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Patients' Experiences at a Comprehensive Long COVID Recovery Clinic: A Qualitative Study

Jennifer B Unger

unger@usc.edu

University of Southern California

Jamieson Wilcox

University of Southern California

Lori Ginoza

University of Southern California

Jeffrey Klausner

University of Southern California

Roxana Gates

University of Southern California

Sandra Vasquez

University of Southern California

Juliana N Fong

University of Southern California

Caitlin H McAuley

University of Southern California

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Abstract

Background

Although the acute phase of the COVID-19 pandemic has receded, many patients still suffer from the chronic effects of Long COVID. Comprehensive Long COVID recovery clinics have proliferated to provide multispecialty care for this complex condition. This study examined the experiences of 21 patients at a Long COVID recovery clinic to understand patients' experiences when seeking multispecialty care at a Long COVID recovery clinic, with the goal of identifying barriers to accessing services and facilitators of helpful treatment.

Method

Individual qualitative interviews were conducted in 2024–2025 with 21 patients who had expressed interest in receiving care at a Long COVID recovery clinic. Qualitative analysis included an inductive thematic analysis process with independent coding and investigator triangulation.

Results

Four themes were identified: Challenges with Registration and Scheduling, Care Coordination Across Disciplines, Challenges with Insurance and Access, and Compassion and Validation.

Conclusion

Multispecialty Long COVID clinics provide comprehensive and compassionate care. Efforts are needed to reduce systemic barriers to ensure equitable, coordinated, and patient-centered services.

Introduction

Since the emergence of SARS-CoV-2 in late 2019, the medical community has mobilized to address the acute manifestations of COVID-19. However, for a substantial subset of individuals, recovery from the initial infection does not mark the end of their illness. Instead, these individuals continue to experience persistent, often debilitating symptoms lasting weeks, months, or even years after their acute illness. This condition, called Long COVID or post-acute sequelae of SARS-CoV-2 infection (PASC), is characterized by multiple fluctuating physical, cognitive, and psychological symptoms, including fatigue, dyspnea, post-exertional malaise, brain fog, and dysautonomia, which adversely impact patients' quality of life, occupational functioning, and psychosocial well-being (Almas et al., 2022; O'Mahoney et al., 2025; Rahmati et al., 2025).

Several studies have documented the lived experiences of patients with Long COVID as they attempt to adjust to their new health status (Razai et al., 2021). Patients have reported feeling ignored, dismissed, and invalidated because of the enigmatic nature of Long COVID (Bontempo et al., 2025), and they have reported difficulty adjusting to having a chronic illness with unpredictable symptoms (Eberhardt et al., 2024; Hossain et al., 2023; Thomas et al., 2023). Patients also have mentioned barriers to healthcare access, lack of coordination across providers, lack of knowledge about Long COVID and its treatment among providers, compassion from providers who recognize Long COVID as a legitimate chronic disease, and lack of support from providers who are unfamiliar with Long COVID or do not believe in its existence (Gardner et al., 2024; Hawke et al., 2023; Laestadius et al., 2024; MacEwan et al., 2024).

In response to the unique needs of Long COVID patients, multispecialty Long COVID recovery clinics have been established to provide coordinated care and symptom management (Santhosh et al., 2021). These clinics integrate medical, rehabilitative, and psychosocial services to address the multifaceted nature of Long COVID. However, the evidence base for effective interventions remains limited. Little is known about patients' experience accessing multispecialty Long COVID clinics, the process of care coordination, and the extent to which patients are able to navigate multispecialty clinics to obtain the services they need, while struggling with the limitations imposed by a relatively new and understudied illness. Understanding these subjective experiences is essential for designing responsive, patient-centered care models and for informing future clinical guidelines and health policy decisions.

This study explores the lived experiences of patients receiving care at a multispecialty Long COVID recovery clinic affiliated with a large academic medical center in United States. Using an inductive, thematic approach, we examined how patients described their experiences accessing the clinic, interactions with providers, and ability to receive appropriate services. This analysis centers the voices of patients to provide insight into the benefits and limitations of multidisciplinary coordinated care models, and to identify opportunities for improving the responsiveness, accessibility, and sustainability of Long COVID services.

Methods

This qualitative study explored the experiences of patients receiving care at a comprehensive, multispecialty Long COVID clinic. The goal was to identify salient themes in their narratives and provide insights to inform improvements in care delivery. Semi-structured interviews were conducted to capture in-depth accounts of patient experiences.

Clinic setting

The Keck Medicine of USC COVID Recovery Clinic provides multidisciplinary care for patients with Long COVID. The care model includes primary care, physical therapy, occupational therapy, social work, nursing and care coordination, with referral to additional specialties such as pulmonology, cardiology, neurology, rheumatology, and behavioral health based on individual patient needs. Patients undergo an

initial assessment and medical evaluation, after which an individualized care plan is developed and referrals and follow-up services are coordinated across disciplines.

Participants

Participants (N=21) were recruited from the COVID Recovery Clinic in Los Angeles, California. Eligible participants were adults who had completed the intake assessment to receive care at the clinic. After completing the intake assessment, patients were invited to provide consent and schedule a qualitative interview by Zoom. The patients' mean age was 42.8 years (range 20-86); 57% were female; 33% were non-Hispanic white, 5% were Black, 33% were Hispanic, 5% were Asian/Pacific Islander, and 24% reported another racial/ethnic group or declined to state their race/ethnicity.

Data Collection

The authors developed a semi-structured interview guide focusing on topics such as registration and scheduling, access to care, treatment experiences, and emotional well-being (shown in Table 1). Interviews were conducted between November 11, 2024 and February 12, 2025 via Zoom. Each interview lasted approximately 30-45 minutes. All interviews were conducted in English.

Table 1 about here

Data cleaning

Zoom automatically generated a transcript of each interview. The staff member who conducted the interviews reviewed the transcripts and corrected errors. All transcripts were combined into one document for analysis, and personal identifiers were removed.

Data Analysis

We conducted an inductive, codebook-based thematic analysis with investigator triangulation (Coulston et al., 2025). Two graduate coders unaffiliated with the clinic independently read all transcripts for familiarization and open-coded meaning units, each developing a provisional thematic framework to capture recurrent patterns and emergent concepts. Each coder then applied their framework across the full corpus to check code–data fit at the transcript and dataset levels. A senior qualitative researcher reviewed both code sets and thematic structures, compared areas of convergence and divergence, and—through discussion with the coders—reconciled discrepancies and synthesized a consolidated codebook that specified theme definitions, boundaries, and inclusion/exclusion criteria. Using this finalized codebook, the senior researcher and a second student recoded all transcripts; intercoder agreement was assessed, and any residual differences were resolved by consensus. Final themes were then reviewed against the entire dataset to ensure internal coherence and external distinction, and representative quotations were selected to illustrate typical and variant cases. We documented coding decisions and codebook revisions throughout to support transparency and replicability. The study was approved by the University of Southern California Institutional Review Board.

Results

Table 2 shows the final set of themes, their definitions, and representative quotes. The qualitative analysis identified four themes: Challenges with Registration and Scheduling, Care Coordination Across Disciplines, Challenges with Insurance and Access, and Compassion and Validation. Cohen's kappa for intercoder agreement was .97. The themes are described briefly below.

Table 2 about here

Challenges with Registration and Scheduling. Some patients found the registration and scheduling process cumbersome, redundant, and time-consuming. Several participants reported receiving multiple calls asking the same questions, which made the process feel inefficient and frustrating, especially for patients who already suffered from fatigue that forced them to limit their daily physical and cognitive activities. The clinic was simultaneously onboarding patients and conducting evaluation research, so some patients indeed were asked the same questions for their medical records and the evaluation. Some patients suggested simplifying communication by consolidating multiple back-and-forth emails or phone calls into a single conversation or automatically populating data from one computer system to the next to reduce confusion and improve the overall patient experience.

Care Coordination Across Disciplines. Patients expressed frustration with delays in the referral process and a lack of follow-up from specialists. Some were unsure about the next steps after their initial visit and felt lost in the system while waiting for specialists to return their calls. Some received a referral to a specialist but never heard from the specialist, forcing them to contact multiple practitioners' offices proactively to complete the handoff to the specialist. Patients acknowledged that external factors such as staffing shortages might contribute to delays, but they still felt that better communication could have improved their experience. Patients expected the clinic to coordinate their care across disciplines, and they were disappointed or frustrated when cross-discipline handoffs were incomplete.

Challenges with Insurance and Access. Some patients struggled with insurance approvals and felt uncertain about their financial responsibility for care. Several noted that the approval process was slow and bureaucratic, making it difficult to get timely treatment that they needed and their clinicians had recommended. Others expressed concern that not all insurance plans were accepted, limiting access to care for those with non-standard plans. Even those patients with insurance coverage worried that other patients would be denied services because of inadequate insurance. There were also instances of miscommunication about insurance details, where patients received incorrect information about their coverage or were unexpectedly billed for services that they expected to be covered by insurance.

Compassion and Validation. Patients praised the clinic staff for their compassion, attentiveness, and willingness to listen. Compared to their experiences in other healthcare settings, they felt that the providers treated them with more empathy and took their symptoms seriously. Some participants noted that this was the first time they had been truly heard, as other providers had dismissed or downplayed their symptoms. Prior to coming to the Long COVID clinic, several had experienced dismissal or

skepticism from other providers who minimized their symptoms or attributed them to anxiety. At the comprehensive COVID-19 clinic, however, they felt that their condition was acknowledged as real and worthy of medical attention, which gave them a renewed sense of hope and legitimacy in their healthcare journey. Patients also appreciated the one-on-one attention and felt that the staff genuinely cared about their well-being.

Discussion

This study explored patients' experiences at a multidisciplinary Long COVID recovery clinic. Their comments highlighted both the benefits and challenges of care in a complex and evolving clinical environment. Participants expressed appreciation for the clinic's compassionate and validating approach to care, particularly in contrast to prior experiences of being dismissed or disbelieved in other healthcare settings. However, participants also reported barriers related to care coordination, registration logistics, insurance coverage, and communication. Although most patients were satisfied with their care overall, these barriers sometimes undermined the supportive environment the clinic intended to provide.

Consistent with prior research (Gardner et al., 2024; Hawke et al., 2023; Laestadius et al., 2024), participants valued clinicians who acknowledged Long COVID as a real and serious condition. Some participants described the clinic as the first place they felt "seen" and "believed," reinforcing the critical role that validation plays in the care of individuals with poorly understood, stigmatized, or contested illnesses (Bontempo et al., 2025). The sense of legitimacy and emotional relief patients experienced at the clinic is a core strength of the comprehensive care model and should be considered an essential component of Long COVID care.

However, participants described multiple structural challenges. Registration and scheduling processes were experienced as redundant or opaque, and delays in follow-up from specialists created uncertainty and frustration. These findings align with other studies documenting poor communication and fragmented care pathways in Long COVID services (Hossain et al., 2023; MacEwan et al., 2024). Even in a clinic designed to centralize and coordinate care, patients often felt left to navigate a confusing and bureaucratic system on their own. This issue might have been exacerbated by the fact that the clinic was providing services, participating in an external evaluation, and conducting an internal evaluation at the same time. Continued efforts are needed to improve the registration process, including avoiding redundant questions and populating data across computer systems.

Insurance-related challenges added another layer of complexity. Participants reported uncertainty about coverage, difficulties obtaining approvals, and a perception that only those with certain types of insurance could access care. These issues raise important concerns about health equity, particularly as Long COVID disproportionately affects people with chronic conditions, lower socioeconomic status, and marginalized identities. Access to comprehensive Long COVID care is needed for all patients who suffer from this debilitating condition.

It is important to note that the barriers described by patients in our study are not specific to Long COVID clinics. Numerous studies have documented similar barriers to healthcare access in general, including lack of information, lack of insurance, out-of-pocket costs, social determinants of health, racism and bias, lack of appointments, communication gaps, and lack of technical literacy (Chen, 2025). Although patients with Long COVID might experience more difficulty overcoming these barriers because of low energy, trouble concentrating and retaining information, and other Long COVID symptoms, these barriers exist throughout the healthcare system.

Although multidisciplinary clinics are intended to reduce fragmentation by bringing relevant expertise into a coordinated model of care, our findings suggest that the presence of multiple specialties does not ensure that patients experience care as coordinated. Participants continued to encounter incomplete referral handoffs, repeated requests for information, uncertainty about next steps, and insurance-related barriers. For patients experiencing fatigue and cognitive symptoms, these administrative demands may be especially burdensome. Multidisciplinary Long COVID programs therefore may benefit from evaluating not only the range of services they provide, but also the extent to which responsibility for navigating those services remains with the patient.

This study has several limitations. First, the sample was small and was drawn from a single Long COVID clinic affiliated with an academic medical center in Los Angeles, which may limit the transferability of the findings to other clinical settings, geographic regions, or patient populations. Second, participants were recruited after completing the clinic's intake assessment, so the study may underrepresent individuals who experienced barriers severe enough to prevent them from successfully entering care. Participation in the interviews was voluntary, which may also have introduced self-selection bias if patients with particularly positive or negative experiences were more likely to participate. Third, all interviews were conducted in English, potentially excluding patients with limited English proficiency and limiting insight into language-related barriers to care. Fourth, the clinic was still evolving while the evaluation was conducted, and some operational issues identified by participants, including redundant questions and communication burdens, may have reflected the simultaneous implementation of clinical services and evaluation activities rather than stable features of the care model. Finally, the findings are based on participants' self-reported experiences and perceptions and were not linked to objective measures of service utilization, clinical outcomes, or recovery. Accordingly, the results should be interpreted as an in-depth description of patient experiences with this particular multidisciplinary Long COVID clinic rather than as evidence of the effectiveness of the clinic model. However, these findings could be helpful to other multidisciplinary Long COVID clinics.

Our findings suggest that multidisciplinary Long COVID clinics can facilitate patient recovery by providing diverse services that address all aspects of this complex condition, including providing validation to patients who feel dismissed by the healthcare system. However, to be maximally effective, clinics need to address operational inefficiencies. Efforts to streamline registration, improve communication between departments, enhance transparency about insurance policies, and proactively follow up with patients may significantly improve the care experience. Providing easily accessible

multispecialty care to all patients with Long COVID has the potential to improve the quality of life of this underserved patient population, especially if structural, financial, and logistical barriers can be minimized.

Declarations

Ethics approval and consent to participate: The study was approved by the University of Southern California Institutional Review Board. All participants provided informed consent.

Consent for publication: Not applicable – no identifiable participant information.

Availability of data and materials: De-identified data are available from the authors upon request.

Competing interests: The authors report no competing interests.

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Authors' contributions: All authors contributed to study design and conceptualization. Sandra Vasquez also collected the data. Jennifer Unger and Juliana Fong conducted the qualitative analysis. All authors contributed to writing.

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Tables

Table 1. Semi-structured interview guide

1. How did you learn about the COVID Recovery Clinic?
2. Please tell me about your experiences signing up for the COVID Recovery Clinic. What was easy and what was difficult? Do you have ideas to make the registration process easier for patients?
3. How easy or hard was it to schedule an appointment? What could we have done better?
4. When you scheduled your first appointment, what kinds of symptoms were you having?
5. What kinds of treatment did you receive?
6. Were you referred to other departments, such as specialist physicians, occupational therapy, physical therapy, or behavioral health support? If so, which ones?
7. Please tell me about your experiences with these other departments.
8. What do you like most about the COVID Recovery Clinic?
9. What ideas do you have to improve our services for future patients?

Table 2

Themes, definitions, and representative quotes

Theme	Definition	Representative Quotes
Challenges with registration and scheduling	Cumbersome registration process, being asked the same questions multiple times, confusion about clinic policies and procedures, multiple calls and emails required to register	"I received two telephone calls asking the same questions. I don't understand why that happened." "The process was easy, but it would have been better if they had informed me about the co-pay upfront. I didn't know, and I was charged twenty-five dollars when I checked in." "It wasn't really a problem for me, but it just seemed to take a long time. If we could have had one conversation instead of all these emails back and forth, it would have been a lot faster."
Care Coordination Across Disciplines	Delays in the referral process, incomplete referrals, waiting a long time to be contacted by the next specialist, feeling unsure about next steps	"They were supposed to call me today or tomorrow to schedule an appointment. I don't think the office is open today, so maybe tomorrow, but I'm not sure." "I have not heard from anybody. I know it's a holiday too, maybe that's the grace we give right now, but still… no communication." "I got a referral to see a neurologist, but I have called multiple times, and no one has returned my calls to schedule the appointment. It has been weeks now."
Challenges with Insurance and Access	Lack of clarity about which services insurance would cover, uncertainty about out-of-pocket costs, slow and bureaucratic insurance approval process, sense of injustice that some insurance plans were accepted and others were not	"Sometimes it's like a process to get approved, so maybe have more openness to different insurance options." "They mentioned something about my insurance that does not apply to me, so I have a feeling they may be getting information mixed up." "I don't know if I would have been able to get in if I didn't have the right insurance. It seems restrictive."
Compassion and validation	Clinic staff treated patients with compassion, listened, took their symptoms seriously, and validated that their Long COVID was a real illness	"I like how understanding and compassionate they are compared to other doctors or even the ER." "When I went to the COVID Recovery Clinic, they actually listened. They actually cared about everything I said." "I finally felt like someone believed me. I wasn't being told it was all in my head." "This is the first time a doctor has taken me seriously. They didn't brush me off."

Theme	Definition	Representative Quotes
		"I left feeling like I was actually being treated like a real patient, not just someone complaining.”