Challenges in Receiving Care for Long COVID: A Qualitative Interview Study Among Primary Care Patients About Expectations and Experiences

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ABSTRACT

BACKGROUND For many patients with post–COVID-19 condition (long COVID), primary care is the first point of interaction with the health care system. In principle, primary care is well situated to manage long COVID. Beyond expressions of disempowerment, however, the patient's perspective regarding the quality of long COVID care is lacking. Therefore, this study aimed to analyze the expectations and experiences of primary care patients seeking treatment for long COVID.

METHODS A phenomenological approach guided this analysis. Using purposive sampling, we conducted semistructured interviews with English-speaking, adult primary care patients describing symptoms of long COVID. We deidentified and transcribed the recorded interviews. Transcripts were analyzed using inductive qualitative content analysis.

RESULTS This article reports results from 19 interviews (53% female, mean age = 54 years). Patients expected their primary care practitioners (PCPs) to be knowledgeable about long COVID, attentive to their individual condition, and to engage in collaborative processes for treatment. Patients described 2 areas of experiences. First, interactions with clinicians were perceived as positive when clinicians were honest and validating, and negative when patients felt dismissed or discouraged. Second, patients described challenges navigating the fragmented US health care system when coordinating care, treatment and testing, and payment.

CONCLUSION Primary care patients' experiences seeking care for long COVID are incongruent with their expectations. Patients must overcome barriers at each level of the health care system and are frustrated by the constant challenges. PCPs and other health care professionals might increase congruence with expectations and experiences through listening, validating, and advocating for patients with long COVID.

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BACKGROUND

Post–COVID-19 conditions (PCC), or "long COVID," is an imminent public health emergency. Long COVID has already contributed to an estimated 3,500 American deaths, resulted in around $200 billion in lost wages, and affected at least 16 million working-age adults.[1,2] These are conservative estimates, however, as the diagnosis of long COVID remains challenging.[3]

Long COVID is defined as the continuation or development of new symptoms 3 months after initial SARS-CoV-2 infection, with symptoms lasting at least 2 months with no other explanation.[4] Generally, people with long COVID experience a variety of symptoms, including fatigue, shortness of breath, smell and taste disorders, concentration or memory problems, and mental health conditions.[5-8] A meta-analysis found that 33% of individuals experienced fatigue, and 22% experienced cognitive impairment 3 months after COVID-19 infection.[9] Those and other symptoms are highly prevalent in non-hospitalized patients in primary care.[10]

Currently, long COVID remains a diagnosis of exclusion; however, the heterogeneity of conditions makes long COVID difficult to identify and diagnose consistently.[11,12] Regarding treatment and management, interim guidance for health care professionals suggests holistic, patient-centered management approaches, including symptom monitoring, setting expectations, providing continuous follow-up,

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establishing partnerships with specialists, and connecting patients to social services.[11,13-16] Primary care provides this type of whole-patient care, and is well-situated to manage long COVID.[11,17] In primary care, however, the strong overlap of long COVID symptoms with common complaints makes the diagnosis even more challenging.[10,18]

Beyond patients' expressions of stigmatization and disempowerment,[19] less is known about the patient's perspective and expectations for the quality of long COVID care overall. Previous qualitative research from outside the United States has suggested that patients struggle to obtain quality health care for long COVID,[20-23] but research in the United States is largely missing.[24] To improve the understanding of long COVID in the United States, this study aims to analyze the expectations and experiences of primary care patients seeking care for long COVID.

METHODS

Study Design

We used the Consolidated Criteria for Reporting Qualitative Research (COREQ). The study took place at University of Utah health clinics. Due to its exploratory nature, this study adopted a phenomenological framework for the semi-structured interviews.[25] The University of Utah Institutional Review Board (IRB #139714) exempted this study from review.

Participant Selection

We purposively sampled adult, English-speaking primary care patients from a long COVID triage clinic at the University of Utah. Admission to the clinic requires a referral from a PCP. Nurses at the clinic identified patients who met the inclusion criteria and were interested in being interviewed. Participants received a study cover letter and discussed questions about the study with the interviewer as needed. Participation in the interview was considered consent to be included in the study. Participants did not receive compensation for their contribution.

Data Collection and Analysis

Interview Guide

A literature review identified gaps in knowledge surrounding patient experiences with care for long COVID. Based on the results, the interview guide (Supplemental Appendix) was developed iteratively. It was revised for clarity and content validity based on feedback from clinicians (B.K., K.L.S., J.P.L.) and a researcher with expertise in qualitative methods (D.J.O.). Data on race, ethnicity, gender, occupation, marital status, and infection year were self-reported during the interview.

Conducting Interviews

Mentored and trained by D.J.O., E.G. conducted 20 interviews between 2022 to 2023, in-person or over the telephone. Interviews lasted 20 to 30 minutes. Two participants had a partner present, especially when their symptoms were memory related. The interviews were audio recorded, deidentified, and transcribed verbatim. All data were safely stored on protected computers. One interview was accidentally deleted and was not transcribed. To address rigor, data saturation was reached around interview 15, but an additional 5 interviews were conducted to ensure the full representation of participants' experiences.[26]

Data Analysis

Three researchers (E.G., A.L., and D.J.O.) used inductive qualitative content analysis.[27,28] Researchers independently reviewed the data, identified themes, and discussed differences until a consensus was reached. We did not review findings with participants.

RESULTS

Participant Characteristics

We contacted 46 patients, and 20 participated in interviews (43% response rate). We analyzed 19 interviews. Participants averaged age 54 years, and 53% were female. Ninety-four percent of participants were White and 89% were non-Hispanic. Most participants were married (74%). Most participants were infected with COVID-19 for the first time in 2020 (32%) or 2021 (47%) (Table 1).

Patient Expectations

Participants described 2 categories of expectations: those for their clinicians and those for treatment. Major themes

Table 1. Cohort Description

Characteristics	Participants
n	19
Age, mean (y)	54 (36, 77)[a]
Sex (female), %	53 (n = 10)
Race, %	
Black/African American	6 (n = 1)
White	94 (n = 18)
Ethnicity, %	
Hispanic/Latine	11 (n = 2)
Not Hispanic/Latine	89 (n = 17)
Marital status, %	
Single	21 (n = 4)
Married	74 (n = 14)
Widowed	5 (n = 1)
Year of first infection, %	
2020	32 (n = 6)
2021	47 (n = 9)
2022	16 (n = 3)
2023	5 (n = 1)

[a] min, max.

included expectations for primary care practitioner (PCP) knowledge, engagement with treatment plans, and collaboration with a care team (Table 2; Supplemental Table 1).

Expectations for PCPs

A major theme was the PCP's knowledge regarding long COVID. Knowledge was demonstrated by answering questions, such as if long COVID is a short or long-term condition. At the same time, some patients recognized that long COVID research is in an early stage and expressed frustrated understanding when PCPs could not give immediate solutions. Patients expected their PCP to take the time to understand their conditions and circumstances, however, and be engaged in their treatment process, especially in the face of a complex condition.

> "I expect her to follow up on things [...] she made sure all the information was along with the referral [...] and I just expect advocacy like that." (I14:553-563)

Expectations for Treatment

Themes about treatment expectations for long COVID were centered around communication and engagement between members of the care team and the patient. Because of the multi-system effects of long COVID, many patients meet first with their PCP and then are referred to specialty care. During this process, patients expected their clinicians to collaborate with them on possible treatment options, such as complementary medicine (eg, supplements or vitamins) or community resources (eg, peer support). Additionally, patients expected collaboration and communication among the care team, including communication about medications for treatment.

> "It's hard when one doctor puts you on a med that causes you to be tired, and then the next doctor gives you a med to not make you tired ... so, a little better communication, a little bit more, um, continuity between appointments and doctors." (I12:282-289)

Table 2. Patient Expectations

Category	Themes
Expectations for primary care practitioners (PCPs)	Knowledgeable practitioners Lowered expectations Individual assessment Engagement
Expectations for treatment	Collaboration with patient Communication across care team Interdisciplinary knowledge sharing

Table 3. Interacting With Clinicians

Category	Themes
Positive experiences	PCP listens PCP is honest PCP is supportive Longitudinal relationship with PCP
Negative experiences	Dismissal Discouragement Inappropriate treatment

PCP = primary care physician.

Interacting With Clinicians

Patients extensively described their experiences with PCPs and specialists. Major themes included positive experiences like honest and supportive clinicians and negative experiences like dismissal and discouragement (Table 3; Supplemental Table 2).

Positive Experiences

Several patients described good quality of care, including their clinicians' support, active listening, and honesty. In addition, patients with an established PCP relationship felt they received better care because their clinician knew them well. Both patients and clinicians were sometimes frustrated, however, with the need for more information about long COVID. Patients appreciated when the PCP was upfront and honest about their frustration. Some patients viewed the referral to the long COVID specialty clinic as an example of support.

> "[The clinician] was a little frustrated because he didn't have the answers. And that's obvious. And he was very upfront and honest with me, and that's why he referred me to the clinic." (I6:236-239)

Negative Experiences

More frequently, however, patients reported challenges when interacting with clinicians, including specialists. Those ranged from dismissal and discouragement to sometimes questionable treatment decisions. For example, feelings of dismissal often surfaced when clinicians were unwilling to acknowledge the existence or severity of long COVID. Instead of offering validation, patients were told "This is just COVID" (I11:496-499) or "This is all in your head. You are fine" (I19:396-402). Particularly among specialists, it seemed to be challenging to acknowledge long COVID symptoms when diagnostics do not show noticeable results.

> "Where I felt more frustrated is where other doctors, like lung specialists or physical therapists [...] say, 'there's nothing wrong with you. Your organs are fine. Your lungs are fine. There's nothing more we can do for you." (I19:396-402)

Other clinicians acknowledged the symptoms but were discouraging in other ways. For example, they told the patient that they would not recover, that they had to live with it, or linked the long COVID symptoms to other patient characteristics, like being overweight. In the quote below, the clinician exclusively recommends weight loss to manage the patient's long COVID symptoms.

"I have had everything from, you know, 'this is as good as you're gonna be so just live with it.' I have had the 'you need to lose weight. That's the only thing that's wrong with you.'" (I12:211-224)

In another example, the clinician prescribed an antidepressant after the diagnostic came back without results, and the patient insisted that they still felt terrible. This inappropriate treatment prompted a clinician change.

"They [PCP] took a chest X-ray, said, 'We don't see anything.' They said, you know, 'try to get some rest. Come back in a week.' Still felt terrible in a week, went back and saw them. And they said, 'oh, well, we think you just have had a lot of life changes … here's some Lexapro' … and that did not help." (I9:477-481)

Navigating the Health Care System

The most extensive group of themes related to patient experiences navigating the health system, including challenges regarding access and coordination, diagnosis and treatment, and the cost of care (Table 4; Supplemental Table 3).

Access and Coordination

Challenges with access to care were common themes, both within primary care and with specialists. Patients frequently struggled to access services in time and even occasionally had to go to the emergency department, especially for long COVID symptoms that were not perceived as urgent (eg, memory problems, concentration problems, fatigue) by health care clinicians. For example, a patient felt that they could not access care because their memory problems were not severe enough compared with shortness of breath, even when the patient experienced this situation as a nightmare.

"I get the runaround. […] Do people not realize, like, literally my livelihood depends on me knowing what the hell is going on, and I can't remember. […] it's a nightmare. If you don't have like, breathing problems, they're just like, 'oh well.'" (I14:489-500)

With referrals to specialists, patients faced challenges when coordinating care between PCPs and specialists. Participants described follow-up on referrals as difficult. In one case, a participant was trying to coordinate referral to 2 specialists with their PCP and described the experience as burdensome.

Table 4. Navigating the Health Care System

Category	Themes
Access and coordination	Lack of timely primary care Barriers to care Challenges with coordinating care
Diagnosis and treatment	Long wait times Lack of treatment options
Costs and payment	High costs for few improvements in symptoms Delayed care leading to emergency department admission and high costs Challenging insurance claims process

"We're … on MyChart with the nurse from his primary care doctor … they're questioning, 'Why do you wanna see a gastroenterologist? Why do you wanna see a neurologist? The doctor has to know before he can refer you.' ... it's a lot of work." (I2:427-439)

Diagnosis and Treatment

Participants frequently described barriers to testing and treatment. Almost all patients referred to specialists for diagnosis and treatment experienced long lag times and rescheduled appointments. For example, a patient with difficulty sleeping waited 9 months for a sleep study and another several months before obtaining the needed equipment. Another patient with difficulty sleeping could not undergo sleep apnea testing for a year after seeking care.

"They set it for January. So, it will be a year since I got COVID to actually get that test." (I1:323-334)

In addition, some patients felt their clinicians were not supportive of non-clinical treatment options (eg, exercise, supplements, or dietary changes), and, overall, treatment options in general.

"The doctor kind of gave a quote/unquote thing... I will—let me just tell you right now, I will not have any magic pills, I will not have any magic potions, and will not be recommending supplements or anything." (I2:244-252)

Cost of Care

Many patients also question the value of pursuing treatment. Some patients described health care costs amounting to thousands of dollars, and said they no longer have the money to continue pursuing treatment.

"Very recently, I ended up with a bill for like almost 1,400 bucks. That's my part to pay, right. And before I was paying, you know, 100 here, 200 there, it was like little stuff. […] I'm like, who knows, almost 3,000 in the hole for nothing. […] so, I don't have the money to do this anymore." (I10:364-400)

A few patients described the costs they incurred after they could not access primary care services, chose to present in the emergency department instead, and received large bills. In addition, navigating insurance claims for these visits is often a challenge. Several patients described delayed care because of a lack of communication between clinicians and insurance companies. One patient described how their insurance company contacted them for more explanation on what their clinician authorized. They could not explain, however, resulting in delayed care.

DISCUSSION

This study aimed to capture patients' expectations and experiences navigating health care with long COVID. Patients expect collaboration across the health care system, interdisciplinary knowledge sharing, strong communication between health care professionals, and, in particular, a strong patient-centered approach, focusing on their situation and needs. Unfortunately, their experiences were largely incongruent with their expectations.

Patients described seeking care for long COVID as an arduous task. Patients must find clinicians who are knowledgeable about long COVID and are not dismissive of their symptoms, endure long wait times for treatment and testing, and have enough time, money, and patience to wade through complex systems of referral and authorization. As a result, patients with long COVID perceived having engaged in extremely challenging yet unrewarding tasks of appointments, waiting, and testing, for little or no relief. While many systemic barriers are largely out of clinicians' control, validation and continuous support from PCPs, alongside coordinated care and communication among the care team, might improve care quality for patients with long COVID.

Patient expectations for general primary care (ie, disease and treatment knowledge, rapport, emotional support) are similar to those for long COVID care.[29] In this study and others, patients expect multidisciplinary, holistic services, continuity of care, and clear clinical responsibility.[20,24] A novel finding is that patients are motivated to be involved in the collaborative process of knowledge generation and sharing with their PCPs and multidisciplinary care teams to promote long COVID treatment. Further, patient's experiences did not always align with expectations. Although similar experiences of dismissal or disempowerment from providers are reported in other qualitative and mixed methods studies, the perspective of US primary care patients is not well represented.[21,30] This analysis contributes necessary context to the evidence regarding patient experiences with long COVID care in the fragmented US system.

Additionally, other studies have reported the frustration of long COVID patients with standard care approaches and often found accessing care expensive, complex, and exhausting.[21,22,24] Comparisons between long COVID and myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), another poorly understood chronic illness with a similar need for improved diagnosis and management techniques, have been made.[31]

The Institute of Medicine and Agency for Healthcare Research and Quality (ARHQ) have defined 6 domains for health care quality in the United States: safe, effective, patient-centered, timely, efficient, and equitable.[32] This study revealed significant challenges in accessing patient-centered, timely, and efficient health care. An important reason for this situation is the highly fragmented, multi-payer health care system in the United States. Complex conditions like long COVID or other multimorbid chronic diseases depend on collaboration within and between primary care and other levels of care, like emergency and specialist care. Instead, complex conditions frequently expose the weak points of a health care system focused on single diseases and clearly defined procedures.

Strengths and Limitations

This study is one of the first qualitative analyses sampling exclusively primary care patients in the United States. Another strength is that these participants were recruited from a long COVID triage clinic rather than social media sampling.[5,20,30,33,34] The population of the long COVID clinic likely includes the most severely affected patients. Responder bias may influence these results, as individuals recruited from this clinic might be more willing to participate in research. The patients interviewed for this study were mainly from a White, non-Hispanic population, and female. Recruiting from the general population could increase understanding of experiences related to gender, race, or disease severity. Asking patients to provide input on the interview guide could improve patient perspectives in future studies. Finally, we did not explore the differences between patients referred to the clinic from clinicians internal to the University health system compared with external clinicians.

CONCLUSION

Primary care patient's experiences seeking care for long COVID are often incongruent with their expectations. Patients must overcome barriers at each level of the US health care system, from PCP to insurance company, and are frustrated by the constant challenges. Despite the emergence of interim guidelines for PCPs on the management and treatment of long COVID, patients are largely unsatisfied with their care. PCPs and other health care professionals might increase congruence with expectations and experiences through listening, validating, and advocating for patients with long COVID.

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Key words: primary care issues; long COVID; COVID-19; qualitative methods; patient perspective

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Data availability: The data sets generated and analyzed during this study are available from the corresponding author upon reasonable request. Complete interviews are not publicly available to protect the participants' privacy.

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Supplemental materials

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