

The Healthcare Experiences of People with Long COVID in the GTA

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INTRODUCTION

Globally, as many as 200 million individuals have experienced long-term health consequences of COVID-19.¹ A recent study estimated that 1.4 million Canadian adults (14.8 per cent of those infected with COVID) would satisfy criteria for long COVID.² Long COVID has many symptoms*—including fatigue, memory problems, shortness of breath and pain—and is linked to reduced quality of life.³ Responses to address this issue have been generally inadequate, despite ongoing advocacy from Canadian and international groups with lived experience.^{4,5}

Some jurisdictions have been quicker to respond to health needs than others. However, barriers to accessing care for long COVID patients have been documented in places such as the UK, even though they have set up specific targeted treatment and support programs.⁶ Healthcare responses to long COVID include *primary care models* with direct assessment by providers, self-management support, medication, comorbidity management, and referral to specialists and other allied health services. Specialized *long COVID clinic models* involve multidisciplinary teams of healthcare providers with expertise to support people with multidimensional care needs. There are also hybrid models that integrate these two approaches.^{7,8}

The experiences of people living with long COVID have been increasingly documented since 2020, including their considerable difficulties within healthcare systems.⁹ Many qualitative studies describe participants' struggles to deal with gaps in knowledge about long COVID, feeling that their experiences were discounted by healthcare providers, and a lack of supports available to them.^{10,11}

Some research has linked these challenges to broader systemic issues.¹² Research conducted in the UK observed that the healthcare experiences of long COVID patients have taken place within systems that have changed to respond to the COVID pandemic (e.g., virtual care, prioritizing acute illness). These changes may have limited system response to long COVID patients who require ongoing monitoring and support by healthcare providers, as well as timely follow up.¹³ In Ontario, this has likely been intensified by the ongoing underinvestment in healthcare services.^{14,15,16,17,18}

Existing research highlights the continued need to focus on health and social equity in experiences of long COVID patients, as well as resultant responses.¹⁹ Generally, research has relied on participants who are active in online communities, advocacy work, or those seeking support for long COVID. This has led to greater representation of White, affluent participants with digital access and excludes the perspectives of racialized groups and those with lower incomes.^{20,21} There is also growing anecdotal evidence that patients presenting at long COVID clinics and related programs do not reflect the heterogeneity of the population impacted by ongoing symptoms.²²

The experiences of people seeking services and supports for long COVID have not been well-documented in the Greater Toronto Area (GTA). Greater inclusion of the perspectives of those with different access to resources and experiences of the healthcare system is also needed. This study aims to address these gaps by providing in-depth information about the healthcare experiences of a small group of people with long COVID in the GTA. The research also explores the ways in which individual experiences differ, highlights what this could mean for inequity in the GTA, and suggests some ways to improve responses moving forward.

* Most medical sources organize Long COVID symptoms according to organ systems, including general (e.g., fatigue), neurological, respiratory, psychological, musculoskeletal, gastrointestinal and neurologic symptoms. (see CADTH 2023 Subtypes of Post-COVID-19 Condition: A Summary of the Emerging Evidence)

METHODS

This paper focuses on the healthcare experiences of people with long COVID. Qualitative, semi-structured interviews were conducted to explore the perspectives of people who self-identified as having ongoing symptoms from COVID-19 that had lasted three months or longer. A three-month duration of symptoms following acute COVID-19 infection was chosen to align with the World Health Organization's Post-COVID-19 condition definition.²³

Participants were recruited through community organizations in the GTA and online long COVID community groups. They were included in the sample if they were 18 years of age or older and lived in the GTA. A purposive sampling strategy was used to increase diverse representation of participants based on self-identified gender, employment status, income, ethnic and racial identity, or age.²⁴

Interviews took place from March to September 2022. They were conducted in English via telephone or video call (e.g., Zoom). Interviews ranged from 30 to 94 minutes in length, were audio-recorded, and transcribed verbatim.²⁵

Interviews focused on participants' experiences living with, and seeking support, for long COVID. Participants were asked about the time leading up to the realization that their COVID-19 symptoms were prolonged. They were also asked about their experiences seeking treatment and support for long COVID within the health care system and how it impacted their work or social life (e.g., social connection, care for children and other dependents). The interviews also explored potential supports that had been or would be helpful to participants in these areas.

Interview transcripts were analyzed by the project team in NVivo using a thematic analysis approach. Analysis involved an inductive technique where emerging codes were generated using a systematic approach and derived directly from the data. A coding matrix was developed which comprised a list of focused thematic codes. The preliminary list and observations were discussed within the project team and thematic codes were revised and then applied across all transcripts. As analysis progressed codes were gathered into broader themes which were then organized and refined with ongoing engagement with the data.

Additional information about the study design, including the rationale for inclusion criteria, can be found in the Appendix. Ethics approval for the research was granted by the Toronto Metropolitan University Research Ethics Board in February 2022 (REB # 2021-548).

RESULTS

Sample description

The sample included 14 people living with long COVID. Most participants identified as women. The average age of participants was 40 years. Seven participants identified as White and four participants identified as South Asian or Indo-Caribbean. One participant each identified as Latin American, West Asian, and Caribbean. Nearly 30 per cent of participants were born outside of Canada.

At the time of the interview half the participants were working, with five employed in full-time work and two in part-time positions. Household income ranged from \$25,000 to over \$80,000. Almost 30 per cent of participants did not report their household income (See Table 1).

Table 1: Sociodemographic characteristics

Sociodemographic factor (self-identified)	Sample breakdown, N=14 (#) (%)
Gender	Women (12) (86) Men (2) (14)
Age	20s (3) (21) 30s (5) (36) 40s (2) (14) 50s (2) (14) 60s (2) (14)
Ethnic/racial identity	Caribbean (1) (7) Latin American (1) (7) West Asian (1) (7) South Asian/Indo-Caribbean (4) (29) White (7) (50)
Born in Canada	Yes (10) (71) No (4) (29)
Employment status	Full-time (5) (36) Part-time (2) (14) Unemployed (2) (14) Student (1) (7) Employed, but on-leave (4) (29)
Household income	Less than \$35,000 (2) (14) \$35,000-\$60,000 (4) (29) \$60,000-\$80,000 (3) (21) More than \$80,000 (1) (7) Not reported (4) (29)

Of the 14 participants, three had experienced persistent symptoms for two years or longer, five had for one year or longer, and six for between four and five months. Participants experienced a broad range of symptoms from long COVID, and many described having to cope with multiple symptoms (Table 2).

The severity of symptoms varied. For example, several participants described relatively mild symptoms of loss of smell or congestion, whereas others explained that they sometimes had difficulty moving around their homes or completing everyday activities, such as showering. Several participants said they had visited the hospital for complications related to long COVID.

Table 2: List of symptoms described by participants

Shortness of breath	Gastrointestinal issues	Nausea
Anxiety	Pain	Wheezing
Depression	Sore throat	Word recall problems
Migraines	Weakness	Skin tingling and numbness
Headaches	Congestion	Insomnia
Fatigue	Memory impairment	Chest pain
Loss of smell	Post-exertional malaise	Dizziness
Dizziness	Heart palpitations	Neuro-fatigue
Brain fog	Difficulty breathing	Tachycardia or racing heart rate
Difficulty concentrating	Loss of taste	
Difficulty walking	Loss of words	

The results that follow explore how experiences of the healthcare system, and in particular primary healthcare, emerged as an important focal point for participants with long COVID. Following the presentation of findings on healthcare, the discussion section offers some analysis about what they mean for equitable healthcare access for people with long COVID.

Building trust and validating lived experiences in the context of medical uncertainty

A key feature of the data was the considerable uncertainty that underpins and structures people's experiences of long COVID. Throughout the pandemic, scientific and medical knowledge about COVID-19 and long COVID has been emerging in real-time and concurrently with the condition itself. Participants described the gap in knowledge about long COVID as a key feature of their interactions with healthcare providers.

Uncertainty was discussed by participants in many different ways, including trying to determine what symptoms were linked to long COVID, as well as questions about living with long COVID (e.g., how long symptoms would last and what their future with long COVID might look like). The following quotes demonstrate the range of uncertainty experienced:

“”

“Every time I’ve had a cough, I’m like, okay, is that from my chest? Is that from my throat? Like, is that allergies or is it something else?”

(L01)

“”

“I can’t get an answer about when I’ll get better...the doctors who are doing {a study L05 enrolled in} are international experts. I’m like, ‘So, what timeline would you anticipate?’ And they won’t even say you’ll recover. They say, ‘Well, most of my patients have improved’, which is a careful language choice...and I guess you’re looking for answers, right? But I don’t think they have answers on my profile, and I got my booster dose earlier than a lot of people, and with my age, the time I was infected, I don’t think that science knows what the outcomes and the trajectory looks like for someone like me.”

(L05)

“”

“I know this thing’s knocked the hell out of me, so to speak...I’m way better than I was, and it’s been a long journey, but now I’m at the point where - am I ever gonna get to be back to where I was? You know, I talked to the doctor, and he doesn’t have any answers, either...Nobody really does.”

(L08)



“That’s been really hard to come to terms...I don’t know if I’ll have a normal life. I don’t know if I’ll be able to work. I don’t know if – you know, now is about the time I...was planning to have kids...I don’t know if I’ll be able to do that. I can’t even care for myself...so it’s like all of my life plans are sort of evaporating.”

(L06)

Along with highlighting the range of uncertainties in their lives, these quotes demonstrate most participants’ objective to find answers about their condition. In this context, participants identified primary care as extremely important to help them navigate uncertainty and seek treatment and management support related to long COVID. In addition to better understanding the condition and symptoms, most participants acknowledged that the response from healthcare providers was important to help access other supports. At the same time, some participants struggled with healthcare providers who lacked knowledge of long COVID in the context of COVID-19 infection and persistent symptoms:



“When I initially talked to my family doctor...he had me sort of get checked out and then monitored me at home...but I didn’t get better...he prescribed an inhaler – Ventolin – in the hopes that that would affect my shortness of breath, but...every time I had an appointment with him...he kept declaring I couldn’t possibly still have [COVID].”

(L06)

Most participants described insufficient awareness about long COVID by their physicians, and gaps in knowledge of ways to address the emergent condition. One participant described this in terms of her family doctor’s “trial and error” approach to addressing her respiratory symptoms:



"I called my family doctor to tell them that I have shortness of breath and that I'm coughing a lot, and she gave me...two different kinds of inhalers...It definitely helped me breathe better, but it didn't help me with the cough...she told me, 'if the puffer doesn't work, give us a call', and I called her again, and then I think she gave me...just a regular cough syrup that's available everywhere...[and] after that, I didn't call her again because, I feel like no medicine is going to work and I just have to deal with it on my own."

(L03)

Other participants described the shortcomings of COVID testing (a tool for determining COVID-19, but not long COVID) or their inability to produce a positive COVID test as further contributing to medical uncertainty. Some participants described their doctors' refusal to definitively accept their condition because they lacked a positive test as validation of initial infection:



"It's almost like having that piece of paper [with a positive covid test result] validates how you're feeling and how you're being treated, and so to always be like, 'Oh well, you just have a presumed case', it's – it's medical gaslighting at its best."

(L04)



"I finally was able to get tested [3 months after being sick with acute COVID], and [my doctor] said, 'Well, since you tested negative, you probably never had COVID because if you still have symptoms, you would have tested positive', which was wrong...and many people knew that... even by May [2020] there was acknowledgement that [people were continuing to have symptoms while testing negative]."

(L06)

These participants found this response to be especially upsetting, and some felt similarly disregarded because they had normal results from diagnostic tests:



“After seven hours [in the hospital], all the tests came back negative in the sense of what they were looking for, but we all know that the tests aren’t necessarily calibrated to find the ways in which COVID is interacting with your body. You know, these aren’t the traditional methods. So, I went home; I spoke to my doctor, and...that’s when the dismissal started.”

(L12)

Several other participants echoed this, explaining that their physician had failed to recognize or validate their symptoms and conditions in the absence of a positive COVID-19 test, other medical tests, and limited or evolving knowledge about the long COVID condition generally.

Some participants explained that their symptoms had been diminished as mental health issues, meaning that their family doctors had questioned whether their symptoms were actually a manifestation of anxiety or depression:



“It’s definitely very frustrating to be told that you’re fine when, in fact, you’re definitely not fine, right? Mental health was raised a lot of times, and that was very frustrating...to have that brought up again and again – that maybe it’s just a mental health problem...you know, ‘You must be just stressed out from pandemic anxiety,’ without actually asking me, ‘Do you have pandemic anxiety? What’s your current anxiety level?’...which is not to say that there aren’t long haulers who also have anxiety and depression, but, you know, that didn’t explain my symptoms.”

(L06)

As the quote above points out, participants described this dismissal of physical symptoms to be undermining and frustrating.

In contrast, other participants detailed more validating experiences with healthcare providers. One participant described successes managing symptoms with her primary care physician:



"I also think I had some success [managing symptoms] with my family doctor 'cause I actually had chronic fatigue syndrome about twenty-five years ago...I got it when I was quite young... and there's a lot of similarities with the fatigue and the post-exertional abnormalities, so it's almost like we've been through something like this together a very long time ago...I've had him [as a doctor] forever...he knows my whole family, so I'm quite comfortable."

(L05)

The above participant explained that her relationship with her physician had developed through a history of addressing another medical condition similar to long COVID, which contributed to a sense of shared understanding and efficacy despite the uncertainty involved.

Another participant described a constructive approach taken by his doctor during a discussion about whether he should get the COVID-19 vaccine despite continued symptoms or wait until the guidance on long COVID and vaccination was further along:



"I really like my family doctor, and he tells it the way it is, and he said, '(L08), between you and me, I don't know what I would do in your shoes, right now, except maybe wait a little longer and get some more data before you take that step.'...So, I did wait a bit longer, and then I talked to the respiratory specialist – and he was the one who talked me into [getting the vaccine] because of the Delta spreading, and from what he was understanding from all of his experiences with other patients, [getting vaccinated] was nothing but the best thing to do..."

(L08)

The participant perceived his physician's willingness to speak openly about the uncertainty involved as important for building trust and the quality of their relationship. This ultimately created conditions for him to make a decision about vaccination based on the best available information and with the support of a specialist.

Other participants who described their primary healthcare experiences in positive terms emphasized the importance of ongoing, regular communication and the openness of their provider to investigate potential resources and options for addressing long COVID. Several participants described feeling supported because they had been offered options despite the limited knowledge around long COVID at the time:



“Yeah, I would say [my family physician has been supportive], I mean, initially, she did suggest that I could just be suffering from depression or anxiety, and wanted me to look into that, but she’d also – every time I’ve had COVID, she’s requested full blood tests, and then the last time I spoke to her, and I said, this is definitely not depression...she’s just very responsive, and trying to find solutions, and supportive, so, I feel...very lucky in that sense.”

(L07)

Participants whose family physicians took action or articulated a plan to deal with long COVID, despite some uncertainty, generally described feeling supported by their providers. In these accounts, the measures that physicians undertook to explore long COVID causes and symptoms (ordering diagnostic tests, researching more about the condition and treatment options, referral) made participants feel validated in their experiences.

While some participants described feeling supported by healthcare professionals despite the medical uncertainty involved, others felt that their doctors and the healthcare system in general, were ill-equipped to address the long COVID condition. These experiences contributed to an overall eroded sense of trust experienced in some cases.

Healthcare system challenges

Participants described a range of interactions with healthcare providers that showed that broader challenges, largely related to a lack of capacity in the healthcare system, also shaped their care experiences. Several participants described facing considerable difficulty in booking appointments to see their physicians, which they explained in terms of workforce shortages and large patient loads:



“My next appointment was over the phone, and the only time [my family physician] was available, was a long time from now...to be honest, she’s an amazing doctor, but she’s just fully booked, she told me there’s a shortage of doctors, shortage of nurses, what can they do?”

(L13)

Another participant described her physician's response to her seeking help for multiple long COVID symptoms which included extreme fatigue, chest pain, sore throat, cognitive difficulties, migraines, and post-exertional malaise:



"And it's to the point where, like, she {general practitioner} got upset with me because I took too long in my appointment, she said, 'You know, these are only supposed to be – I think it was ten minute appointments or five – I can't recall, and so I said, 'Well, can I book a few then?', because I said, 'What I'm going through right now, I'm not meaning to drone on and on. I'm just trying to tell you all the different things that are going on.'"

(L04)

The above quote demonstrates the challenges of short "one issue per visit" appointments in addressing multi-system conditions such as long COVID.

Several participants, like the one quoted above, expressed frustration about challenges booking appointments far into the future for what felt like urgent issues, and others echoed the limitation of only having access to phone or online appointments. One participant who was having difficulty speaking due to her symptoms was instructed by her family physician to visit a walk-in clinic when she requested an in-person appointment:



"This doctor is so busy...Over the phone he is talking, and at that time I cannot talk that much... It was hard for me, and then one day...he says to me, 'Go to the walk-in' because, you know, he is not...going to give me the in-person [appointment]. So one day I went to the walk-in, and then that doctor says, 'You have to go to your family doctor.'"

(L09)

System issues were also described in terms of doctors with large patient groups suffering from ongoing illness:



“My doctor said that so many of her other patients are also complaining about the same [long COVID symptoms]...she says that it’s just something that some people are left with, the symptoms, and when she said that, I felt like it’s not going to go away, but I didn’t want to think negatively. So, I don’t know why, but she kind of talked, like, she was very pessimistic. She just said, like, ‘So many of my patients have it – they just have it.’”

(L03)

This quote from a participant with ongoing respiratory symptoms highlights the magnitude of the issue as communicated by her doctor at a community health centre in Toronto. While the participant had been prescribed some medical treatment (puffers) for her symptoms, she ultimately felt that her doctor had resigned herself to the reality that too many of her patients were facing long COVID, and that she lacked solutions to the problem.

Some participants attributed the long wait times to pandemic circumstances, where healthcare systems were overstretched in the context of greater illness in patients and staff. One participant, who considered his long COVID symptoms to be relatively mild, explained:



“I think for me...when I got it...COVID was raging at that point, and it was so terrifying for people – Delta was such a terrifying kind of thing - and I know that doctors were so busy and doing phone appointments, and hospitals were jam packed all the time. I felt as though – although I would have liked to get some support on it, at the same time, I’m like, I don’t want to take that spot away from somebody else.”

(L01)

The decision of this participant to avoid potentially beneficial healthcare access for fear that others may be in greater need of limited services exemplifies a challenge of an overburdened and under-resourced healthcare system.

Other participants described situations where they had accessed support for urgent issues through the hospital system (e.g., ER and hospital-based) because they were unable to access primary care or felt that their health concerns could not be addressed in this context, and some described being “sent home” from the hospital after an initial assessment and without any major intervention.

The descriptions of challenges related to the healthcare system similarly extended beyond primary care to specialized services. Most participants who had received referrals from their family physicians to medical specialists or long COVID clinics described long wait times to access these:

““”

“I was really noticing that I didn’t have enough energy to do the things I normally did... So, she referred me to the long COVID clinic...and that was I believe [four months ago]. I just heard from them maybe two weeks ago...It’s an outpatient clinic, and so...I haven’t had any treatment.”

(L07)

““”

“[My family doctor] sent me to a cardiologist who specializes in POTS[†] {postural orthostatic tachycardia syndrome}, and...I finally feel like I’m dealing with a healthcare professional who knows something about it. She had a very long waitlist. There aren’t very many people who deal with POTS.”

(L06)

[†] POTS is a disorder of the autonomic nervous system experienced by some people with long COVID. It involves a complexity of symptoms including heart palpitations, extreme fatigue, dizziness, nausea, headaches and brain fog



“I got an appointment with the internal medicine specialist, but there’s such a long wait list, I haven’t even seen this person yet, and then the post-COVID clinics, there’s one or two that’s covered by OHIP, and there’s some others that are private...[for those who] have coverage... when I called one of the OHIP clinics, they said, ‘Well, you can only join if you’re a patient of the ...hospital network.’”

(L05)

These quotes suggest an overall gap in services, barriers to accessing specialists and clinics that treat long COVID (e.g., wait times), and challenges around the referral process and eligibility for programs. Several participants who were in the financial position to be able to pay private clinics (e.g., rehabilitation, private long COVID clinics) out-of-pocket chose to expedite their access to care while waiting for publicly funded options.

Self-reliance in identifying and advocating for supports

In response to the issues described in the previous sections—an over-burdened healthcare system, medical uncertainty and having their experiences discounted—some participants explained that they had taken a proactive approach in their own care, including seeking out information, access to tests, and referrals to specialist services:



“Now, any time that I go into a conversation with my GP, I have to – like, I arm myself with all this information, so that when she starts dismissing me, I can actually try and hold my own, which is difficult when you also are not feeling well, and when you have brain fog, and you’re not operating as cognitively – you know, as strong as you would like.”

(L04)

In response to the lack of support, some participants like the one quoted above described using information to advocate for themselves. Participants pointed out how difficult this can be when coping with long COVID symptoms and felt frustration over having to undertake this work because the healthcare system had not responded to their needs:



“I’ve been doing my best to research my condition...which is remarkably difficult when you can’t read for very long. That’s one thing I wish the doctors would do this because I can’t do it. You know I...don’t have a medical background. I’m doing my best to wade through things. I can barely read...and it’s sort of frustrating that...it shouldn’t have to be me who’s doing all of the legwork and coordinating the care...I had assessed myself for POTS [Postural Orthostatic Tachycardia Syndrome]. The way the clinical criteria are – a change in heart rate, from within ten minutes of going from lying to standing, of over thirty beats, which I measured myself, and that happens.”

(L06)

While this participant was compelled to conduct research on long COVID symptoms, she also drew attention to her lack of medical training which was a clear barrier to her accurately interpreting the resources she uncovered. Another participant who had contracted acute COVID at the start of the pandemic when there was little knowledge of long COVID described feeling that she had no other choice but to seek out supports on her own:



“My GP...kept saying, ‘It’s not COVID, don’t worry...Just because there was absolutely no knowledge of long COVID [in early 2020]...I told her, ‘I’ve never been this tired in my life. I can’t do anything. I’m freaking beyond exhausted...I just realized at that point that I wasn’t gonna get any help from her, and that I was on my own...that I would need to find my own support to get through this-- because my sister didn’t understand, my friends...Nobody could wrap their mind around what I was going through.”

(L12)

This quote points to the degree of social isolation that some participants felt in the context of feeling misunderstood and unsupported in their long COVID experience. In this case, the experience strengthened the participant’s resolve to find their own answers to the problem.

Other participants described similar experiences where the wait time in primary care or lack of understanding by healthcare providers and support networks necessitated that they be proactive, build knowledge on their own, and then identify health and social supports to address their symptoms. Several participants had joined online long COVID community support groups to gain insights and resources from others with shared experiences.

While some participants described cultivating a level of self-reliance researching options, preparing for medical appointments, and advocating for referrals and other interventions—not all described engaging this kind of approach. By contrast, other participants such as L03, a recent immigrant, expressed greater resignation about her situation, explaining that *“I didn’t call [my family doctor] again because, I feel like no medicine is going to work and I just have to deal with it on my own.”* While no-one explicitly said that they had given up on the healthcare system, other participants expressed that they had decided not to rely on their physicians and had not discussed options like access to additional supports from specialists with them.

Access to follow-up, referral, and other supports

Accounts from this study highlighted the importance of primary care as a starting point for managing the condition and facilitating access to other parts of the healthcare system. Even in the early stages of the pandemic, some participants described how their family physicians started researching long COVID to provide options for their care.

Primary care providers frequently provided access to exploratory/diagnostic testing and specialized services to support management of symptoms and recovery:



“[My doctor] was all over it, and he...sent me to a respiratory therapist because of the breathing problems...He did a small test on me, and on top of that, he sent me for four other tests...I had an allergy test at the hospital, and some other test to do with your heart and...an asthma test...and they all came back fairly average or where I should be, right...everything, except for my [breathing]. I’m diagnosed as asthmatic now, whereas I wasn’t before.”

(L08)



“So, my family doctor told me there’s sort of two areas...one is the internal medicine specialist, who’s like a detective, but he told me, I almost don’t recommend it ‘cause you clearly have post-COVID...And the second option was a post-COVID rehab clinic. Oh, and there was one other thing he did, as a precaution – a blood test just to rule out other causes of fatigue – and he said, ‘It’s probably gonna come back great, but let’s do it just to rule out things like low iron or thyroid issues’, and that came back fantastic...so I was like, ‘Great, I will do anything’, and I followed up on every single option that came about.”

(L05)

Another participant received a lot of support from her family doctor to access diagnostic services, referrals to long COVID clinics, and additional supports:



“I had talked to my doctor about it, and she referred me to the long COVID clinic because I was really noticing that I didn’t have enough energy to do the things I normally did, and then...the breathlessness...even coming up the stairs, I noticed – if I was...carrying laundry, I’d have to stop and catch my breath – just one flight of stairs. So, she referred me to the long COVID clinic, and then I also went for the CTs...”

(L07)

Several participants explained how they gained access to numerous other healthcare options, including diagnostic testing, long COVID clinics, and even research study participation. One participant identified potentially helpful supports within the healthcare system:



“So, I have been fortunate to see, you know, a pulmonary specialist; I’ve seen an allergist; I’ve had a lot of blood work done...and my cardiologist was the first one who believed me, and to this day, just having somebody say – and I know it sounds so rudimentary...now that people [healthcare professionals] have believed me...it definitely has made my journey easier.”

(L04)

With a referral from her physician, the participant worked to access a range of different supports and eventually received the validation and treatment that she was seeking from medical specialists.

Several participants described experiences of accessing medical specialist and allied health services such as cardiology, neurology, respirology/pulmonology and physiotherapy, massage, and acupuncture to help cope with long COVID. Participants with access to specialists such as respirologists explained that they played an important role in monitoring symptoms to determine progression and whether treatments were adequate.

Some participants also explained that their experience with long COVID had taken a substantial toll on their mental health. Several participants described dealing with high levels of anxiety which in many cases worsened symptoms (e.g., difficulty breathing). Others described feeling sad and depressed, especially in realizing that their futures might be different than they had imagined because of long COVID (e.g., rethinking plans to have children). Despite these experiences, only a few described having access to mental health supports through primary care, work, or other avenues.

There were other participants who did not access any additional healthcare supports for a variety of reasons. Some did not feel their symptoms were severe enough while additional supports or referral processes were not offered to others. Many of these participants and their physicians expressed a “wait and see” type approach to accessing further testing or care.

Healthcare providers were also described by several participants as important for facilitating access to other forms of support such as workplace accommodations and paid time off. Several participants described their reliance on healthcare providers for supporting these applications and processes. In particular, eligibility for work leaves due to disability were identified as an ongoing process requiring the support of family doctors:

““”

“I just called my doctor, and I told them what’s going on, and I said, ‘I need to take a break [from work]’, and at first he’s like...‘Let’s just start and see how you do, and let’s reassess you before we get to the end of that three week period’, and that brings us to this week. I’m talking to him later this week.”

(L05)

““”

“When I was off on the short-term part of it, {the insurance company} was okay with it all, but as soon as you go from short-term to long-term, then they put this huge amount of pressure on me to go back to work, and I actually had a huge fight with a guy on the phone, and I said to him, ‘My doctor is not prepared for me to go back to work yet, right, and even though your {Post COVID clinic} guy says, ‘Hey, he can walk around the building’, whatever, I can’t work yet, pal, you don’t understand...Anyway, at the end of the day, I had to appeal the decision, and after them talking to my doctor they okayed me to go on long-term disability.”

(L08)

As demonstrated by these quotes, participants relied on their family physicians to advocate for them to their workplaces and third-party insurance companies so that they could take time off work to recover. These processes often involved ongoing check-ins and assessments with physicians who were considered objective experts but were still scrutinized at times by other parties, especially when applying for longer term leaves. Other participants described interactions between several healthcare providers (e.g., physiotherapists and physicians) to support or monitor their applications for sick leave or income benefits.

One participant identified the need for people who are making decisions about work arrangements to have a good understanding of long COVID so that they are able to accurately assess how it might impact workers:



“People who are at work, trying to get back to work – they need all kinds of accommodations... [from people] that actually understand what it is they’re suffering from ‘cause so many people now are being made to go back to work in conditions that they can’t manage because it’s not understood that long COVID is a disease of episodic nature, and so, like, one day you might be able to do the job, where, you know, you’re running around, collecting – doing whatever you can – and then in two days you might not be able to do that same job because you’ve done too much and now you’re in a crash.”

(L12)

In the context of gaps in understanding by employers and insurance companies, healthcare providers are well-positioned to act as a source of knowledge for and advocacy so that long COVID patients get the supports that they need. This data suggests that consistent contact with the healthcare system through primary health care can facilitate access to follow-up, referral to specialist services, and access to other supports such as those needed in the workplace

DISCUSSION

The findings presented in this report describe how the scientific and medical uncertainty about long COVID shaped many participants' experiences of the healthcare system. In this context approaches by healthcare providers that build trust and validate lived experiences emerged as particularly important. Systemic challenges, such as the lack of capacity in an overburdened healthcare system, also shaped how people were able to access necessary supports including information about the management and treatment of their condition.

Participants' experiences with primary care providers as they navigated the healthcare system played an important role in enabling responses to address long COVID symptoms and underlying causes. They were key to facilitating access to diagnostics, supports and referrals. Where participants lacked support from healthcare providers, some undertook their own research and self-advocacy for accessing these resources.

In this section, findings are discussed in terms of how they align with and contribute to existing evidence on this topic. Their relevance for promoting equitable responses to long COVID is explored.

Long COVID healthcare system response

The challenges detailed in this report suggest that the healthcare system is falling short of addressing the needs of people with long COVID in the GTA. While this work is based on interviews with a small group of people in the GTA the results align with the experiences documented from other jurisdictions.

Like research from elsewhere, these findings demonstrate the considerable role of uncertainty in experiences of people with long COVID.^{26,27,28} Participants in our study described gaps in knowledge and awareness about long COVID by healthcare providers, which is supported by other research that calls for better awareness of the condition for different audiences, including those in the healthcare system.^{29,30}

Research participants in this study had to navigate uncertainty within the healthcare system and described healthcare providers' varying responses to knowledge gaps and the absence of conclusive diagnostic results. The dismissal of patients' long COVID symptoms by medical professionals as mental health issues have also been documented in research from the UK.^{31,32} Studies report those with long COVID building connections with community social groups to develop knowledge about the condition. These community groups also act as coping strategies in response to medical uncertainty and negative experiences in healthcare systems.^{33,34}

Some participants detailed positive experiences where they felt supported and were provided with resources for treatment, self-management, and referrals for long COVID symptoms. For these participants, primary care providers were key points in the healthcare system and enabled access to other supports including work-related accommodations and leaves. Having options presented by physicians regardless of uncertainties was additionally described as important for validating their challenging experiences.

Participants in this study described diminished healthcare capacity including workforce issues, healthcare providers having to respond to the needs of large patient loads, insufficient time to address multiple complex needs, and long wait times for accessing specialist services and clinics. Other research from Ontario shows that long COVID sufferers increased healthcare use after infection with COVID-19 which suggests that the healthcare system is not well positioned to respond to the needs of these patients.³⁵ The same research indicates that family doctors in Ontario lack the capacity to deal with the number of long COVID patients

indicates that family doctors in Ontario lack the capacity to deal with the number of long COVID patients coming down the pipeline.

Patients with complex health issues, such as multiple chronic conditions, have faced greater barriers to healthcare access during the pandemic in Canada.³⁶ Other sources in Ontario have called for a strategy to increase the number of family doctors and improve access to primary care in the province while acknowledging the role that this level of care has played in COVID related care since 2020.³⁷

Many long COVID patients can be effectively supported in primary care if the system is sufficiently resourced and organized.³⁸ Primary care can enable access to management support, recovery planning, and referral to specialists and other areas of the healthcare system when needed.^{39,40} Sources from the UK indicate that a primary care long COVID response must be underpinned by comprehensive training programs for clinicians along with clear care pathways, guidance, and criteria for referring patients. Presently, there are multiple guidance resources on long COVID for primary healthcare providers from other jurisdictions^{41,42,43} and Ontario.^{44,45}

While there was a general awareness of the long COVID clinic model by some participants, most did not have access to these services and the few that had referrals faced considerable wait times. Given that multidisciplinary teams are recognized as a promising treatment model,^{46,47} these experiences reinforce reports that indicate a need for substantially greater investment into these programs.⁴⁸

In the context of medical uncertainty and difficulties accessing supports through the healthcare system, some participants used their own private resources (e.g., money, time) to access information about the condition and services for support. While in-depth research on how economic resources are mobilized by those living with long COVID to improve experiences and outcomes does not exist at the time of writing, several sources have noted the importance of financial resources in cultivating resilience for those with long COVID.^{49,50}

Some considerations for facilitating equity in healthcare system response to long COVID

These findings describe some barriers to healthcare for early diagnosis, guidance, and treatment for people living with long COVID in the GTA. There are also some considerations about equitable access to healthcare services that surface from this discussion.

The small number of participants in this study were all living in the GTA. Although many of the themes presented here are consistent with research from other jurisdictions, there was generally greater diversity in the sample compared to earlier qualitative studies on long COVID.

Half of the sample identified themselves as belonging to an ethnic/racial category other than White. Although almost 30 per cent of the sample chose not to report income, 60 per cent of participants who did report had a household income of less than \$60,000 (with an average household size of 3 people), which is substantially lower than the average for Toronto (\$109,000).⁵¹

Due to the design of this research, it is not possible to generalize the differences in experiences across sub-sections of the sample (e.g., based on income, ethnic/racial identity, occupation). At the same time, the healthcare experiences of individual participants suggest inconsistencies in the system. Most stark is that some participants were able to access treatment, management, and supports when needed, whereas other

individuals were not. These findings prompt thinking for how inequities might play out in relation to healthcare, especially since interactions with primary care providers were central to connections to referrals and supports.

The participants in this study all described accessing some form of primary care. By contrast, nearly 1.8 million people in Ontario lack or are only loosely connected to a regular primary care provider.⁵² This access is also inequitable, with fewer new immigrants and lower income Ontarians connected to primary care compared to those who are not new immigrants and those in the highest income brackets.⁵³ It has been projected that rates of attachment to providers will decline and inequities will worsen in the future.⁵⁴

Many people with long COVID require time off work to rest and recover. Their needs can be unpredictable as symptoms sometimes re-appear after a period of recovery. In these situations, primary care is important for facilitating access to relevant social and economic supports such as work accommodations, paid sick leave, and income support programs.^{55,56,57} For people living in the GTA who do not have a primary healthcare provider, specialist referrals and other supports are likely to be more difficult to access.

Despite health challenges that negatively impacted their lives, some participants in this study were well-positioned compared to others to manage their symptoms and seek solutions. Several participants were able to access health supports (e.g., allied health providers, mental health support, private long COVID clinics) through private insurance, employment benefit plans, or out-of-pocket payments. Participants found this necessary, partly, to compensate for a lack of public supports available, and several described accessing private and public health-related services to increase their potential for recovery.

This level of access advantages some groups with greater resources. We know that inequities within the healthcare system in Canada pre-existed the COVID-19 pandemic. Research has shown inequities in specialized healthcare access, where those with higher incomes and education levels have greater access.⁵⁸ This differential access to healthcare services and related supports is likely to exacerbate long COVID inequities, such as those linked to social and economic risk factors, when combined with inequities in access to healthcare services that are privately covered.^{59,60,61}

There is also a need to recognize how additional barriers to those described in this research, such as an inability to take time off work for appointments, challenges around travel to clinics, language barriers, stigma and fear of discrimination, combined with a lack of access to primary care, will further disadvantage some with long COVID.^{62,63} Although not captured by this study, people with long COVID who due to social circumstances (e.g., work and other responsibilities) face these additional barriers are likely to be in a different position altogether. People who are isolated and not connected to healthcare or other systems may not have made the connection between their persistent symptoms and acute COVID-19 infection.

As raised earlier in this paper reports from long COVID clinics in other jurisdictions suggest that there are indeed barriers to accessing services experienced based on race and income.⁶⁴ Researchers have also highlighted the increased likelihood that Black patients will receive inequitable treatment, including inaccurate diagnosis and treatment recommendations, in healthcare settings due to systemic racism.⁶⁵

Investment into long COVID services and supports requires solutions that address barriers faced by groups already disadvantaged in the pandemic. Without representation of Black, Indigenous, and other racialized and low-income groups in research and intervention development, inequities in outcomes will persist.^{66,67}

The risk and effects of long COVID are inequitably distributed and influenced by the social determinants of health.^{68,69} In Toronto, racialized and low-income groups have faced inequities in rates and outcomes of acute COVID-19.⁷⁰ Communities disproportionately impacted and experiencing barriers to support should be included in the design and execution of programs to address health and social inequities that have been intensified by the COVID-19 pandemic. In addition to resource allocation, efforts are needed to build awareness around long COVID health services and to design and deliver appropriate, accessible services.

Study limitations

Although this study was designed to include participants with a range of sociodemographic features in the sample, there were some gaps in representation due to challenges with recruitment. For example, the gender distribution included mainly participants who identified as female, with few male and no non-binary participants. There were also gaps in the ethno-racial representation, as most of the sample was comprised of participants who identified as White or South Asian. It will be important to continue efforts to reach and include other groups, such as Black and Indigenous people, in both research and program and policy response design.

Although participants represented a range of different age groups and income brackets the perspectives of those who were very isolated or disconnected are no doubt missing from this research, as participants gained information about the study either through community organizations or online social groups, and all study participants had access to a primary care clinic or provider. Despite the focus of this paper on healthcare experiences, the research did not include data about the experiences or perspectives of healthcare providers. Although much research early on in the pandemic focused on healthcare providers with lived experience of long COVID, the inclusion of healthcare providers in future research would enhance knowledge on possible interventions to improve healthcare experiences.

Finally, when asked about their healthcare experiences participants focused exclusively on their relationship with their family physician, and there was limited description of interactions with other primary care providers (e.g., nurses or allied health professionals). When asked about other providers or sources of support, participants typically referred to specialists or allied health providers in a specific long COVID team or private multidisciplinary clinics. This may represent a gap in the whole picture of primary care, when other professional groups such as nurses are often the first point of contact for the healthcare system.

CONCLUSION

To our knowledge, this research is the first in-depth qualitative study of experiences of people with long COVID in the GTA. As these findings and other emerging research on long COVID show, healthcare systems and primary care are important points of access to health and other supports such as community care. Inequities will result from barriers in access to primary care and specialized health services, as well as inconsistencies in the capacity of primary care to deal with long COVID. Adequate investment into publicly accessible, universal healthcare by governments is necessary to improve the capacity to treat and support people living with long COVID.

The experience of long COVID and barriers to healthcare, combined with related difficulties accessing support for work, income, and other supports has the potential to substantially exacerbate the existing inequities that have played out since the beginning of the pandemic. System-wide interventions to address long COVID must address barriers to healthcare. Services and supports specific to long COVID should be designed with communities so that additional barriers are avoided, and social and economic contexts are accounted for in the delivery.

The policy implications of the findings presented in this report have been developed in a companion piece. This piece outlines specific actions to be taken to address long COVID healthcare challenges. Where feasible, recommendations for community involvement are also included. The general areas of recommended policy action relevant to healthcare are as follows:

1. Mobilize knowledge to increase awareness and access to information for clinical management of long COVID for primary healthcare providers.
2. Mobilize knowledge for public awareness more generally.
3. Address systemic issues of overburdened primary healthcare system.
4. Improve equitable access to multidisciplinary long COVID healthcare services, primary healthcare and mental health services.
5. Develop mechanisms to connect socially isolated populations and those with limited access to healthcare services to long COVID health services and social supports.

In addition to healthcare, this study explored the related experiences of people with long COVID in accessing work and community supports. These experiences, and their implications for policy action, will be presented in forthcoming reports.

APPENDIX

Additional information about study design, inclusion criteria, and recruitment strategy

The inclusion criteria were developed to fulfil the objective of better understanding the experiences of adults living in the GTA and that many people with long COVID would not necessarily have a formal diagnosis from a healthcare provider. In fact, it was postulated that including any criteria around COVID-19/long COVID diagnosis would exclude individuals with barriers to access to healthcare services and related socioeconomic resources from study participation. As such, potential participants were asked to self-identify as having ongoing symptoms from a previously acute COVID-19 infection that lasted three months or longer, in line with the WHO definition of post-COVID-19 condition (2021).

Participant recruitment required ongoing dissemination of study information over a six month period. Study recruitment information were shared using several strategies to reach eligible participants. Information was shared with various community organizations offering health and social services to residents in the GTA. Community agencies were asked to disseminate study materials via email lists and newsletters and to staff members who might have the opportunity to share materials with potential participants. Individuals interested in participating in the study contacted researchers via email or phone and were screened for their eligibility.

Recruitment efforts were initially targeted to community agencies located in GTA neighbourhoods where the negative impacts of COVID-19 were greatest (e.g., highest rates) during the first year and a half of the pandemic. In April 2021, Ontario's Science Table found that Toronto neighbourhoods with the highest proportion of essential workers in non-healthcare settings continued to experience a three-fold higher incidence of COVID-19 infections as compared to neighbourhoods with fewer essential workers. The disproportionate burden of COVID-19 on low income, essential workers, and racialized people has been confirmed by other studies. For these reasons recruitment began in outer suburb areas in Toronto which had been particularly hard hit in an effort to reach participants who had been particularly impacted by COVID-19, who faced greater barriers accessing the healthcare system, and who were from a more diverse sociodemographic background than had generally been represented in qualitative research on long COVID at that time.

The recruitment approach was expanded over the course of recruitment to reach a broader number of organizations and participants across the GTA. Study and recruitment information was also posted on social media and shared with administrators of online social media groups of people living with long COVID in Ontario and Canada. Online community group administrators were also asked to share study materials with their members.

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