lacking expertise in the public system with 74% each. Moreover, 73% of participants perceived the self-organization of their treatment and patient pathway a major problem, while 70% reported insufficient available information as a significant issue. Although most barriers were applicable to the majority of patients, the ones related to hospital outpatient clinic care were assessed less frequently. The three barriers applicable to the fewest participants were very specific, enquiring problems with obtaining state disability pension (50% not applicable) or private disability pension (85%) and being able to work part-time as part of a reintegration program (64%), indicating limited utilization of those services. Detailed results are presented in Fig. 2.

On an individual-barrier level we find statistically significant differences between non-CC/CC states for the availability of specialists and hospital outpatient clinics as well as for specialist, medication and dietary supplement costs. Moreover, the need to resort to private doctors due to either lacking expertise in the public sector or public sector waiting times varied significantly. This can be illustrated looking at the perceived lack of public sector expertise: While 81.7% of participants in non-CC states perceived this to be a major problem, 50.5% did so in CC states. Detailed results are presented in appendix Table A3.

Facilitators

The mean number of facilitators perceived as somewhat or very helpful was 5.0 (SD 1.7) and the mean number of very helpful facilitators was 2.6 (SD 1.7) out of ten. The mean facilitator score was 7.6 (SD 3.0) out of 20. In the sensitivity analyses only considering applicable facilitators the mean percentage of somewhat or very helpful facilitators was 75.2% (SD 22.0) and 39.0% (SD 25.2) when restricting analyses to very helpful facilitators. Overall facilitator measures did not significantly differ between CC/non-CC states, also in the sensitivity analyses. Detailed results are presented in Table 2.

We find the main facilitators to be participants' social environment (perceived by 62% as very helpful), exchange with other patients (52%), and the *Long Covid Austria* Facebook group (40%). By contrast, GPs coordinating treatment and encouraging the perception of the condition were considered of no help by 46% and 39.7% of the participants, respectively. Least applicable

Table 1 Study sample characteristics overall and by availability of central coordination of treatments in the federal state

	Total ***n*** **(%)**	**No central coordination** ***n*** **(%)**	**Central coordination** ***n*** **(%)**	***P*-value**
Gender				
Female	364 (84.1%)	272 (84.5%)	92 (82.9%)	χ^2 test: 0.705
Male	66 (15.2%)	47 (14.6%)	19 (17.1%)	
Diverse	1 (0.2%)	1 (0.3%)	0 (0.0%)	
I do not want to answer	2 (0.5%)	2 (0.6%)	0 (0.0%)	
Age (mean, SD)	43.0 (11.0)	42.0 (10.7)	45.9 (11.4)	t-test: 0.001 **
18–30	67 (15.5%)	56 (17.4%)	11 (9.9%)	Mann-Whitney U test: <0.001 ***
31–40	118 (27.3%)	92 (28.6%)	26 (23.4%)	
41–50	124 (28.6%)	96 (29.8%)	28 (25.2%)	
51–60	108 (24.9%)	70 (21.7%)	38 (34.2%)	
Older than 60	16 (3.7%)	8 (2.5%)	8 (7.2%)	
Migration background				
Yes	49 (11.3%)	33 (10.2%)	16 (14.4%)	χ^2 test: 0.350
No	382 (88.2%)	288 (89.4%)	94 (84.7%)	
I do not want to answer	2 (0.5%)	1 (0.3%)	1 (0.9%)	
Education				
Below A-levels equivalent	111 (26.1%)	73 (22.7%)	38 (25.7%)	Mann-Whitney U test[a]: 0.001 **
A-levels equivalent	70 (16.5%)	48 (14.9%)	22 (19.8%)	
Higher than A-levels equivalent	244 (57.4%)	197 (61.2%)	47 (42.3%)	
Other	8 (1.8%)	4 (1.2%)	4 (3.6%)	
Urbanicity				
Urban	228 (52.7%)	175 (54.3%)	53 (47.7%)	χ^2 test: 0.230
Rural	205 (47.3%)	147 (45.7%)	58 (52.3%)	
Household financial situation during disease				
Good or very good	91 (21.0%)	62 (19.3%)	29 (26.1%)	Mann-Whitney U test[a]: 0.172
Medium	162 (37.4%)	122 (37.9%)	40 (36.0%)	
Bad or very bad	177 (40.9%)	136 (42.3%)	41 (36.9%)	
I do not want to answer	3 (0.7%)	2 (0.6%)	1 (0.9%)	
Private complementary health insurance				
Yes	111 (25.6%)	82 (25.5%)	29 (26.1%)	χ^2 test: 0.943
No	319 (73.7%)	238 (73.9%)	81 (73.0%)	
I do not want to answer	3 (0.7%)	2 (0.6%)	1 (0.9%)	
Self-reported long COVID-19 onset year				
2020	48 (11.1%)	37 (11.5%)	11 (9.9%)	Mann-Whitney U test[a]: 0.905
2021	95 (21.9%)	71 (22.1%)	24 (21.6%)	
2022	187 (43.2%)	134 (41.6%)	53 (47.8%)	
2023	74 (17.1%)	56 (17.4%)	18 (16.2%)	
2024	23 (5.3%)	19 (5.9%)	4 (3.6%)	
Not provided	6 (1.4%)	5 (1.6%)	1 (0.9%)	
Federal state				
Burgenland	17 (3.9%)	17 (5.3%)	0 (0.0%)	*not applicable*
Carinthia	10 (2.3%)	10 (3.1%)	0 (0.0%)	
Lower Austria	57 (13.2%)	57 (17.7%)	0 (0.0%)	
Upper Austria	51 (11.8%)	51 (15.8%)	0 (0.0%)	
Salzburg	19 (4.4%)	19 (5.9%)	0 (0.0%)	
Styria	52 (12.0%)	52 (16.1%)	0 (0.0%)	
Tyrol	92 (21.2%)	0 (0.0%)	92 (82.9%)	
Vorarlberg	19 (4.4%)	0 (0.0%)	19 (17.1%)	
Vienna	116 (26.8%)	116 (36.0%)	0 (0.0%)	
Total	**433 (100.0%)**	**322 (74.4%)**	**111 (25.6%)**	

a) "Other", "I do not want to answer", and "Not provided" excluded for testing to ensure ordinal variables

* < 0.05, ** < 0.01, *** < 0.001

Table 2 Overall barriers and facilitators by availability of central coordination of treatments in the federal state

		Total mean [95% confidence interval]	No central coordination mean [95% confidence interval]	Central coordination mean [95% confidence interval]	T-test *p*-value	Regression[1] *p*-value
Barriers overall	Count of barriers perceived as *minor or major* problems	31.9 [31.1–32.7]	32.9 [32.1–33.8]	28.9 [27.1–30.8]	< 0.001 ***	< 0.001 ***
	Count of barriers perceived as *major* problems	20.0 [19.2–20.9]	21.0 [20.0–22.0]	17.4 [15.5–19.2]	< 0.001 ***	0.001 **
	Barrier score (minor problem = 1, major problem = 2)	52 [50.3–53.6]	53.9 [52.1–55.7]	46.3 [42.7–49.9]	< 0.001 ***	< 0.001 ***
	Percentage of encountered *minor or major* problems out of all applicable barriers	79.2 [77.6–80.8]	81.4 [79.8–82.9]	72.9 [68.9–76.9]	< 0.001 ***	< 0.001 ***
	Percentage of encountered *major* problems out of all applicable barriers	49.3 [47.3–51.4]	51.4 [49.1–53.7]	43.4 [39–47.8.8]	< 0.001 ***	0.001 **
Facilitators overall	Count of facilitators perceived as *somewhat or very helpful*	5.0 [4.9–5.2]	5.1 [4.9–5.3]	4.8 [4.5–5.2]	0.0978	0.070
	Count of facilitators perceived as *very helpful*	2.6 [2.5–2.8]	2.6 [2.5–2.8]	2.5 [2.2–2.8]	0.4953	0.269
	Facilitator score (helpful = 1, very helpful = 2)	7.6 [7.4–7.9]	7.8 [7.4–8.1]	7.3 [6.7–7.9]	0.1909	0.104
	Percentage of encountered *somewhat or very helpful* facilitators out of all applicable facilitators	75.2 [73.1–77.3]	75.1 [72.8–77.4]	75.5 [70.7–80.2]	0.8941	0.853
	Percentage of encountered *very helpful* facilitators out of all applicable facilitators	39.0 [36.7–41.4]	38.6 [35.9–41.4]	40.3 [35.4–45.1]	0.5510	0.940

[1] Controlling for gender, age, migration background, education, urbanicity, household financial situation, private complementary health insurance, self-reported long COVID-19 onset year. * < 0.05, ** < 0.01, *** < 0.001

facilitators included direct or indirect payments to doctors in return for shorter waiting times albeit applicable to 79 (17.3%) and 114 (26.3%) participants respectively. Detailed results are visualized in Fig. 3.

We find statistically significant differences in individual facilitators by non-CC/CC state for the use of telemedicine (24.2% compared to 6.3%). Detailed results can be found in appendix Table A4.

Discussion

This study finds severely impeded healthcare access for LC patients in Austria. Barriers perceived as major problems persist along all dimensions of access to care, from approachability of services all the way to appropriateness of received treatment. Our findings particularly lay bare patients' problems with the overall foreseen patient pathway. Almost 75% of the patients deemed the self-organisation effort to be a major problem and almost as many did so for too little available information. Moreover, patients felt they had to resort to private doctors due to lacking expertise or long waiting times in the public sector, posing a financial barrier. While difficulties in diagnosing LC and treating the respective symptoms have to be at least partially attributed to the condition's novelty and ongoing research, specialists were perceived to fare better than GPs in this regard. However, specialists (perceived by 51% as very problematic) and GPs (48% very problematic) alike were reported not to take patients seriously. Furthermore, 39% of participants reported specialists attributing symptoms to mental health conditions as very problematic and 37% did so for GPs. Availability and costs of GPs were largely not perceived as problematic whereas the majority of participants indicated the opposite for specialists. The main facilitators in healthcare access for LC patients notably were of informal nature and related to support by participants' social environments and other patients both directly and via the *Long Covid Austria* patient-led support group. Lastly, we find statistically significant differences between non-CC and CC states both overall and particularly regarding the availability and affordability of services with participants from CC federal states reporting fewer problems. This is despite the fact that in our sample participants in these regions were, on average, slightly older and less educated than those in non-CC states.

Central coordination in Austria was introduced individually by federal state rather than nationwide. The comparison in this study is consequently not just between LC care pathway models but also between Tyrol and Vorarlberg and the other federal states. Structural differences could therefore present potential mediators in the discussed associations, and our results should be interpreted accordingly and within the appropriate context. Neither Tyrol nor Vorarlberg have an exceptionally large number of GPs per capita, ranking seventh and last out of the nine federal states in terms of GP density [21, 37]. Regarding specialists per capita, Tyrol ranks third and Vorarlberg eighth. Looking at disciplines particularly relevant for LC care such as neurology (Tyrol 3rd, Vorarlberg 9th) and internal medicine (Tyrol 5th, Vorarlberg

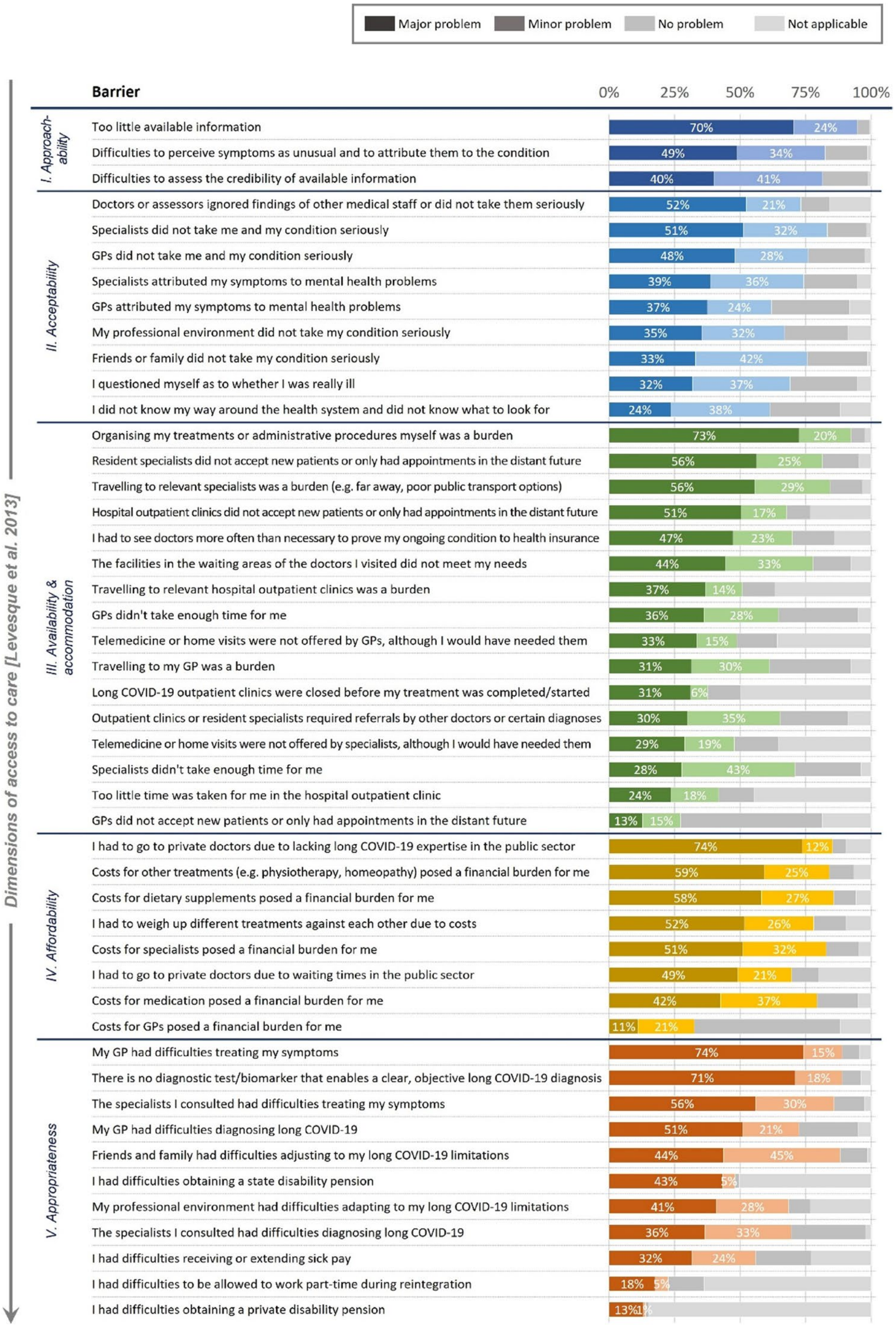

Fig. 2 Healthcare access barriers along the dimensions of access to care among 433 adult long COVID-19 patients in Austria

8th) the ranks are similar [21, 37]. Given the close geographical proximity of the two federal states, these rankings may imply a spillover of patients from Vorarlberg seeking treatment in Tyrol – the larger federal state, which also hosts a medical university and associated university hospital [38]. These rankings indicate that there are no structural advantages in these states compared to other federal states that could otherwise explain our findings. However, when considering only contracted resident neurologists per capita, Vorarlberg ranks first and Tyrol second [39]. For contracted specialists in internal medicine per capita Vorarlberg ranks second and Tyrol shares the third place [40]. In this context, our identified associations between CC and availability and costs

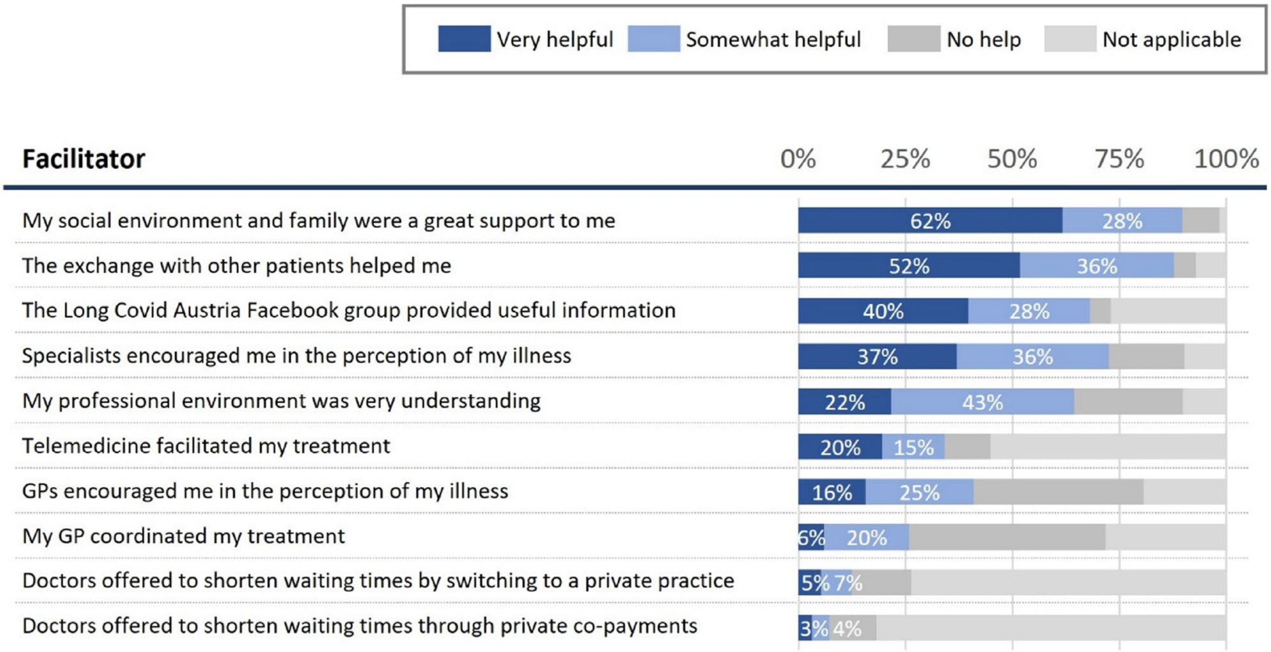

Fig. 3 Healthcare access facilitators among 433 adult long COVID-19 patients in Austria

of specialists could be affected by this comparatively high density of contracted specialists.

Our findings are in line with the so far only other study assessing access barriers to LC patients quantitatively. Brus et al. also find a lack of guidance and expertise being major barriers in the Netherlands, however, at much lower rates (50.9% and 36.8% of participants, respectively). Moreover, respondents in the Dutch study only encountered a median of two out of 11 assessed barriers (18%), which is substantially less than the (median) 32 out of 47 (68%) in our study. [17] However, contrasting to Austria, the Dutch Ministry of Health commissioned a non-profit organisation to provide support and information to LC patients, and Dutch LC patients are eligible for a dedicated extended care package covered by insurance [9, 11, 17]. Comparing Austrian and Dutch findings consequently is also a comparison of different system-level LC care approaches – a comparison we were able to partially replicate regarding the role of (regional) central coordination in Austria. Our findings highlight potential benefits of having CC units in improving LC healthcare access as showcased in Tyrol and Vorarlberg – provided that adequate treatment structures are in place to be coordinated. This conclusion is in line with international non-LC research on benefits of case management [41–43] and interdisciplinary treatment approaches such as tumour boards [44–46]. Further research should be conducted evaluating different LC care pathways in light of available pre-existing structures.

Comparing our results to the current Austrian LC guideline [24] and foreseen patient pathway [22], particularly difficulties by primary care to diagnose, treat, and coordinate LC become visible discrepancies to the envisioned target picture. Notably, only 26% of the participants perceived their GP coordinating treatment as somewhat (20%) or very helpful (6%) although this role is foreseen in the current pathway and guideline [22, 24]. Moreover, 37% stated that closures of specialized LC clinics were problematic while the guideline specifically recommends their setup. Based on a report commissioned by the Ministry of Health in 2022 outlining problems in LC care [47], the ministry established a national reference centre for post-viral syndromes at the Medical University of Vienna as a knowledge and training hub for professionals in September 2024 [48, 49], and initiated the creation of an action plan to improve care for LC and post-viral conditions in general, published in November 2024 [50]. This non-binding 50-point action plan addresses important issues in line with our findings such as improved diagnostics, creation of specialized clinics, improved training for medical staff, and social system adjustments to alleviate the current financial burden. Interestingly, the introduction of central coordination on the example of Tyrol/Vorarlberg is not included despite it being explicitly mentioned – in a footnote [50]. However, in May 2025 it was announced that the action plan would be revised until mid-2026 in response to the Austrian national broadcaster highlighting many LC-related issues also presented in this study such as incorrect mental health diagnoses [51–53].

This study has potential limitations. First, this is the first study to characterize the Austrian LC patient population so we cannot make any inferences on the representativeness of our sample, highlighting the need for a national LC registry for research purposes. We used convenience sampling and recruited mainly through patient support groups and physicians. This approach may overrepresent more engaged and/or more severely affected LC patients. At the same time, we observe a potential bias towards women, better educated, and severely affected patients in our sample. The former, however, could be expected considering the higher LC risk of women [54, 55]. Second, we included both active and recovered LC cases, potentially leading to recall bias. We believe this to be negligible though as the vast majority of participants were still active (92%). Third, using cross-sectional data, we are in no position to establish causality and further research in this regard is required, assessing the role and mechanisms of CC in alleviating patient burden. Fourth, while the BACE instrument that guided survey development shows acceptable test-retest reliability and internal consistency [31], we did not evaluate the psychometric properties of our questionnaire; accordingly, this may limit generalisability and comparability of our findings. Finally, the participant lottery may have introduced a response bias due to the financial incentive. However, as email addresses were collected separately and cannot be matched to individual responses, this potential bias could not be assessed. Given the high level of patient involvement in LC research [6, 56] and anonymous nature of the survey, we argue that participants most likely provided truthful accounts of their experiences, despite the lottery.

The study has three main strengths. First, it is the first Austrian among the few international quantitative studies assessing LC healthcare access. Second, we take a comprehensive approach based on prior exploratory research to characterize healthcare access for LC patients, uncovering implementation gaps of the current patient pathway. Third, we provide insights on the role of central coordination, thus providing a tangible potential way forward nationally and internationally. While Tyrol and Vorarlberg have a comparatively high density of relevant specialists, our findings indicate that CC builds on those structures and enables further patient benefits beyond specialist care. The findings bear substantial policy implications, emphasizing the importance of timely implementation of the national action plan and in extension also consideration of central coordination units across Austria.

Conclusion

Building on prior qualitative findings, this study provides quantitative evidence on LC healthcare access in Austria. Given the high number of barriers perceived as problematic, we conclude that access to LC care is obstructed, with barriers reported at all access steps. We also provide initial evidence that central coordination units may improve healthcare access, conditional on adequate available treatment infrastructure. This paper provides a call for action to address the most pressing barriers, particularly deficiencies in information availability, treatment structures, and public health sector-expertise. Further longitudinal research is needed to evaluate the effectiveness of different LC treatment pathways, including the role of central coordination, in improving healthcare access and health outcomes.

Supplementary Information

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Supplementary Material 1.

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Authors' contributions

AŁ and SM acquired funding for the study, and AŁ, JS, and SM provided the resources, including software. PG, AŁ, and SM were involved in project administration and conceptualized the study. PG, AŁ, KH, and SM were responsible for data curation. PG, AŁ, and SM conducted the formal analysis and investigation, and PG created the visualizations. PG, AŁ, JS, and SM developed the methodology. AŁ, JS, and SM supervised PG. AŁ, KH, SM, and JS validated the study findings. PG wrote the original draft of the manuscript, and PG, AŁ, KH, JS, and SM revised and finalized it. All authors read and approved the final manuscript.

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Data availability

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and national research committee and with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. The study was approved by the Ethics Committee of the Medical University of Vienna. All participants provided informed consent to participate.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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