

# “We’re drowning and we’re alone”: a qualitative study of the lived experience of people experiencing persistent post-COVID-19 symptoms

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## Abstract

**Background:** The “long tail” of the COVID-19 pandemic will be reflected in disabling symptoms that persist, fluctuate or recur for extended periods for an estimated 20%–30% of those who had a SARS-CoV-2 infection; development of effective interventions to address these symptoms must account for the realities faced by these patients. We sought to describe the lived experience of patients living with persistent post-COVID-19 symptoms.

**Methods:** We conducted a qualitative study, using interpretive description, of the lived experiences of adults experiencing persistent post-COVID-19 symptoms. We collected data from in-depth, semistructured virtual focus groups in February and March 2022. We used thematic analysis to analyze the data and met with several participants twice for respondent validation.

**Results:** The study included 41 participants (28 females) from across Canada with a mean age of 47.9 years and mean time since initial SARS-CoV-2 infection of 15.8 months. Four overarching themes were identified: the unique burdens of living with persistent post-COVID-19 symptoms; the complex nature of patient work in managing symptoms and seeking treatment during recovery; erosion of trust in the health care system; and the process of adaptation, which included taking charge and transformed self-identity.

**Interpretation:** Living with persistent post-COVID-19 symptoms within a health care system ill-equipped to provide needed resources profoundly challenges the ability of survivors to restore their well-being. Whereas policy and practice increasingly emphasize the importance of self-management within the context of post-COVID-19 symptoms, new investments that enhance services and support patient capacity are required to promote better outcomes for patients, the health care system and society.

Pandemics leave “long tails” in their wake — substantial numbers of survivors likely to experience high levels of symptom burden and disability, decreased quality of life, high rates of health care utilization, potentially reduced life expectancy<sup>1,2</sup> and reduced economic productivity. According to a recent large study using electronic health record data of American adults,<sup>3</sup> nearly 1 in 5 COVID-19 survivors aged 18–64 years and 1 in 4 survivors aged 65 years or older experienced at least 1 incident condition that could be attributable to previous SARS-CoV-2 infection. These results are consistent with findings of other studies that found that post-COVID-19 incident conditions occur in 20%–30% of survivors.<sup>4,5</sup> A systematic review reported the most common among the more than 60 physical and psychological post-COVID-19 symptoms with wide prevalence were weakness (41%), general malaise (33%), fatigue (31%), concentration impairment (26%) and breathlessness (25%),<sup>6</sup> with similar trends reported in another systematic review by Han and colleagues.<sup>7</sup>

Increased susceptibility to persistent symptoms may be driven by the unique health and social characteristics of particular populations, such as racial and ethnic minorities, those experiencing complex clinical conditions, older age groups and rural residents.<sup>8</sup> Economic barriers (e.g., health care expenses and interference with ability to work), geographic barriers (e.g., living in medically underserved or geographically distant areas), precarious housing, and employment as an essential worker or in close proximity to other workers have been noted as potential contributors to health inequity in post-COVID-19 syndrome.<sup>9</sup>

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The personal, health care, economic and societal impacts resulting from post-COVID-19 symptoms will become increasingly apparent as the numbers of people affected rise. Disability is anticipated to account for most of COVID-19's burden and to disproportionately affect women, especially those who were infected at a young age.<sup>10</sup> Mental health sequelae, including posttraumatic stress disorder, anxiety and depression, have been reported to be comparable in frequency in both previously hospitalized and nonhospitalized people post-COVID-19.<sup>11</sup> A large cohort study<sup>12</sup> found that the risk gradient for excess health care burden post-COVID-19 increased with the acuity of the initial setting of care, with intensive care admissions being the highest risk. Patients with COVID-19 had an increased risk of requiring outpatient care beyond 30 days of COVID-19 diagnosis (estimated excess burden: hazard ratio 33.22 [95% confidence interval 30.89–35.58] per 1000 patients). Up to 22% of people with post-COVID-19 symptoms (also known as long COVID) reported being unable to work owing to ill health, and 45% were forced to reduce the hours worked.<sup>13</sup> Recent testimony to the US government estimated that the workforce effects of post-COVID-19 symptoms were equivalent to 3.3 million Americans leaving their full-time job.<sup>14</sup>

The experiences of people living with post-COVID-19 symptoms are an important source of information that can inform clinical interventions and professional education. A qualitative systematic review of 5 studies<sup>15</sup> found that people living with post-COVID-19 symptoms experience a variety of physical and emotional consequences and that greater knowledge of post-COVID-19 symptoms was required by stakeholders. The aim of this study was to describe the lived experiences of people with persistent post-COVID-19 symptoms.

## Methods

We conducted a qualitative study, using interpretive description, of the lived experiences of individuals experiencing persistent post-COVID-19 symptoms. Interpretive description reflects the epistemology of constructionism, with meanings and experiences considered to be socially produced and reproduced through subjective and intersubjective construction.<sup>16</sup> Whereas we primarily adopted an inductive (data-driven) approach to coding and analysis, our work was informed by several theoretical lenses, in keeping with Braun and Clarke's guidance.<sup>17,18</sup> We considered sociological perspectives on chronic illness, including burden of treatment,<sup>19</sup> biographical disruption<sup>20</sup> and loss of self,<sup>21</sup> as well as Robinson's framework on trust, health care relationships and chronic illness.<sup>22</sup>

### Participants and recruitment

We drew a convenience sample of people with persistent post-COVID-19 symptoms who had participated in a separate app-based COVID-19 survey and had consented to be contacted about other studies. The aim of the app-based survey was to describe the self-reported symptoms, functional status, treatment-seeking and satisfaction with treatment of individuals with persistent post-COVID-19 symptoms over a period of 1 year.

Recruitment occurred in February 2022. We sent 124 consenting survey participants an email invitation to participate in the focus groups. Individuals eligible to participate in the focus groups were English-speaking adults reporting 1 or more persistent post-COVID-19 symptom for a period of 3 months or more.

All participants received instructions on using Zoom and troubleshooting standard technical issues. Online data collection provided the opportunity to engage with participants in different geographic locations across Canada and reduced the burden of travel to interview sites for participants who had already engaged in the online survey and had demonstrated access to technology. At each focus group, a dedicated virtual "room" was provided in which the research assistant (K.C.H.) could debrief with any participant who chose to take a break from the discussion. No participants chose to use this service.

We followed the Consolidated Criteria for Reporting Qualitative Research.

### Data collection

We constructed a semistructured interview guide (Appendix 1, available at [www.cmajopen.ca/content/11/3/E504/suppl/DC1](http://www.cmajopen.ca/content/11/3/E504/suppl/DC1)) based on our clinical experience and prior discussions with people experiencing persistent post-COVID-19 symptoms. We identified additional probes to supplement the primary questions through a review of the academic literature and a scan of national and international "long hauler" websites. The interview guide was pilot-tested with 2 community-based volunteers with persistent post-COVID-19 symptoms to assess the clarity and flow of questions, identify potential technical issues and ensure acceptability of the questions to participants, with no substantial changes suggested. Data from the pilot test were not incorporated in the final analysis. Demographic data and consents were collected 3 to 7 days before each focus group. A list of free online mental health resources was provided to all participants at the time of consent.

Because of the degree of detail provided and the duration of participant responses in the pilot-testing phase, and to minimize the burden of online interaction for individuals who were likely to be easily fatigued, we aimed for 3 to 7 participants for each focus group.

The focus groups were held between Feb. 20 and Mar. 17, 2022, and were cofacilitated by D.G. (female nurse researcher) and 1 other health professional researcher (J.P., female nurse; T.O., male physician; or S.B., male physiotherapist researcher) with technical assistance from K.C.H. and B.D. Coauthors D.G., K.C.H. and S.B. received training in focus group facilitation through their doctoral studies. D.G., J.P., T.O. and S.B. have experience facilitating focus groups with patients living with chronic illness from previous studies. Individual meetings between D.G. and cofacilitators occurred before the focus groups to review the protocol and ensure a shared understanding of focus group methodology. Participants in the focus groups were encouraged to tell their stories to the extent they felt comfortable. Field notes were kept by K.C.H. Each focus group lasted 90 minutes and was audio-recorded, professionally transcribed and checked for accuracy.

The 10 focus groups generated more than 200 pages of transcripts, yielding rich, high-quality data. The facilitators agreed that consistent themes were evident across the focus groups, thus addressing the criteria of data saturation.<sup>23</sup> As the key strategy to promote transferability,<sup>24</sup> the “thick description” that characterizes our data provides insights about participants’ behaviour, emotions and context. “Thick description” facilitates readers’ judgment regarding transferability of the findings to their own context.<sup>24</sup>

### Data analysis

Data analysis was conducted after completion of all focus groups. Data were entered into NVivo software and analyzed using reflexive thematic analysis,<sup>18</sup> informed by interpretive description.<sup>16</sup> Five medical students (S.C., F.N.H., M.H., T.N.L. and R.V.S.) received intensive training in thematic analysis and interpretive description, coding and use of NVivo software from D.G. The team of students met for 2 hours weekly with D.G. and K.C.H. for 10 weeks. We kept detailed meeting notes of the discussions and the decisions taken at each meeting as part of the audit trail. After the entire team had read, line by line, the 200 pages of transcripts from all 10 focus groups, 2 gender-balanced pairs (S.C. and F.N.H., and T.N.L. and R.V.S.) met to identify semantic (explicit or surface meanings of the data) and latent (meanings, underlying assumptions, ideas or ideologies)<sup>17,24</sup> codes from 5 transcripts each, which were then discussed in depth at the weekly meetings. The next stage, generating themes, involved the review and organization of codes into themes reflecting aggregated meanings and meaningfulness across the data set agreed on by the team. The associations between data items and codes informing candidate themes were reviewed to ensure the codes formed a coherent pattern.

All focus group participants were invited to participate in member-checking. Five individuals volunteered, but 2 felt unwell on the day of the first member-checking session and decided they could not participate. Three focus group participants met with the coding team to provide feedback on the preliminary themes, which were refined based on the participants’ comments.

The relations between the candidate themes and the data set were evaluated at our weekly meetings to determine how well they provided an accurate interpretation of the data set. We then examined each data extract in relation to its constituent theme to ensure that we had captured the diverse expressions of meaning and to ensure coherence of the data extract within the theme. We had a second member-checking meeting with the same focus group participants who participated in the first session, along with another of the original volunteer participants, to establish the fit between the respondents’ views and the researchers’ representation of their views.<sup>25</sup> Credibility was operationalized through this process of member-checking. The themes were then presented to an interdisciplinary team of health professionals interested in post-COVID-19 condition to solicit further commentary and peer debriefing. Appendix 2

(available at [www.cmajopen.ca/content/11/3/E504/suppl/DC1](http://www.cmajopen.ca/content/11/3/E504/suppl/DC1)) describes the strategies used to ensure criteria for rigour were met.

### Ethics approval

The study was approved by the Behavioural Ethics Committee of the University of Saskatchewan (BEH No. 2975). Prospective participants were emailed a copy of the consent form, which was reviewed in detail during a telephone call before obtaining witnessed verbal consent.

### Results

We sent an email invitation to 124 consenting survey participants in February 2022, and 54 individuals responded. Nine respondents declined participation because the 90-minute online focus group would be too taxing, and 4 were not available at the time of the focus groups. Forty-one participants from 8 Canadian provinces participated in 1 of the 10 virtual focus groups held in late February and March 2022 using Zoom technology. The participant characteristics are described in Table 1. Focus groups included between 3 and 6 individuals who self-selected the session attended based on their personal schedules. All focus groups lasted 90 minutes.

We identified 4 overarching themes from the data: the unique burden of living with persistent post-COVID-19 symptoms; the complex work of seeking treatment; the erosion of trust in health care; and the evolving process of adaptation to new realities.

#### The unique burden of living with persistent post-COVID-19 symptoms

“My body felt so incredibly terrified, right? It’s like my body had PTSD.” (F1) Living through the acute infection was a traumatic and clearly recollected experience, although participants reported relief at sharing their journeys in the supportive environment of the focus group. “To hear other people’s experiences ... is healing ... there is importance in being able to share those experiences.” (F1)

Participants reported a wide array of new and debilitating physical, emotional and cognitive post-COVID-19 symptoms that profoundly affected function and quality of life. Whereas some symptoms had partly or fully resolved, all participants reported 1 or more ongoing, fluctuating or recurring symptoms. Representative quotations describing the nature of frequently reported symptoms are in Table 2, and the impacts of symptoms on participants’ personal lives are highlighted in Table 3. Financial hardships resulting from time away from jobs figured prominently across all focus groups. The suffering and life-altering repercussions of these symptoms were summarized by 2 participants: “The sad thing is I can’t even function at home, let alone think about going back to work ... . It sounds so ridiculous and almost embarrassing, but it’s insane how much it takes out of a person to do the littlest things.” (F2) and “The overwhelming feeling that all of us have is that we miss our life.” (F6)

**Table 1: Participant characteristics**

Characteristic	No. (%) of participants* n = 41
Age, yr, mean ± SD (range)	47.9 ± 10.4 (29–83)
Sex	
Female	28 (68.3)
Male	13 (31.7)
Residence†	
Western Canada	33 (80.5)
Central Canada	4 (9.8)
Atlantic Canada	4 (9.8)
Time elapsed since acute SARS-CoV-2 infection, mo, mean ± SD (range)	15.8 ± 6.4 (3–27)
Pre-existing chronic illness	
Yes	11 (26.8)
No	30 (73.2)
Hospitalization during acute SARS-CoV-2 infection	
Intensive care	3 (7.3)
Hospitalized	9 (22.0)
Not hospitalized	29 (70.7)
Employment status	
Full-time	15 (36.6)
Part-time	12 (29.3)
On sick leave owing to post-COVID-19 symptoms	6 (14.6)
On paid long-term disability owing to post-COVID-19 symptoms	3 (7.3)
Retired	2 (4.9)
Unemployed	3 (7.3)
Changes in employment due to post-COVID-19 symptoms	
Reduced hours	10 (24.3)
Had to change jobs	7 (17.1)
No change in employment status (including retired and unemployed)	24 (58.5)
Note: SD = standard deviation.	
*Unless stated otherwise.	
†Western Canada: British Columbia, Alberta, Saskatchewan and Manitoba; Central Canada: Ontario and Quebec; Atlantic Canada: New Brunswick, Newfoundland and Labrador, Nova Scotia and Prince Edward Island.	

The persistent and apparently inexplicable nature of many post-COVID-19 symptoms engendered feelings of uncertainty and fear. Some participants voiced concern about their long-term implications: “COVID basically did permanent damage, so I don’t know, should I push? Should I not push? I don’t know what I should do.” (F9) and “Will this shorten our lifespan, or what are we looking at in the future? Are ... we going to be disabled?” (F3)

Participants often felt stigmatized and isolated during both the initial infection and afterwards. “I felt like I was treated like we were antivaxxers ‘cause we got COVID.” (F4) Some workplaces created additional psychological burden. “You get looked at when you come back [to work] and you get looked at when you leave, because people are, ‘Well, are they really sick or what’s going on? Are they [just] taking some time off?’” (F1)

### The complex work of recovering from persistent post-COVID-19 symptoms

Given the intensity and complexity of symptoms experienced, participants required a high degree of personal agency to undertake the work of recovering from their post-COVID-19 symptoms, which was influenced by personal, systemic and societal factors. Strong support networks during the recovery journey mitigated the stresses of managing symptoms and seeking treatment, although issues such as caregiving responsibilities, costs and managing comorbidities added to overall burden. Self-advocacy was a critical, but taxing, component of the work undertaken by these participants. “It’s hard for long COVID patients to speak up ... it’s hard for us to advocate for ourselves.” (F6) Many participants described the frustration of having their symptoms discredited by others. “I want to be

**Table 2: Description of frequently reported post-COVID-19 symptoms**

Type of symptom	Representative quotation
Tachycardia/hypotension	"Any time I rise or change position, my heart rate goes really high, 140 usually, and then my blood pressure drops ... every time I stand up, every time I get moving. And then it causes dizziness, nausea, all those fun symptoms." (F1)
Dyspnea	"It would take me an hour to walk up the flight of stairs and back down ... 'cause I was so short of breath." (F5)
Exercise capacity	"I can go out to take the garbage bin down, and I sound like I ran a mile coming back into the house. I'm panting and my heart rate is just — it's wild." (F2)
Sleep problems	"I'll sleep for 20 minutes and then I'll be awake ... when you add that all up, it's like 3 hours of sleep I've had, but all broken up." (F10)
Headache	"One of my goals is I want to have a day without a headache. I don't even remember what that's like." (F3)
Pain	"I was just hurting, my muscles and joints were just hurting so bad, I could hardly move around ... I was in so much pain all over, from the top of my head to the bottom of my feet." (F9)
Fatigue	"I could do ... a kids' puzzle for 15 minutes, and I would have to rest physically and cognitively for 14 hours and try again the next day." (F6)
Memory impairment	"I haven't been able to remember what I had for supper the next day for a year." (F4)
Brain fog	"The memory fog is horrible. I used to have a mind of a steel trap, now I'm the Post-it note girl." (F6)
Word-finding difficulty	"I started losing words, so I forgot the word for spoon. I forgot the function of a spoon, I was trying to get food from a container into another container and I thought, 'if only there is a tool that I can use to get this food from here to there,' and I couldn't think of a spoon." (F7)
Tinnitus	"I've got ringing ears since May of 2020 ... falling asleep, that can sometimes be a problem ... I know I've overdone it if my ears are extra loud ringing." (F8)
Phantosmia	"I thought I was crazy because I'd say to my husband, 'I don't know what's wrong with me, I keep smelling this smell,' and he'd go, 'I don't smell it' ... , it was bizarre and you think you're losing your marbles because you'd smell this smell." (F9)
Anxiety	"I'm always scared I'm going to have a heart attack ... . If I go too far, am I going to have a heart attack, and I'm by myself, so I try not to push too hard." (F9)
Depression	"It's hard to try and stay optimistic ... you can get down in the dumps and be like, [sighs] this sucks. You do get into that depressive state and 'am I ever gonna get better?' And if I'm not, what's the point?" (F6) "You feel like you're a burden to everybody. And it's not — when you're sick, and then you feel like you're a waste of skin to people. It's not a conducive thing for healing or getting better." (F1)
Suicidal ideation	"I probably would've killed myself at the rate I was going. 'Cause it's a steep decline." (F5)

believed by my doctor. I want to be believed by my employer. I wish more people were aware of it. Instead, people are being gaslit. I think the big thing moving forward is to be believed." (F1) Table 4 describes factors that affected the ways in which participants managed their efforts to recover.

Difficulties in negotiating with employers and insurers to access benefits seriously complicated the work of recovery, particularly for those without confirmation of a positive COVID-19 diagnosis. Participants frequently described out-of-pocket expenses for therapies, navigating complex paperwork, and denial of benefits. In spite of these challenges, many were motivated to independently seek rehabilitation services, particularly physiotherapy, as well as complementary medicine, through private clinics, sometimes out of province.

The general public was perceived to neither understand nor appreciate the realities associated with living with persistent post-COVID-19 symptoms. Government policies, particularly around access to information about rates of COVID-19 and the end of mandatory masking, were sources of frustration and anxiety that complicated patient work to regain health. Participants voiced concern about the ongoing

dismissal of physicians' concerns and expertise by governments. "The government just does not trust our medical community and I don't know why." (F7)

### Erosion of trust in health care

Participants were extremely grateful for their positive experiences with the health care system and their providers — "My family doctor is amazing and, honestly, was like the rock that has gotten me through this." (F8) For others, however, negative experiences shook their foundational beliefs about the ability of science to diagnose and cure, and the capacity of the health care system to care. The implications of systemic issues such as long wait times and lack of access to primary care were often magnified for those living with debilitating and unexplained post-COVID-19 symptoms. A multitude of systemic (Table 5) and health care provider and relational (Table 6) factors challenged participants' ability to navigate and negotiate the services they felt they required, and generally eroded the level of trust in the health care system and health care providers. Participants did not know where to turn for help when the health care system proved unresponsive.

**Table 3: Impacts of living with persistent post-COVID-19 symptoms**

Type of impact	Representative quotations
Family unit	"It definitely affects ... your life with your family because they see me struggling. It's very hard to remain positive, but every day I try to put on a bright face, to try to not make my family worry. It's just the mental toll's been tremendous." (F2) "So you don't say anything to them, and you don't want them to be worried and feel like they have to jump." (F7)
Spouse	"When I was off, my wife took on 2 other jobs after her full-time job to make up the downfall or the shortfall of the money that we weren't bringing in ... it's affecting my wife and her health and the health care system for her because eventually, she's gonna burn out." (F1)
Children	"I notice a lot of change in my 7-year-old because it's just kind of her normal now that Mom's in bed a lot and Mom can't come ... just don't know how is that gonna affect them in a couple of years when a big chunk of their childhood, Mom's just been sick." (F1)
Friends	"You're bombarding your family, your friends with how you feel all the time." (F1)
Family activities	"I've been robbed of being the mother that I want to be. And as well, the wife. We don't have energy to go out on dates. If I can get out of bed and go to activities and do a little bit of meal prepping, that's a big day for me. So, it's really impacted my family a lot." (F1)
Finances	"There's gotta be something for us that have suffered and been through it and lost salary and credit cards are maxed out and you've borrowed money from your parents or you've borrowed money from here and you're looking at doing something to take a high interest loan out just to pay the bills." (F3)
Employment	"I'd go home just exhausted and I'd be useless the next day, because it just would wear me out, and I mean, it's not physical work, it was the mental. It can be very stressful work." (F9) "I've been off from work for 2 years now. Fortunately, I have a really good disability plan through my company, and they've been very understanding." (F6) "How do I go back to work as a nurse when I have good days, bad days, and I don't see them coming?" (F1)
Function	"I live out on an acreage, so I'm by myself. I have to haul bales, I have to haul water ... it's very physical work, where it used to be a piece of cake for me ... now, it's a huge, huge effort." (F9) "I haven't driven hardly at all for the last 2 years and I have driven all over North America. Put me in a car that's my happy place, and now I do not trust myself to drive." (F6)

"I will not go back unless I think that I'm dying. Cause they won't do anything." (F4) "I don't want to go back to this doctor now because I don't trust her ability to figure out what's wrong with me." (F8)

In spite of debilitating symptoms, the failure of diagnostic tests to provide objective evidence of treatable disease for some participants further eroded trust. "I've been to a multitude of specialists and doctors, and they say, 'Everything is normal from what we can see. We don't know what to do with you' ... then why do I feel the way I feel?" (F9) In spite of sometimes being unable to provide conclusive answers, physicians who were attentive, responsive and caring were highly valued. "The most important thing that the health care or health care in general can provide for me ... is actually not competence or knowledge, it's ... humility." (F4)

### Process of adaptation

"We were navigating a path that we never intended to take, a journey we never intended to embark on." (F5) The journey of living with often unpredictable post-COVID-19 symptoms evolved for many into an ongoing process of adaptation (Table 7), frequently characterized by grieving losses, an uncertain future, living with relapses, the development of new self-care strategies, a growing acceptance of new realities and limitations, and transformed self-identities. A pivotal moment in the process of adaptation proved to be recognizing the need to take charge. "What I've found is that there's really nothing

they can do for you, if the damage is there. How are they going to fix it? They can't. You have to do that by yourself, and it does take a multitude of different things." (F9) Participants found new courage to be their own advocates in the face of ongoing symptoms.

Hope, for some participants, was found in small, but promising, milestones that pointed to recovery. Resilience was fostered by drawing on optimism and gratitude for what remained.

### Interpretation

We identified key aspects of the lived experience of adults in Canada living with persistent post-COVID-19 symptoms. The key contribution of this study is the in-depth characterization of the many ways in which post-COVID-19 symptoms test the capacity of individuals to manage and recover from their illness over a protracted period (average of 15 months post-acute infection), including key insights into the process of adapting to living with an unpredictable and uncertain illness trajectory. Given the anticipated "long tail" of the COVID-19 pandemic, societies will need to address the profound physical, psychological, social and economic impacts on those with post-COVID-19 symptoms for years to come.

Participants, most of whom continued to experience persistent symptoms more than a year after their acute SARS-CoV-2 infection, clearly articulated the multiple ways in

**Table 4: Factors affecting the complex work of recovering from persistent post-COVID-19 symptoms**

Factor	Representative quotation
Family support	<p>“I got my family to drop some vitamins, just bring me juice ... my husband was stuck at home, I was stuck at home. Eventually, I got him to take me to the hospital, I spent the whole day there.” (F9)</p> <p>“Our family has helped as well, but at times, they’re kind of scared to come over.” (F1)</p> <p>“I’ve had to have my husband come to all my doctor’s appointments because I just can’t process quick enough and answer questions and remember things.” (F4)</p> <p>“People that live with the long haulers, they deserve an award, or the people that have helped us through this, because they do know, and they understand.” (F6)</p>
Level of support from friends	<p>“I have a good set of friends who come clean my house, get groceries when I can’t get groceries, all of that.” (F6)</p> <p>“I have some friends that kinda don’t believe in COVID and think it’s nothing more than a cold. So, it’s been a bit difficult that way.” (F3)</p>
Support groups	<p>“I joined the American survivor group on Facebook ... I’m in a lot of these support groups where we help each other out, thank goodness.” (F6)</p>
Need for self-advocacy	<p>“I’ve been doing a lot of research, a lot of investigating because I’ve been on my own and the doctors have done nothing but gaslight me.” (F6)</p> <p>“A lot of times, we’re guiding what [providers] are doing, right? We’re — especially because I have a medical background, so I’m researching and I’m looking and I’m doing anything I can to try to help my situation, right? Which, again, when you’re going through long COVID is extremely exhausting. A lot of people don’t even have the energy to be their own advocate, right?” (F8)</p>
Frustration of having symptoms discredited by others	<p>“I’ve gotten to the point where I’ve given up trying to explain anything to anyone anymore. It’s just believe it or don’t believe it, I know what I’m going through. And that’s just the way it is.” (F3)</p> <p>“I’m struggling with the lack of belief. People think I’m faking all the time and I’m like, seriously? Look at my thermometer, it’s 104. I’m not faking!” (F4)</p>
Caregiving for others while symptomatic	<p>“My mom was immunocompromised ... My mom was not with it. She almost died if I wouldn’t have been looking after her ... I didn’t even have a chance to heal from my COVID. I was sick, looking after her. [Cries]” (F4)</p>
Concurrent life stresses	<p>“My son sort of had a crisis in the fall because after his dad was diagnosed with the second cancer, it just — you know, losing his sister [through death] ... and my diagnosis, and my husband’s diagnosis. He thought he was going to lose us both and he wouldn’t have anybody.” (F6)</p>
Managing comorbidities alongside post-COVID-19 symptoms	<p>“I was able to have 4 of the immunotherapy combo treatments and did quite well, but as soon as that was done, I ended up with something called pneumonitis and then sarcoidosis, so for many, many months, I did not feel well. Felt like I had the flu every day.” (F8)</p>
Costs of local private rehabilitation and complementary medicine providers	<p>“[The physiotherapist] told me he was limited with what he could — cause I’m funding it myself, cause I have no benefits left at this point.” (F3)</p>
Navigating benefits and insurance coverage	<p>“When you’re tired and you have fatigue and you have brain fog and you can’t think like you normally did and you don’t have the physical abilities that you normally did, how can you even begin to go through the system of applying for disability, long-term disability, CPP disability? It’s like an endless cycle. You need it but you don’t have the ability to do it. And then when you do, no one believes you and you have to fight through the whole system.” (F9)</p>
Denial of benefits on the basis of lack of confirmation of SARS-CoV-2 infection	<p>“My work decided ... [I] didn’t qualify for short-term disability. From the loopholes of their crap system. [Workers’ Compensation Board] said it was too bad cause I never had the positive [confirmation]. Cause there was nothing.” (F5)</p>
Denial of benefits and insurance coverage on the basis of diagnosis	<p>“An internal medicine specialist concluded that my symptoms were due to my depression and anxiety solely, so basically ... that was the writing on the wall, so I couldn’t challenge that ... I could challenge that diagnosis I guess, but I don’t know how I would do that, so that basically wrote me off for long-term disability.” (F8)</p>
Surveillance by insurer	<p>“Disability’s like, ‘Well, where are you at? We need an update.’ Well, I’d love to give you an update. I wish I felt better to give you a positive update.” (F2)</p>
Public perceptions	<p>“There’s definitely nothing worse than people that don’t even feel that COVID was a real virus...They don’t believe it’s not a thing, like you can’t still be suffering a year later. Yeah, I am!” (F9)</p> <p>“There’s really little recognition of long COVID in general. There’s a lot of disbelief and the government doesn’t seem to be doing anything to support people and to understand it more.” (F1)</p>
Government policies	<p>“We are very upset about this lack of information ... we can’t get any information. I really blame the government for that.” (F7)</p>

Note: CPP = Canada Pension Plan.

**Table 5: Systemic factors contributing to erosion of trust in health care**

Factor	Representative quotations
Wait times for primary care physicians, specialists and diagnostic tests	“Two and a half hours [on hold on the phone] ... when you're not feeling well, and you can't even get through to your doctor. You're better off to go down and make the appointment.” (F7)
Lack of access to primary care physician	“The first year [of having post-COVID-19 symptoms], there was no help whatsoever. Cause my family doctor moved away a few months after I was sick.” (F5) “I no longer got a yearly check-up. I no longer got regular blood work. I felt like I was no longer being cared for.” (F4)
Living in a rural area	“I've had no contact with doctors except 1 time, and this was probably going on maybe 9 months ago now, pushing a year ... . We don't have the best service here because it's a small town.” (F9)
Need for patient-centred care	“You need somebody who is familiar with dysautonomias or nervous system disorders, who looks at the body as a whole and not just go, ‘Okay, you have a heart problem, go to a cardiologist. You have a headache, go to a neurologist,’ right? They're just looking at it from a 1 system perspective, they're not looking at it from your whole body and no one's talking to each other.” (F1)
Coordinating appointments with multiple health care providers	“I have, like, 10 different areas of the city I have to randomly go to and find.” (F5)
Difficulty accessing services	“He just kept deteriorating and the doctor said call 9-1-1. Called 9-1-1, they said we'll be there, and then 5 minutes later they called back and said, ‘We'd prefer not to take him, it sounds like he has COVID, and we don't want to expose our paramedics to COVID. Can you take him to the hospital?’” (F6) “It's just so hard to get anything here. It's all cost cutting. You're not dying, they're not gonna do it.” (F4)
Inadequate communication between providers	“When I first saw my family doctor, I had asked her, ‘Did you get the report of what happened in the hospital?’ And the doctors don't even get a report.” (F2) “What I've seen in all of it, after seeing an ENT, a dermatologist, an allergist, a neurologist, a hematologist, none of them are connected. They don't have any communication.” (F4)
Inadequate standard of care in hospital	“Once I left the ICU ... you just kind of got thrown in a room and you never saw anybody. I never saw anybody to come up to assess my oxygen. I never saw physio come, I never saw anybody come up there.” (F2) “They left me in isolation — because I had a mild sore throat at the same time. They left me in isolation for 4 hours. Wouldn't let my husband in with me. No one checked on me. And my blood pressure was super elevated. So, the standard of care is nonexistent, really.” (F4)
Lack of follow-up	“It's like when you get let out of the hospital, you're just let out to the wolves. And you sit at home and you're like okay, the first month, I know I'm ill, I know I was really ill, you gotta get better. But now what? What do you do to recover? Who do you talk to? Who's gonna help you?” (F2) “Nobody's phoned up, nobody's ever followed up with me. But again, I've never followed up with anybody either. So, it's kind of, they give you the start and then they kind of just vanish.” (F1) “When I contacted my family doctor and said ‘Hey, things aren't going away’ and he said, ‘Yep, you probably have long COVID.’ And that was it.” (F2)
Lack of access to long COVID interdisciplinary clinics	“There is a long COVID clinic in Toronto, but first of all I can't drive that kind of distance now, and ... their wait-list is literally 2 and a half years. So what good is that going to do for me?” (F6) “I feel like there needs to be COVID recovery specialists.” (F2) “Something along the lines of the multidisciplinary assessment. Where you can get a neurologist in the room and the physiotherapist in the room. Get everybody in 1 room. I talked to my family doctor, well then she's gotta send a letter to the neuro. It's like okay, can't we all talk at 1 time in the room? I would like to have a few experts at a table at a time.” (F3) “A 1-stop shop probably would be the best way to do it is have a COVID long haul assessment clinic where you have a respirologist, maybe a cardiologist, a rheumatologist.” (F5)

Note: ENT = ear, nose and throat specialist, ICU = intensive care unit.

which these symptoms dominated and transformed their lives. Fear and uncertainty about the implications of their symptoms were exacerbated by limited scientific evidence and by shortcomings of systems that were themselves challenged on multiple fronts.

The burden of treatment described by May and colleagues<sup>19</sup> results from demands on patients to organize and

coordinate their own care and to manage escalating arrays of health care-related tasks. The patient work involved in attempting to secure diagnoses and treatment for post-COVID-19 symptoms was complicated by the need to self-advocate for services at a level unusual for most other conditions, and at a time when health services were already strained. Burden of treatment increases when patients are not



**Table 6: Health care provider and relational factors contributing to erosion of trust**

Factor	Representative quotations
Perceived lack of effort	“My family doctor was supportive, but she had nothing she could do for me ... . She validated that, yeah, this sounds like long COVID, but there was never any attempt to do anything else for me.” (F8)
Feelings of abandonment	“We go to them for the answers, right? We’re looking to them to help us and they’re not ... . But I just felt like I was left alone to deal with everything. [Crying]” (F4) “Just imagine you’re in the middle of the ocean without a life jacket and you’re struggling to keep your head afloat. And a boat comes by and start clapping at you and says, ‘Man, you’re doing a good job,’ and drives off. That’s sort of what I feel like right now.” (F4) “We’re drowning and we are alone.” (F6)
Expectations that providers know the answers	“Physicians here are not equipped to deal with this, and I know we don’t know what we don’t know, we’re living in real time, but it’s frustrating as a person when they’re supposed to be the experts.” (F9) “They kind of ameliorate things, but you know, no one seems to know anything about really getting down to how do we cure this.” (F8) “Nobody ever gives you the process of these are the steps to take.” (F2)
Feeling disbelieved	“My family doctor doesn’t believe me that I have it at all. ‘Your tests come back fine.’” (F1) “My biggest frustration is my neurologist right now. I don’t think he believes me. I don’t think he believes that I have the headache I have ... oh man, how am I gonna convince this doctor that I really do have headaches? I don’t know.” (F3) “You can almost hear them or see them rolling their eyes in their head.” (F9)
Concerns dismissed	“I still think he’s a wonderful physician, but feeling like I was written off, when I came in, ‘It’s all in your head, you’re immune, you’re good to go, you’re not sick anymore,’ but I don’t feel well.” (F10) “When I was talking to him over the phone and trying to go through these issues, he basically said, ‘This conversation’s been on for 15 minutes, it’s been going on too long’ ... It really left me ..., basically just feeling defeated. What do I — I don’t know what to do?” (F9) “I felt like they don’t really want to talk to me anymore because I should be better by now, but I was like, ‘But I’m not, I’m still running a fever of 39°C, I’ve got diarrhea, my head hurts, all I can do is sleep.’” (F10) “I’ve been on my own and the doctors have done nothing but gaslight me.” (F6)

highly skilled at assembling and using collective resources.<sup>19</sup> With functional performance already constrained by persistent symptoms, the burden of cognitive and practical tasks required to regain health was often overwhelming. Participants’ calls for a more fully informed and supportive health care system are supported in a qualitative systematic review of living with long COVID.<sup>15</sup>

The conceptual tool of biographical disruption<sup>20</sup> is useful for unpacking the multiple impacts of persistent post-COVID-19 symptoms and the process of adaptation reported by participants. As the onset of illness fundamentally ruptures the patterns and assumptions that structure daily life and create personal coherence, this theory contends that individuals are forced to deal with these disruptions, consciously consider their life trajectory and mobilize novel resources to cope with the chaos.<sup>19</sup> These patterns were evident in the descriptions of how participants adapted to their altered circumstances, which reflect the course of adaptation to chronic illness described by Gignac and colleagues:<sup>26</sup> compensating for losses, optimizing performance, limiting or restricting activities, and seeking help from others.

Erosion of trust in health care may be especially important within the context of persistent post-COVID-19 symptoms, in which there may be enhanced vulnerability, uncertainty about outcomes, and reliance on health care providers over extended periods.<sup>27</sup> Patient trust is dynamic and relational,<sup>27</sup> based on expectations that the health care system and providers demonstrate knowledge, skill and competence, as well as

behaving in the patient’s best interest with integrity, fairness and beneficence.<sup>27</sup> When patients perceive discrepancies between these expectations and the care they receive, trust in the health care system as a whole can be eroded.<sup>28</sup>

Our study is unique in that our Canadian participants had lived with post-COVID-19 symptoms for an average of 15 months, in contrast to other studies,<sup>29,30</sup> where symptoms had been present for much shorter time frames, at an earlier stage in the pandemic and when health care services may have been more compromised. We have demonstrated that the long-term burden of living with post-COVID-19 symptoms can continue well beyond the first months of recovery and can result in undesired, substantive personal and occupational accommodations that have substantial implications for well-being. Although multiple challenges with access to and quality of services for persistent post-COVID-19 symptoms had been reported by these studies,<sup>29,30</sup> these issues have remained largely unaddressed for our participants within the Canadian context. The themes reported in a patient-led thematic analysis<sup>31</sup> of 66 stories submitted online in 2020 included the life-changing impact of the condition, the importance of validation and seeking alternatives as the only option. Our study builds on these themes to include the erosion of trust in health care and process of adaptation. Avoiding key methodological issues identified by MacPherson and colleagues,<sup>15</sup> we had no previous relationships with participants that may have introduced bias, did not compensate participants and ensured all transcripts were complete.

**Table 7 (part 1 of 2): The process of adaptation to living with post-COVID-19 symptoms**

Process	Representative quotations
Grieving losses	<p>"I'm missing out on being a mom, like for my 18-month-old. I can be a mom, bits and pieces. I've missed out on so many activities." (F1)</p> <p>"I feel life COVID ... has taken the simple things in life I used to enjoy away from me ... The overwhelming feeling that all of us have is that we miss our life." (F6)</p> <p>"I'm stupider than crap now compared with how I used to be." (F5)</p> <p>"It's very sad and depressing when you see the life you have now compared with the life you had pre-COVID. It's not the same." (F1)</p>
Considering the prospect of permanent disability	<p>"Some of the questions my mom has posed to me is like trying to get me thinking about what happens if this doesn't go away. What happens if I'm at 60% forever?" (F2)</p> <p>"I'm coming to that, that I'm going to be living with this. I think I have to learn to live with it. I just don't know how." (F3)</p> <p>"Basically, my symptoms have progressively gotten just very, very gradually worse the whole time, so this is 2 years on." (F8)</p>
Adapting to changes in energy and function	<p>"I decide not to participate in a conversation. If I'm not 100% sure what's going on, then I just don't say anything. And that's not like me ... it's like oh, I don't know if I got that right so I'm not gonna say anything cause I don't want to look stupid." (F3)</p> <p>"I used to be a voracious reader. I find now that I can read, but I don't retain it, so I read 3 pages of a book and if somebody asked me, 'So, you know, what happened in those 3 pages,' I couldn't tell you, so there's just no point in reading anymore." (F10)</p> <p>"I'm just trying to live life normally right now and it's not been easy ... I've always been at 120% ... And I was always going and never stopped." (F2)</p> <p>"When I was home, I was pacing [activities], unknowingly. But when you go into an environment where you cannot pace, and on top of it, the physical stress of not being able to pace and stop." (F4)</p>
Living with relapses	<p>"I woke up and I thought, 'Oh, gosh, it feels so good to feel myself, I feel pretty good.' The little getaway, the greenery, the nice, hot sun, it was great. Well, I did a bunch of stuff around my house that I'd sort of let go, and by 3 in the afternoon, I just felt like a truck had run over me, and that's what I have trouble dealing with, that I'll have a day or 2 where I sort of feel like myself, and then the next day, it's just like I — I just feel horrid." (F8)</p> <p>"It cycles. You're good for a couple of days and then I walk too far because I'm trying to get more exercise because that's what my doctor said to do, and it sets me back for 2 days, your joints hurt, it hurts to sit, it hurts to stand up." (F10)</p> <p>"First days in a month that I had not had a fever. And I actually — I was able to sweep my kitchen floor and I wiped down a bathroom, and those were huge victories for me. Then, the fourth day, first day of no cortisone and I was back to a fever of 104. And couch bound again." (F4)</p>
Maintaining personal safety	<p>"My group is still very small. I see the same 1 friend." (F2)</p> <p>"I remember my parents' anniversary and they really wanted everybody to get together, but I was still being really cautious about being around people without masks on." (F4)</p>
Transformed identities	<p>"I have always defined myself for working and volunteering and being there for everybody else, and now I can't, and it's been very hard for me." (F6)</p> <p>"I feel like I'm nothing like myself that I was pre-COVID." (F2)</p> <p>"I would consider myself an extrovert and I think have become so much more introverted in the process of this, you know. The thought of spending time with other people is difficult for me right now." (F7)</p> <p>"It's just been so long already that sometimes now, you just live with it. I've just had it for so long that now it's just kind of me." (F1)</p>
Adopting new self-care strategies	<p>"I know a couple of people have mentioned going vegetarian and vegan. I am not sure if I could do that, but I almost think I need to change my diet too." (F3)</p> <p>"Even with my pain, I do all these things, all these exercises, all these extra things I'm supposed to do." (F4).</p> <p>"Word findings, crossword puzzles, I was trying to keep my mind active and the other thing when I was really stressed, I started just listening to classical music, no other music." (F6)</p> <p>"No matter how much I was trying to sleep or how much sleep I was getting in the night, I wasn't getting a good rest, and after I think about 3 sessions of acupuncture, I finally got a good sleep and it felt like the difference between when you have a dead battery that won't take a charge, and then having a battery that can recharge and plug it in, it was that kind of difference. I just felt recharged again and able to sense a big difference after that in my energy level." (F10)</p>

**Table 7 (part 2 of 2): The process of adaptation to living with post-COVID-19 symptoms**

Process	Representative quotations
Taking charge	<p>“I would have never thought of mast cell activation if I hadn't gone to that [support] group and then it turned out that the doctors agreed with me.” (F5)</p> <p>“You put together your own team. I think that's the only thing that works because I don't have access to a long COVID clinic.” (F6)</p> <p>“I thought, ‘Okay, well, self-advocate. What can I try and do? Let's try some acupuncture, let's try some therapy, the naturopath,’ and I think there's been some good results at that, but taking 40–50 different supplements a day — I can't stomach taking all these pills.” (F10)</p> <p>“She was a young emergency doctor filling in to do this assessment. Took 5 minutes and didn't — hadn't even read my chart, didn't look at my echo result. Was just like, ‘I think antidepressants are the answer.’ ... I was like, ‘You absolutely are incorrect and this isn't a depression. You know, I've monitored my heart rate, monitored my oxygen. And it's almost like POTS-like symptoms. I'm like, I'm not making it up in my head.’” (F1)</p> <p>“[Participant asked] ‘Should I do anymore tests or is there anything I can do?’ [Physician said] ‘No, just rest. Keep on doing what you're doing.’ I'm going to put my foot down on Friday and try to get more answers, but I'm still at the beck and call of the health system.” (F9)</p>
Acceptance of a new normal	<p>“For me, it's not over yet. I don't know when it is going to be. It's getting better, but it's not over yet. It may never be over.” (F7)</p> <p>“If this is my new me, I'm learning to live with it ... I can't do much physically and I can't do much cognitively ... coming to understand that right now, this is my normal.” (F1)</p> <p>“How you feel about yourself [is different]. Your energy levels, all of those kinds of things. It's a different normal than anything that you ever had to deal with before ... but you have to start accepting this is what you're going to be living with.” (F2)</p>
Finding hope in milestones	<p>“I suspect that [my energy] just isn't going to come back at this point, because it's been this long, but I'll keep working on it. I will, I'm going to just keep pushing because I mean, there has been, you know, very tiny, baby step kinds of improvements all the way along.” (F7)</p> <p>“A lot of the people said that once you're able to do your regular activities, so if you can get up, get your son to school, make lunch, have supper, do the bedtime routine, once you can do your normal activities at home, that's the standard of when you can try adding on more.” (F8)</p> <p>“I was happy at 5 months when I started eating again, got my appetite back.” (F5)</p> <p>“Because I sing ... I'm in a band. I find singing, interestingly, a very great exercise for working on gaining back some lung capacity because you really, really have to work on sucking a lot of air in when you're singing all the time ... so that's kind of a bonus. I didn't realize that it would make that kind of difference.” (F9)</p>
Optimism	<p>“You just have to have faith that you're going to get better.” (F6)</p> <p>“I'm trying to remain positive, trying to hang in there.” (F2)</p>
Finding gratitude	<p>“There are so many things to be grateful for, honestly. All the little things I kind of celebrate. Some of the brain fog has lessened, and compared with where I was, say a year ago, there's huge improvements ... I feel like I shouldn't complain because I lived when I didn't think I would live.” (F6)</p>

Note: POTS = postural tachycardia syndrome.

The findings of our study point to the need for new and targeted investments to better address the needs of those with persistent post-COVID-19 symptoms. The creation of voluntary patient registries that are co-designed with patients could serve a dual purpose of service improvement and research.<sup>32</sup> In addition, these registries would allow for long-term follow-up and greater understanding of both long-term socioeconomic implications and population health.<sup>32</sup> Increased awareness of the post-COVID-19 condition through public and professional education, as well as the development of supports for patient advocacy within workplaces and institutions, will be foundational to improving outcomes for people with persistent post-COVID-19 symptoms.

**Limitations**

Limitations of our study include the convenience sample of Canadian adults who had consented to be contacted about future studies in a longitudinal, English-only, app-based survey on COVID-19 with recruitment through social media, support groups and media coverage. Because we did not include non-English-speaking individuals and those without access to or comfort with technology, there may be additional themes that reflect the lived experiences of these populations. Factors such as ethnic background, complexity of clinical conditions, rural or urban origin, geographical distance, housing, income and pre-existing health inequities could not be related to our findings. Most participants were of middle age, and experiences of younger and older adults were not fully captured. Because two-thirds of our

participants were female, the perspectives of males with persistent post-COVID-19 symptoms may require future elaboration. The virtual nature of the focus groups may have altered the interactions between participants. Because the focus groups were audio-recorded, but not video-recorded, we were not able to attribute quotations to individuals. This limited the ability to establish relations between participant characteristics and their responses.

## Conclusion

Living with persistent post-COVID-19 symptoms within a health care system ill-equipped to provide needed resources profoundly challenges the skills and abilities of survivors to restore their well-being. Whereas policy and practice increasingly emphasize the importance of self-care and self-management within the context of post-COVID-19 symptoms, new investments that enhance services and support patient capacity are required to promote better outcomes for patients, the health care system and society.

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