



Opportunities to Improve Long COVID Care: Implications from Semi-structured Interviews with Black Patients

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Abstract

Background Long coronavirus disease (COVID) is an emerging condition that could considerably burden healthcare systems. Prior qualitative studies characterize the experience of having long COVID, which is valuable for informing care strategies. However, evidence comes from predominantly White samples. This is a concern because underrepresentation of Black patients in research and intervention development contribute to racial inequities.

Objective To facilitate racial equity in long COVID care, the purpose of this qualitative study was to inform the development of care strategies that are responsive to the experiences and perspectives of Black patients with long COVID in the United States of America.

Methods Using convenience sampling, we conducted race-concordant, semi-structured, and open-ended interviews with Black adults (80% female, mean age = 39) who had long COVID. We transcribed and anonymized the recorded interviews. We analyzed the transcripts using inductive, thematic analysis. Theme development focused on *who* can help or hinder strategies for reducing health inequities, *what* should be done to change care policies or treatment strategies, and *when* are the critical timepoints for intervention.

Results We developed four main themes. Participants reported challenges before and after COVID testing. Many participants contacted primary care physicians as a first step for long COVID treatment. However, not all respondents had positive experiences and at times felt dismissed. Without a qualifying diagnosis, participants could not obtain disability benefits, which negatively influenced their employment and increased financial hardship.

Conclusions There are possible targets for improving long COVID care, from COVID testing through to long-term treatment plans. There is a need to increase long COVID awareness among physicians. Diagnosis and a standardized treatment plan could help patients avoid unnecessary healthcare utilization and obtain comprehensive support.

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Key Points

When discharged from the hospital for acute coronavirus disease (COVID), patients value guidance on follow-up visits and symptom management recommendations.

There is a need to increase long COVID awareness and education among primary care physicians.

Black patients face barriers to seeking care for long COVID because of their race.

Long COVID patients would benefit from standardized care approaches and comprehensive support.

1 Introduction

Long coronavirus disease (COVID) refers to new or persistent health impairments following acute infection from the novel coronavirus, severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2), and is also known as long haulers syndrome and post-acute sequelae of COVID infection (PASC). As an emerging condition without an agreed-upon case definition, the incidence depends on how long COVID is defined (e.g., the symptoms that must be present, the length of time following COVID infection) as well as the source population [1]. For example, among outpatients with mild COVID, 32.7% had at least one persistent COVID symptom 3–9 months after illness onset [2]. Among those who received inpatient care, 87.2% reported the persistence of at least one symptom an average of 60 days after COVID onset [3]. Commonly reported symptoms include anosmia, fatigue, dyspnea, memory and concentration problems, headaches, body aches, joint pain, paresthesia, depression, and anxiety. In the United States of America (USA), long COVID could cost \$2.6 trillion and result in 1 million people being out of the workforce at any given time [4]. Long COVID represents a considerable public health problem, and science is racing to advance our understanding of its risk factors, pathogenesis, and treatment options [5].

As science advances, racial inequities in long COVID care and research are a concern. The COVID pandemic is associated with stark racial differences, encompassing infection rates, proportion of severe cases, mortality, and vaccination status [6, 7], with clear disparities within Black communities relative to White communities. This is demonstrated by a recent study of an integrated-delivery health system in Louisiana, USA [8], where Black patients—who made up 31% of all patients—were overrepresented in COVID hospitalizations (77%) and deaths (71%). These racial inequalities are due to an inequitable burden of social risk factors in Black communities relative to White communities, which stems from underlying policies and norms like systemic racism [9]. Given that COVID infection rates are higher in Black communities than White communities [10], the long COVID patient population is expected to be inequitably Black. Black patients can also expect to receive inequitable treatment in healthcare settings regardless of their underlying condition due to implicit bias, racism, and colorism [11–14]. For example, physicians are more likely to underestimate pain among Black patients than White patients [15], which reduces the accuracy of treatment recommendations [16]. Among patients presenting to the emergency department for abdominal pain, Black patients have longer wait times and are less likely to be admitted relative to White patients [17].

Another barrier to ensuring equity in long COVID care is the underrepresentation of Black patients in research and

intervention development, which exists across medical specialties [18–20]. Public health policies and care approaches that fail to prioritize marginalized communities can exacerbate health inequities [21]. Thus far, qualitative research provides insight into the experience of having long COVID [22–30], which can be useful for informing patient care [31]. However, existing evidence comes from predominantly White samples and samples that do not report race/ethnicity. To facilitate racial equity in long COVID care, the purpose of this qualitative study was to inform the development of care strategies that are responsive to the experiences and perspectives of Black patients with long COVID in the USA.

2 Methods

2.1 Reflexivity

We had two primary preconceptions when initiating this study: (1) social determinants of health and systemic racism contribute to racial inequities in patient care; and (2) it can be challenging for patients with complex chronic conditions with diverse sequelae like long COVID to navigate healthcare settings. These preconceptions informed the scope of our literature review, development of the interview guide, and interviewer prompts during data collection. During analysis, we paid continual attention to the ways that systemic and structural barriers could influence patient experiences.

2.2 Participant Recruitment

The University of Michigan Institutional Review Board approved this study (HUM00197791). We used convenience sampling to recruit participants between May and September 2021 via UMHealthResearch.com, word of mouth, and posting study flyers on Facebook. To be eligible, participants had to be 18 years or older, self-identify as Black or African-American, and report one or more mental or physical health symptoms at least one month following acute COVID infection. This study was part of a broader project to tailor an online chronic pain self-management resource for patients with long COVID. Therefore, participation required access to the internet. KC-P contacted those who expressed an interest in the study to explain the project in more detail and schedule interviews. Participants received the informed consent via email, which KC-P reviewed with them over the phone or computer. Participants provided verbal consent prior to the recorded interview. All data was self-reported. We did not link the data with diagnostic interviews or medical records. Participants received \$25 for completing the interview.

Table 1. Semi-structured interview guide

1. Tell me about your experience with COVID-19.
2. Do you have any lingering physical or mental health effects from COVID-19? Tell me about it/them.
3. Are there any other physical or mental health effects that you attribute to being infected with COVID-19?
4. I'm going to ask about aspects of life that may have made it harder or helped you deal with these symptoms.
 - (a) Starting with harder, what aspects of your life do you think have made it harder to deal with these symptoms? How so?
 - (b) Now let's talk about what has made it easier. What aspects of your life have helped or made it easier to deal with these symptoms? How so?
5. What are your thoughts about the COVID-19 vaccine?
6. Have you had the vaccine, or do you plan to get it?
 - (a) *If yes*: Why did you decide to get it?
 - (b) *If no*: Why did you decide not to get it?
7. Is there anything else you would like to add about your experience with COVID-19?

COVID-19 coronavirus disease 2019

2.3 Interviews

Following a review of the literature on long COVID, authors with expertise in health equity and qualitative research (RSB, KC-P, MD) developed a semi-structured, open-ended interview guide (Table 1). We designed this guide to characterize the experience of having long COVID and to identify barriers and facilitators to managing long COVID symptoms. Content revision was not required after pilot testing with the first two study participants. The semi-structured interview was paired with the eligibility survey (Table 2), which collected information on participant age, gender, date of most recent acute COVID infection, and whether a diagnostic test (i.e., nasal swab or saliva sample) confirmed the acute COVID infection.

KC-P (gender: female; job title: Community-Engaged Research Coordinator), conducted race-concordant interviews using Zoom [32], a virtual meeting software that is compliant with the *Health Insurance Portability and Accountability Act* of 1996 (HIPAA) for collecting Protected Health Information. KC-P has experience in community engagement and as a patient liaison. Prior to conducting the interviews, KC-P completed training with MD, who has expertise in qualitative interviewing. Interviews were audio and video recorded and transcribed verbatim, with personal identifiers removed. Participants could opt to turn their camera off or access the Zoom meeting via telephone. During the interviews, KC-P queried participants to ensure that we collected information on all the sequelae that participants attributed to long COVID. KC-P wrote summary statements following each interview. Fifteen individuals participated in this study. Interviews lasted an average of 54 min and ranged from 19 to 139 min. We reached data saturation after 13 interviews. Participants did not review the interview transcripts or summaries.

2.4 Analysis

Presented in Fig. 1, we implemented an inductive, thematic analysis using the *Sort and Sift, Think and Shift* approach [33]. First, we extracted descriptive information from the transcripts and summary statements including age, gender, state of residence, long COVID sequelae, and acute COVID hospitalization status. In a round of open coding, three authors independently reviewed the transcripts to identify meaningful data segments (i.e., codes), and then created memos and diagrams that summarized experiences and relationships between codes within each participant.

Next, we compared memos and diagrams across participants to identify categories that revealed opportunities for improving long COVID care. When identifying these categories, we focused on (a) *who* can help or hinder strategies for reducing health inequities; (b) *what* should be done to change care policies or treatment strategies; and (c) *when* are the critical timepoints for intervention. We then condensed the categories into preliminary themes. To be certain that we captured all relevant quote segments and assigned them appropriately within our theme development, we created a coding scheme for focused coding. Two authors applied this coding scheme to the transcripts using MAXQDA 2020 (VERBI Software, 2019). During this iterative step, we refined and finalized our four main themes. All authors reviewed the themes and discussed areas of disagreement to reach final consensus.

3 Results

A total of 24 individuals expressed initial interest in the study. Of these individuals, nine did not respond to any study-related emails or missed their interview appointment and chose to not reschedule. In total, we completed interviews

Table 2. Eligibility survey

1. What is your age? [Must be 18 or older to be eligible]
2. What is your gender?
3. What is your race/ethnicity? [Must identify as Black or African-American to be eligible]
4. Have you had or do you now have COVID-19, the disease caused by the novel coronavirus? [Must answer 'Yes' or 'Probably yes' to be eligible]
 - (a) Yes
 - (b) Probably yes (I think so)
 - (c) Probably No (I don't think so)
 - (d) No
5. Was this confirmed by a physician or a test designed to detect COVID-19, such as nasal swap or saliva sample? [Select all that apply]
 - (a) No, not confirmed by a physician or a test designed to detect COVID-19
 - (b) Yes, confirmed by a physician
 - (c) Yes, confirmed by a nasal swab
 - (d) Yes, confirmed by a saliva sample
6. When did you first get COVID-19? [Must be at least 1 month ago to be eligible]
7. Do you currently have COVID-19?
8. Do you currently have any lingering physical or mental health effects from COVID-19? [Must have one or more lingering symptoms to be eligible]
9. Can you access the internet using a phone, computer, or tablet? [Must have access to be eligible]

COVID-19 coronavirus disease 2019

with 15 participants (Table 3). Participants were predominantly female (80%), residents of Michigan, USA (73%), and aged 39 years on average. A nasal swab confirmed acute COVID diagnosis status for all but one participant, and five participants were hospitalized for acute COVID. On average, participants completed interviews for this study 10 months following their most recent acute COVID infection. Participants reported a range of long COVID sequelae. At least two participants reported one or more of the following symptoms: fatigue, insomnia, or trouble sleeping; brain fog, memory, or concentration problems; loss or change in taste or smell; trouble breathing, shortness of breath, or low blood oxygen levels; headache or migraine; chest pain, heart palpitations, or elevated blood pressure; a worsening of pre-existing conditions like asthma and diabetes; joint pain, back pain, swollen joints, or muscle weakness; paresthesia; anxiety; depression or loneliness; rash, dry skin, brittle nails, or hair loss; fever or diarrhea; swollen lymph nodes, thrush, or strep throat; blurry vision; and trouble losing or maintaining weight.

Presented in Table 4, our analysis identified four main themes concerning opportunities to improve long COVID care. Examples within each theme provide additional detail on participants' qualitative experiences.

3.1 Theme 1: The Challenge of Navigating COVID Testing and What a Positive Test Means

Participants reported a variety of challenges before and after COVID testing. Navigating questions like how to get tested,

where to get tested, and when to get tested could be mentally taxing and was associated with uncertainty about what would or should happen next. For example, one participant sought multiple COVID tests over multiple days due to her symptoms. Once she received her positive COVID test, she was taken to the hospital directly from the COVID testing site.

"They said, 'You can't go. The fire truck and the EMS [emergency medical services], they're on the way.' And I said, 'What was going on?' I said, 'Am I positive?' She said, 'Yes, it's positive, we can't allow you to leave. Your [blood oxygen] is 89, your temperature is 103, and your heart rate is 132.'" [Participant (P) 5]

One participant reported COVID testing hesitancy due to uncertainty about what would happen with her personal health information, which may reflect the historical treatment of Black communities in medical and research settings.

"It's that fear in the Black community that prevents them from going to get tested."/"It wasn't a quick decision to get tested on my part, I thought it was a sinus infection, I was like, 'Oh, my throat is a little scratchy.' And then I said, 'I don't want to be in anybody's database tied to COVID.' ... I was prostrate praying, 'Lord, show me what I'm supposed to do because I don't want to be in anybody's database.'" (P4)

Fig. 1 Study methods. *COVID* coronavirus disease, *IRB* institutional review board

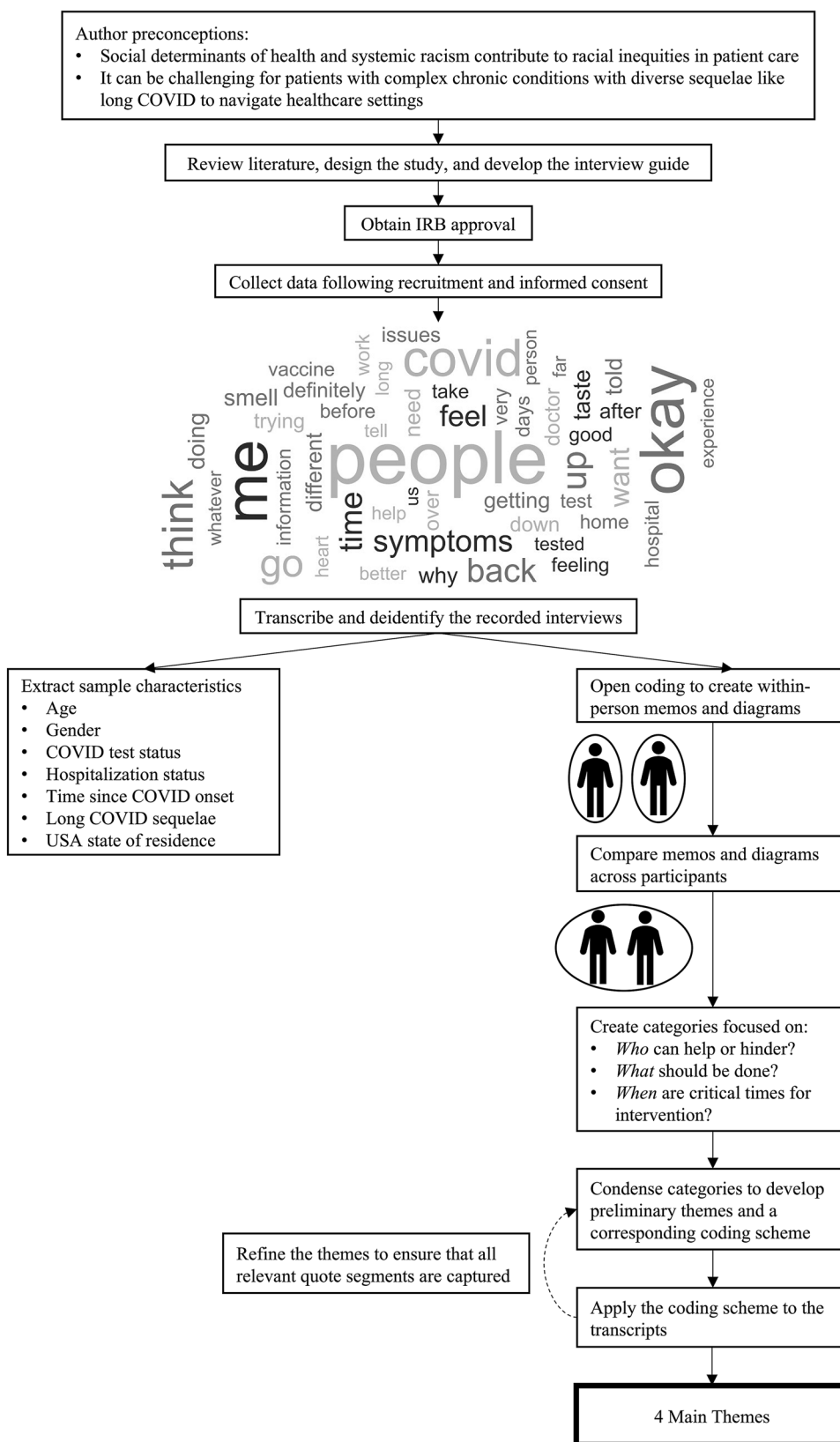


Table 3. Sample description

Respondent	Gender	Age ^a	State of residence	Months since COVID onset	Hospitalized for COVID
1	F	60–65	Michigan	15	No
2	M	50–54	Michigan	4	Yes
3	F	55–59	Michigan	6	No
4	F	45–49	Illinois	15	No
5	F	55–59	Michigan	13	Yes
6	F	30–34	Michigan	14	No
7	F	20–24	Michigan	5	No
8	M	20–24	South Carolina	5	No
9	F	25–29	Michigan	15	No
10	F	25–29	Michigan	10	No
11	F	30–34	Louisiana	19	Yes
12	F	20–24	Michigan	16	No
13	F	30–34	Michigan	9	No
14	F	40–44	Michigan	2	Yes
15	M	55–59	Georgia	13	Yes

COVID coronavirus disease, *F* female, *M* male

^aNot specified to protect participant confidentiality

Once they received the test results, participants expressed feeling afraid, ashamed, and/or obligated to disclose their COVID status.

- “I had forgot that I even had taken the COVID test and so, I was like, ‘Oh, well let me see what my COVID test results were.’ And I go and I log into the [online patient portal] and it was positive. And I don’t know if I freaked out, but kind of, because I have pre-existing conditions and I was one of the people who they said had a higher fatality rate.” (P13)
- “If you’re negative, no harm, no foul, but if you’re positive, you have some moral obligations, basically, you know, otherwise you could impact an entire city.” (P4)

3.2 Theme 2: The Lack of Best Practices for COVID-Related Hospital Discharge and Outpatient Follow-Up

Among those who were hospitalized for COVID, participants reported fear and confusion related to the discharge process, including the risk to themselves and their community. One participant talked about how she felt a nurse’s instructions compromised the health of her sister:

“The nurse called my sister who didn’t have COVID and asked her if she could pick me up and my sister

didn’t want to leave me stranded. I cannot believe [the nurse] was saying, yes, she could pick me up. And the nurse told [me], as long as I don’t cough, [my sister] should be safe. And then [the nurse gave] me some masks for my sister to put on. I was like... if it was a stretch limousine maybe. We might have been 6 ft away with a bus, if [my sister] came and picked me up in a bus. Or maybe a van we might have been okay. But no, that was just not safe for [my sister] to do that. And it wasn’t right for her to do that.” // “When I got out of the hospital, they told me to go home and quarantine too... So, why would you put me in a car with somebody if you’re telling me to go home and quarantine?” (P5)

Another participant reported multiple hospital trips for acute COVID treatment, suggesting that discharge may have been premature.

“[At the hospital] they said, ‘Your oxygen levels, your heart rate, all these things are a concern and we’re just going to just keep monitoring you. You got to make sure you hydrate yourself.’ And so, in the beginning stages I had multiple trips back and forth to the hospital because I had really really bad chest pain and I just really couldn’t breathe.” (P13)

Among outpatients, participants identified barriers to seeking care due to their Black identity. One participant explained that Black communities avoid seeking care

Table 4. Four main themes concerning opportunities for improving long COVID care

Theme	Examples of qualitative experiences	Representative quotations
1. The challenge of navigating COVID testing and what a positive test means	<p>(a) Unclear how to get tested for COVID or what test to get</p> <p>(b) Feeling obligated to disclose COVID status, afraid, and/or ashamed</p> <p>(c) Confusion about what steps to take next for their health and the health of their community</p>	<p>"That first week, I went to get checked. I told 'em I felt bad. The lady was like, 'You're a little dehydrated.' They gave me a shot on my back for pain because I had back pain. She didn't test me for COVID. She just sent me home and was like, 'yea, hydrate yourself with Pedialyte and water,' you know 'Drink plenty of fluids.' I was like 'Okay,' and I did that for the start of the week, went back and I was like, 'I feel bad,' you know. I told her, I was like, 'I do not feel good.' Another nurse, she was like, 'Okay, we going to run all kind of tests,' which I didn't know why the other doctor didn't." // "She say, 'Do you want to get tested for COVID?' I said, 'Yes, what you think it is?' And she came back in there like, 'You got COVID,' and I was like, 'What?'" (P11)</p> <p>"Initially when I was diagnosed, I was like, 'Oh my gosh, I got a big C+ on my forehead.' You know, literally, people are like, 'Oh no, you can't come to my house,' or 'Stay away from me.' And that take a toll on you, when all of a sudden, your relatives, your friends are like, 'Oh, I'm sorry to hear that but stay away.'" (P3)</p> <p>"It was weird too, because with the contact tracing they didn't ask me for the names of the people that I've been with. They just asked for the flight information, for the flight that I was on, and I had to call people myself and be like, 'Hey, I got COVID, but I'm fine now. But just so you know when we hung out, I was feeling tired, and I may have had COVID then.'" (P12)</p> <p>"The nurse made it a point to say, 'We don't have a treatment plan for you, we just tell people to stay at home, isolate, and ride it out.' Now, I was like really, okay so is this how we behave in a pandemic? 'We don't have any treatment plan for you.' If you get worse, if you can't breathe and yes go to the hospital but by that time, it's probably too late." (P3)</p> <p>"I received the results, a nurse called me to let me know I tested positive. And then also the county called me and asked me about any contact tracing, my symptoms. And they, you know, made a note of that. And I really didn't get any instruction but to quarantine, until I went to the hospital." (P14)</p>

Table 4. (continued)

Theme	Examples of qualitative experiences	Representative quotations
2. The lack of best practices for COVID-related hospital discharge and outpatient follow-up	(a) Feelings of confusion and concern during hospital discharge (b) Barriers to seeking care due to Black identity	<p>"I was pretty much told by ER doctors that I have COVID. You know, there's nothing pretty much that they could do. They don't know much about it. Just, you know, go home and rest and take it easy. And the main thing that really bothered me was them telling me or asking me all the time, 'Are you anxious about anything? Has anything in your life changed?' And it irritated me." (P11)</p> <p>"Some of it is also rooted in our culture of not going to the doctor, or we use urgent care as our physician." // "I don't like going to see the doctor, I hate going to the doctor. My father died because he didn't go to the doctor, I get it. So, I try to go at least more than he did, but it's not my favorite place to go." (P2)</p>
3. Primary care providers are gatekeepers for quality healthcare and effective healthcare navigation	(a) Receiving helpful information and support from primary care physicians (b) Seeking care from primary care physicians before specialists	<p>"I ended up contacting my doctor's office. And believe it or not, they sent me a package that was really good. He had a lot of information about COVID and things like that, so it was really good." (P5)</p> <p>"I was told to follow up with my primary care physician and my cardiologist. Yeah, so, she was like you need to go see somebody about your lungs, and I was like, they didn't say so. So, she called around in her little network of friends and she found me somebody, and he you know he tested me, he's like yeah, I can still hear some stuff going on in there, you know, he said you still dealing with some issues, I'll give you this steroid so we can start clearing this up and he gave me this steroid and it start clearing up like three or four days." (P2)</p>

Table 4. (continued)

Theme	Examples of qualitative experiences	Representative quotations
(c) Having long COVID symptoms dismissed by a primary care physician		<p>“My doctor said that I was severely depressed and that there was no way that COVID could be affecting me still. She said that. Yeah, this is my family physician... She worked really close with COVID patients, and she told me that there was no way that any of this could be related to COVID. So, then at that point I began to think that I’m going crazy, because now you’re telling me that all these things that I’m feeling, they’re not happening.” (P12)</p> <p>“I have insomnia but how do I explain this? I’m afraid to sleep a lot of time because sometimes I’ll have the shortness of breath.” // “At one point I was really, really tired but really, really scared to sleep. So, I set my phone alarm to go off every hour.” // “And my doctor he’s like well maybe you should sleep on your left side, or some people can just feel their heartbeat, like, he just wouldn’t budge. He just wouldn’t listen to anything I say.” (P11)</p>
4. Diagnostic and treatment plan shortcomings	(a) Feelings of burnout after seeking care from multiple specialists	<p>“[Over the past 6 months] I have had at least 30 doctors’ appointments at minimum. I’ve had probably 30 draws blood I’ve had a CT scan, I’ve had multiple CT scans, I’ve had a PET scan, I’ve had an MRI of the brain, I’ve seen neurology, I’ve seen endocrinology, internal medicine, I’ve seen specialists at [an academic medical center in Ohio, USA], I’ve seen rheumatology, infectious disease, pretty much everything, and I’m still not better.” // “Why do I have a fever every day? No one still can tell me that.” (P13)</p> <p>“And he did not do a tilt table test. And I explained to him that I may have something called POTS, because due to COVID and I was told that they don’t do that there. So, I reached out to another cardiologist that I will be seeing in [three months] because that’s the first opening.” (P11)</p>
	(b) Being denied a particular treatment or test for long COVID symptoms	

Table 4. (continued)

Theme	Examples of qualitative experiences	Representative quotations
(c) Difficulty maintaining employment or obtaining social assistance	<p>“Luckily, I qualify for unemployment extension from a gig that I did a while ago that just kept me current. Come to find out that now the new mandates are coming out that while you’re doing unemployment, you have to actually go look for a job. Look for a job doing what exactly? Because if it is a job that requires me to actually be present, I can’t.” (P2)</p> <p>“When I caught it in January, I was like, ‘To heck with this job, I’m going home’. I’m going to take care of myself. I end up getting terminated.” // “I was working on a plant, and they cut my [health] insurance... I had to get government [health] insurance and ... they sending me all this bills and stuff. I didn’t get [government health insurance] until [4 months after I quit my job].” // “But like, going back to work, I don’t know when... I’ve been wanting to go back but it’s just like, no.” (P8)</p>	

COVID coronavirus disease, *CT* computed tomography, *ENT* ear, nose, and throat doctor, *ER* emergency room, *MRI* magnetic resonance imaging, *P* participant, *PET* positron emission tomography, *POTS* postural orthostatic tachycardia syndrome

because of the expectation that they will receive worse care than White patients.

“So, this is my thing, same scenario, a White person, ‘Oh, come right in. We’re going to do a chest X-ray; and we’re going to give you a prescription; and we’re going to give you a breathing treatment and send you home with this, this, and this.’ I mean I’ve seen it is totally different and those are the scenarios that prevent our community from seeking help.” (P3)

3.3 Theme 3: Primary Care Providers are Gatekeepers for Quality Healthcare and Effective Healthcare Navigation

For many participants in our study, their personal primary care physicians were a first point of contact for treating long COVID symptoms and receiving referrals for specialists. For example, one participant talked about how clinicians were the first to attribute her recent symptoms to long COVID:

“I went to the doctor and asked if they could take a look and they were like, ‘We think you have excessive hair loss, have you had any stressful events that have happened in the past?’ I think they said like three months or so. March is when I had COVID and then June is when the hair started falling out. They were like, ‘Oh, it’s because of having COVID.’” (P12)

One participant described feeling grateful that their primary care physician attended to their long COVID symptoms, despite facing skepticism from others.

“By December I was complaining about shortness of breath and stabbing chest pains that almost made me go to my knees. So, I called my doctor. She was concerned and she sent me to have a cardio workout.” // “When you tell people what’s going on, the first thing they say is, ‘Oh, that can’t be from the virus,’ and I was just blessed because I had a doctor that listened to my symptoms and recognized that there was something going on and so she stayed on top of.” (P1)

However, not all respondents had positive experiences with primary care physicians and at times faced skepticism.

“My family physician... worked really close with COVID patients and she told me that there was no way that any of this could be related to COVID.” // “At that point I became to think that I’m going crazy because now [my doctor is] telling me that all these things that I’m feeling, they’re not happening. That’s what you’re saying because before COVID they were not happening. So why are they happening now? And no one could tell me.” (P13)

The financial cost of seeking care made feeling dismissed by doctors even more difficult for participants. One participant explained:

“And [my doctor] told me to take Claritin for like two months to see if anything happened. If not, go see the ear, nose, and throat doctor. I took the Claritin, that didn’t work. And medical bills are high, so, I’m not going to the ear, nose, and throat doctor if nobody can tell me anything. That’s just wasting money, wasting time, and nobody really has a cure.” (P4)

3.4 Theme 4: Diagnostic and Treatment Plan Shortcomings

Participants in our study reported difficulties related to the lack of formal diagnosis for long COVID or standardized care approaches. For example, participants reported burnout and hopelessness after seeking care from multiple doctors and specialists:

“I’ve seen two different cardiologists trying to get diagnosed with POTS [postural orthostatic tachycardia syndrome]... I’ve also seen my neurologist numerous times for it. Just trying to (exasperated sigh) explain things to him and trying to get him to give me a diagnosis of something.” (P11)

Being denied treatment or testing for long COVID symptoms was disheartening for participants. One participant expressed that her race plays a role in decisions related to care and screening:

“They’re not giving us the medication, period. Yes, it probably could save your life. It probably could keep you from getting to that point. But you can’t even get to the hospital unless you’re deathly ill. You go there, you test positive, they tell you stay at home, don’t go around anyone. They’re not writing any prescriptions for you. ... So, you know, there’s bias in healthcare. Unfortunately.” (P3)

The lack of adequate treatment for long COVID symptoms like pain, fatigue, and dyspnea hindered participants’ ability to maintain their employment status, and without a qualifying diagnosis, participants struggled to obtain social assistance. One participant talked about being repeatedly denied short-term disability benefits for long COVID despite trying to advocate for herself.

“When I pleaded my case to the short-term disability company ... I tried to advocate and explain to them about my symptoms and what I was experiencing and that I wasn’t well enough to go to work. And they denied my claim, every time, even still to this day.”
// They’re telling me now that there isn’t anything that

shows post-COVID affects me from doing my job.” (P13)

4 Discussion

We aimed to inform the development of care strategies that are responsive to the experiences and perspectives of Black patients with long COVID in the USA. Opportunities for intervention start with acute COVID testing and hospital discharge to address patient concerns and uncertainty. Findings indicated the importance of primary care physicians who affirm and proactively treat long COVID patients. Participants also noted how their Black identity can be a barrier to seeking care. Lastly, we observed that the lack of appropriate diagnosis or a standardized treatment plan for long COVID erodes patient morale and can prevent receipt of comprehensive support.

The results of this study extend prior work. Existing studies on the experience of having long COVID primarily draw data from communities in the United Kingdom and predominantly White samples [22–30]. This foundation of research describes the detrimental and inconsistent impact of long COVID on functional capacity [22, 25–28, 30], and how patients feel that their healthcare providers may be falling short when it comes to monitoring and treating long COVID symptoms [23–25, 27, 29]. In this study, our main themes elaborate on distinct healthcare settings and timepoints during the long COVID patient journey that offer opportunities for intervention. Results which indicate that Black patients may at times consider their race to affect their quality of care or be a barrier to seeking healthcare for long COVID symptoms are another novel contribution of this study.

Any confusion or hesitancy towards COVID testing and care seeking is problematic. Those who delay or are unable to receive a timely COVID test may end up with a worse prognosis, which is associated with the risk of long COVID [34]. Additionally, to receive a referral for a specialized long COVID clinic, a positive COVID test may be required [35]. Feelings of hesitancy among Black patients may reflect the historical mistreatment of Black communities in medical and research settings [36]. More transparency on the use of COVID-related health information could facilitate patient trust. For example, COVID test results are stored within multiple governmental and non-governmental systems including local hospital systems, the USA Centers for Disease Control, USA state registries, and the World Health Organization [37]. To reduce confusion surrounding COVID and pandemic-like events in the future, public health agencies may also reconsider how they disseminate guidelines and recommendations. In prior work, Black women expressed difficulty discerning

whether the information that they encountered related to COVID and the pandemic was reliable or accurate [38].

When acute COVID patients are hospitalized, hospital discharge presents an opportunity to recommend follow-up visits and share educational resources that could be helpful for those who go on to experience long COVID symptoms. Other work demonstrates racial inequities in COVID-related hospital discharge and patient follow-up. In a study that monitored patients discharged with COVID from 38 hospitals in Michigan, USA, Black patients had lower rates of follow-up visits with primary care physicians and higher rates of hospital readmissions relative to White patients [39].

Researchers have likened long COVID to other chronic pain and fatigue conditions, including fibromyalgia [40], myalgic encephalomyelitis [41], post-intensive care syndrome [42], and postural tachycardia syndrome [43], which may represent subsets of long COVID patients. While these conditions could provide a model for long COVID diagnosis and treatment, racial inequities in chronic pain and fatigue conditions are the status quo, thus novel strategies are needed to prevent inequities in long COVID. For one, Black patients are more likely to be uninsured [44], reducing their capacity to seek care from specialists, let alone multiple specialists. Additionally, when navigating care for long-term, medically complicated conditions, patients must advocate for themselves in healthcare settings [45–47], but Black patients have a disadvantage. Long COVID symptomology includes subjective outcomes like fatigue and pain, which opens the door to implicit bias and the risk that doctors will underestimate symptoms among Black patients to a greater extent than White patients [15]. This could reduce access to supplemental resources for Black patients. For example, long COVID is a disability under the *American Disabilities Act* if it substantially limits one or more major life activities [48]. However, obtaining appropriate documentation to receive disability benefits depends heavily on a clinician's willingness to perform the required testing and documentation [49]. Educating primary care physicians on signs and symptoms of long COVID, and increasing their sensitivity to implicit bias in healthcare decision making could mitigate long COVID-related inequities [50].

4.1 Strengths and Limitations

The focus on long COVID in Black communities is a strength of our study, and we did not aim to compare experiences by race/ethnicity. Thus, results may be applicable within other racial/ethnic groups. Race-concordant interviews are a strength of this study because race is a social construct, and participants may moderate their responses if they perceive the interviewer to have a social advantage

or disadvantage, which can introduce response bias [51]. However, since we did not match for other social factors (e.g., gender, age group, income, educational background, employment status), response bias is still possible. Conducting virtual interviews can increase access to participation among those who may be limited by transportation or logistical barriers [52]. For participants who experience symptoms like fatigue, virtual interviews may be a more appropriate option. Subsequently, study eligibility required access to the internet, which could reduce representation of those with lower income levels. We used convenience sampling, which can be effective for reaching participants within marginalized communities, but this limits the ability to verify external validity. The sample composition was uneven; most participants were female and lived in Michigan. However, we did not aim to compare experiences between genders or geographic locations.

5 Conclusions

In this qualitative study, we interviewed Black patients to inform the development of care strategies for long COVID. Our results extend prior work that primarily reflects the experience of having long COVID in predominantly White samples and communities outside of the USA. The main themes in this study describe multiple targets for improving long COVID care. Given that long COVID is influenced by acute COVID prognosis, greater transparency and guidelines concerning COVID testing, hospital discharge, and outpatient follow-up could be beneficial. There is a need to increase long COVID awareness and education among primary care physicians as gatekeepers to quality healthcare and effective healthcare navigation. Lastly, appropriate diagnosis and standardizing a long COVID treatment plan could help patients avoid unnecessary healthcare utilization and obtain comprehensive support for their condition.

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Author Contributions RSB conceived the study. RSB, KC-P, and MD designed the study and contributed to data acquisition. RSB, DA-H, SD, AM, RW-J, LZC, CY, and MD analyzed the data. RSB, KC-P, DAW, DJC, and MD interpreted results. RSB drafted the manuscript. All authors critically revised the manuscript and gave final approval for publication.

Declarations

Competing interests Dr. Daniel J. Clauw reports consulting fees from Tonix Pharmaceuticals Inc. Dr. David A. Williams chairs the PASC PIPP subcommittee and the Interventions work group for RECOVER.

The other authors do not report conflicts of interest regarding the content of the article.

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Ethics approval The University of Michigan Institutional Review Board approved this study (HUM00197791).

Consent to participate/publish Not applicable.

Availability of data and material Not applicable.

Code availability Not applicable.

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