



# "I feel like my body is broken": exploring the experiences of people living with long COVID

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## Abstract

**Purpose** Long COVID, an illness affecting a subset of individuals after COVID-19, is distressing, poorly understood, and reduces quality of life. The objective of this sub-study was to better understand and explore individuals' experiences with long COVID and commonly reported symptoms, using qualitative data collected from open-ended survey responses.

**Methods** Data were collected from adults living with long COVID who participated in a larger observational online survey. Participants had the option of answering seven open-ended items. Data from the open-ended items were analyzed following guidelines for reflective thematic analysis.

**Results** From 213 participants who were included in the online survey, 169 participants who primarily self-identified as women (88.2%), aged 40–49 (33.1%), who had been experiencing long COVID symptoms for  $\geq 6$  months (74%) provided open-ended responses. Four overlapping and interconnected themes were identified: (1) *Long COVID symptoms are numerous and wearing*, (2) *The effects of long COVID are pervasive*, (3) *Physical activity is difficult and, in some cases, not possible*, and (4) *Asking for help when few are listening, and little is working*.

**Conclusion** Findings reaffirm prior research, highlighting the complex nature of long COVID. Further, results show the ways individuals affected by the illness are negatively impacted and have had to alter their daily activities. Participants recounted the challenges faced when advocating for themselves, adapting to new limitations, and navigating healthcare systems. The varied relapsing–remitting symptoms, unknown prognosis, and deep sense of loss over one's prior identity suggest interventions are needed to support this population.

**Keywords** Post-acute COVID-19 syndrome · Post-COVID-19 condition · Post-viral fatigue · COVID-19 · Qualitative

## Introduction

The acute impact of SARS-CoV-2 (the virus that causes COVID-19) infection varies widely, with some individuals experiencing no symptoms and others experiencing adverse effects that vary from mild to critical severity [1, 2]. Diverse responses to COVID-19 persist beyond the initial presentation, with a subset of the population experiencing complicated, disconcerting, prolonged illness [3], widely known as long COVID [4] (or post-acute sequelae of SARS-CoV-2 infection). Though much remains unknown, long COVID is characterized by multiorgan impairments that span respiratory, cardiovascular, neurological, dermatological, and gastrointestinal systems [5]. Commonly reported symptoms include fatigue, shortness of breath, dry cough, cognitive impairment, headache, heart palpitations, chest tightness, and dizziness [6–8]. Symptoms can co-occur, vary

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in severity, and be cyclical or episodic in nature [9, 10]. Initially, the prevalence and seriousness of chronic symptoms after COVID-19 were underrecognized, contested, or dismissed [11, 12], and much of the early research on long COVID was led by patients [8]. Researchers and healthcare providers worldwide now recognize the significant burden and detrimental impacts on quality of life associated with long COVID [13, 14].

Nevertheless, there is still a relatively poor understanding of the lived experience of long COVID. For example, much of the early evidence describing long COVID came from individuals who were hospitalized for COVID-19 [15–19] or excluded those without a laboratory-confirmed COVID-19 infection, despite numerous reasons why this may not have been accessible [20]. Furthermore, despite a highly engaged patient population whose activism collectively made long COVID's complex symptomatology visible [4, 8, 21], studies have mainly used quantitative surveys [22], and few studies have included the patient voice through qualitative approaches. Of the studies that have used qualitative approaches [23–27], the patient experience has been explored via interview and focus group methodologies with individuals affected by long COVID residing in the United Kingdom. In these studies, patients offer detailed accounts of navigating skepticism from the healthcare system and their social networks, the challenges of managing inconspicuous symptoms, the inability to perform physical activity or activities of daily living, and the importance of seeking refuge and information from similar others [23–27]. However, few studies have analyzed open-ended survey items using qualitative approaches as a lower burden approach to gathering in-depth information or captured experiences of individuals with long COVID residing outside of the United Kingdom. Although interviews and focus groups can enable researchers to probe and further explore patients' lived experiences, in the case of long COVID, such emotionally, socially, and time-consuming methods could preclude those with the most severe symptoms from participating.

Therefore, using data from a larger online survey conducted in 2021, the specific objective of this sub-study was to better understand and explore individuals' experiences with long COVID and commonly reported symptoms using qualitative data collected from open-ended survey items.

## Methods

The qualitative data reported herein were collected as part of a larger observational study using an online survey [7], which was approved by the University of Calgary Conjoint Health Research Ethics Board (REB21-0159). Initially, the qualitative data were collected to enable participants to qualify or elaborate on their closed-ended responses, with

planned content analysis if data were sufficient. However, upon exporting the qualitative data, it became apparent that rich and important insights were offered and that in-depth reflexive thematic analysis [28] of this survey data [29] was warranted. A pragmatic approach [30] and constructivist paradigm [31] were adopted, wherein participants' voices were centered and reality was viewed as varied and socially created.

## Participants

Individuals were eligible if they could read and understand English and self-identified as (1) an adult aged  $\geq 18$  years; (2) currently experiencing long-term symptoms due to COVID-19 (at least 4 weeks since the acute illness or positive COVID-19 test, with symptoms not pre-dating the acute illness); and (3) having tested positive for COVID-19, or with probable infection (based on an illness mimicking the acute phase of COVID-19, having close contact with a confirmed case, or being linked with an outbreak), in line with the clinical case definition post-COVID-19 condition [32].

## Procedures

Individuals were recruited internationally between February and April 2021 from long COVID networks on social media (Twitter and Facebook). The study team shared a recruitment slide (i.e., advertisement) with community leaders, patient advocates, and patient support groups (where permission was granted) via these social networks. In addition, the study team shared the slide with their network of physiotherapy/rehabilitation professionals. A snowball recruitment strategy was also used to allow patients and clinicians to identify other people living with long COVID. Advertisements included a link that took potential participants to a page where they could read information about the study and review the eligibility criteria before being directed to provide informed consent. Following consent, participants gained access to the secure online survey housed on Qualtrics.

## Measures

The larger online survey consisted of a socio-demographic and medical questionnaire, five closed-ended questionnaires assessing fatigue, post-exertional malaise, health-related quality of life, breathing discomfort, and physical activity (described and presented elsewhere [7]), and seven open-ended items. The seven open-ended items, which are the focus of this manuscript, were presented after each of the five closed-ended questionnaires, or block of questions, via stems such as "*Please use this space for any other comments about your experience with symptoms that continued or developed after acute COVID-19, or the support you have*

received for long COVID. This is optional, please skip this question if you have no other comments." The survey took approximately 30 min to complete ( $29.2 \pm 17.1$  min), and responses to open-ended questions ranged from 5 to 290 words.

## Data analysis

Descriptive statistics were computed for socio-demographic and medical data using Jamovi [33]. Open-ended qualitative data were de-identified, transferred to an Excel spreadsheet, and uploaded to be managed in NVivo (QSR International; 12.6.1). Following guidelines for reflexive thematic analysis [28], two authors (AW, RT) independently familiarized themselves with the data by reading the responses several times. Next, data were coded inductively by a single author (AW) who identified salient features within responses to generate initial codes. Salient features were determined based on their relevance to the topic, this sub-study's objectives, and the author's judgment. Similar codes were then grouped together into subthemes and main themes that summarized the raw data and conveyed the salient features. At this point, two authors (AW, RT) convened to review the subthemes and main themes and to challenge one another's interpretations of the data and explore alternative perspectives. The authors also reviewed the themes to check for internal homogeneity (i.e., data within themes fit together meaningfully) and external heterogeneity (i.e., clear distinctions between themes). A theme table including representative quotes was generated, iterated upon, and circulated to a patient partner and the third author (KF) to critically review. Following this, the three authors (AW, KF, RT) met to further discuss and challenge one another's understanding of and experience with the data (see Supplementary File 1 for the authors' reflexivity statement). The theme table was then finalized and sent to all authors to review.

Several strategies were employed to ensure sensitivity to the context, commitment and rigor, transparency and coherence, and impact and importance [34]. For example, the authors sought to ask and answer an important, practical, and timely research question and recruited a sample who could provide firsthand accounts. As well, the stages of the research process have been concisely presented above to elucidate the iterative and reflexive nature of the data collection and analysis process and to enhance transparency. Finally, representative quotes are included herein, and a table was generated so that readers may review and critically reflect upon the authors' interpretations.

## Patient involvement

Within the larger study, a patient partner was involved (March 2021 onward) and contributed to the interpretation

of the results. For this sub-study, the same patient partner contributed to data analysis and interpretation. The patient partner and co-author (KF) critically reviewed and reflected on the theme table and was actively engaged in iterative discussions, aiding the interpretation of findings. The patient partner also contributed to three team meetings (60–75 min each) to discuss the research objectives, review subthemes and themes, and comment on (and approve of) the final version of the manuscript.

## Results

Of the 213 participants who were included in the larger study, 169 (79%) provided responses to the open-ended items and were included herein. Of note, most ( $n = 105$ ; 62%) provided responses to three or more of the open-ended items. The remaining ( $n = 64$ ; 38%) responded to one or two open-ended items.

## Participants

The socio-demographic and medical characteristics of participants in this sub-study are presented in Table 1. Most participants identified as women (88.2%), and were aged 30–39 (21.3%), 40–49 (33.1%), or 50–59 (23.1%). The majority identified as White (93.5%) and from Canada (37.3%), the United Kingdom (39.6%), or the United States of America (15.4%). Most participants (58.6%) described managing long COVID symptoms for more than 10 months. Visual comparison of participants in this sub-study and the larger study suggested the samples were similar.

## Main results

Participants' insights into their long COVID experience and commonly reported symptoms are summarized across four overlapping themes and eight subthemes, which are described below. Table 2 contains representative quotations associated with each theme and subtheme. To respect participant confidentiality, the larger online survey was anonymous, and any potentially identifying information was redacted. Spelling and grammar were edited for readability, and where necessary, additional descriptive information was added, which is presented within square brackets.

## Long COVID symptoms are numerous and wearing

This theme captures when participants described the nature of their illness and its symptoms.

**Table 1** Socio-demographic and medical characteristics of participants

	<i>n</i>	%
<b>Age category</b>		
18–29	16	9.5
30–39	36	21.3
40–49	56	33.1
50–59	39	23.1
60–69	18	10.7
70–79	4	2.4
<b>Gender</b>		
Woman	149	88.2
Man	16	9.5
Non-binary	3	1.8
Prefer not to answer	1	0.6
<b>Population Group(s)</b>		
White	158	93.5
Hispanic, Latino, Latina, or Latinx	3	1.8
Black or African American	1	0.6
Asian or Asian American	1	0.6
British Indian	1	0.6
East Indian	1	0.6
Malagasy	1	0.6
Ashkenazi Jewish & White	1	0.6
Middle Eastern or Northern African & White	1	0.6
Native & White	1	0.6
<b>Country of residence</b>		
United Kingdom	67	39.6
Canada	63	37.3
United States of America	26	15.4
Other Europe	6	3.6
Brazil	1	0.6
Not reported	6	3.6
<b>Months experiencing long COVID symptoms</b>		
1–2 months	15	8.9
3–5 months	29	17.2
6–9 months	26	15.4
10+ months	99	58.6

Numbers may sum to 100.1% due to rounding

### Symptoms are numerous

Participants described navigating a wide range of symptoms. For many, the sheer volume of symptoms was described as overwhelming and unmanageable. Indeed, while some participants attempted to list each of their symptoms, many indicated it was far too many to count. Others only described select (or few) symptoms.

### 'Common' long COVID symptoms

In response to open-ended items asking about some of the more commonly reported long COVID symptoms (fatigue, post-exertional malaise, shortness of breath), most participants shared that they experienced high levels of fatigue. Participants explained how their fatigue was so much more than being tired. They described it as unrelenting and unlike anything else they had ever experienced. Of note, few participants described little or no fatigue but went on to share their experiences with other 'common' long COVID symptoms (e.g., post-exertional malaise). Participants also shared that post-exertional malaise was experienced often and was seemingly triggered by a wide range of activities, from physical activity to cognitive tasks. Finally, participants shared their variable breathing challenges, which ranged in severity and impact on day-to-day functioning. While many described the debilitating nature of their breathing challenges, others indicated that shortness of breath had not been among their most concerning symptom(s).

### Symptoms vary in presentation and intensity

Participants offered their perspectives on the nature of long COVID when they recounted navigating relapsing and remitting symptoms. For most, symptom presentation was described as completely unpredictable and puzzling. In these cases, participants described how their symptoms would relapse and remit, often seemingly at random. For others, symptoms did not cycle through increasing and decreasing severity. Instead, their symptoms remained heightened or tapered off as they slowly returned closer to their prior level of functioning.

### The effects of long COVID are pervasive

This theme captures when participants mentioned noticing marked changes in their functional capacity and ability to maintain their responsibilities and roles. Consequently, participants described the many ways they modified their day or accepted being unable to complete necessary activities of daily living.

### Modified sense of self

The debilitating impact of long COVID on participants' lives (whether short- or long-term) was made apparent and discussed as a major concern. Participants expressed a deep sense of loss over their changed health, functional capacity, and overall reduced quality of life. Many expressed feeling trapped or stuck within a disabled body that they no longer recognize or understood, which was described as frustrating and scary. Of note, few participants did not share in this experience. In these cases, participants described enjoying

**Table 2** Illustrative quotations for themes and subthemes capturing participants' experiences with long COVID and commonly reported symptoms

Theme	Subthemes	Example quotes
Long COVID symptoms are numerous and wearing	Symptoms are numerous	I have had many, many more types of symptoms after the acute period, hundreds. (P00)
		Now have nerve damage and muscular issues. (P01)
		Ongoing fatigue since acute COVID symptoms. [...] Flare up of viral symptoms, [which have been] reducing, but fatigue remains an issue. (P02)
		Neurological, short term memory loss, loss concentration, unable to retain information when reading, difficulty with math, dizziness, blurred vision, severe tinnitus with hearing loss, bilateral ulnar neuropathy, sleep apnea with hypoxia, abdominal pain and cramping, diarrhea, temperature intolerance heat and cold, toenails falling off. Fatigue is horrible. Daily constant headache. Lots more can't remember. (P03)
		I have had some 40 different symptoms since [date]. (P04)
		[I have] multiple, ongoing symptoms that appear (some intermittently): night sweats, brain fog, left shoulder/arm pain/numbness, leg cramps, earaches, dizziness, vivid dreams, blisters, fatigue, enlarged veins, loss of smell, anxiety, shortness of breath. (P05)
		Ongoing symptoms some are those I had during initial infection and some are new symptoms. (P06)
		Symptoms vary and are ongoing, namely palpitations, shortness of breath, chest pain, fatigue and dizziness. With little to no return in taste or smell, with 'phantom' smells too. (P07)
		Brain fog, short term memory loss, rashes, skin irritation, continuing high temperature in evenings, muscle aches, cough, increase in migraines, post activity malaise, nausea, diarrhea, smelling strong smells that often others can't. (P08)
	'Common' long COVID symptoms	Common symptoms: fatigue
		I describe COVID and long COVID fatigue as crushing. So many days these last 8 months I've gotten out of bed only to be hit with a crushing wave of fatigue immediately that forces me to go back to bed. (P09)
		The fatigue is like nothing I've experienced before when it takes over it's like being on a sedative and I have to sleep for days. [It] constantly feels like I have a brick sat on my stomach a lead weight in my head for a brain and lead weights on my legs and arms. (P18)
		The fatigue is not exactly tiredness as in sleepiness. It is fatigue as in how a healthy person would feel the day after they ran a marathon. Aching and physically exhausted, even when you have done very little. (P11)
		The fatigue is constant. (P12)

**Table 2** (continued)

Theme	Subthemes	Example quotes
		No fatigue, or very little. (P13)
		[The] fatigue is unmanageable. (P14)
		The level of fatigue I've experienced, I've described as 'all the way weary'. There aren't any fumes in my tank I can run on. (P15)
		Common symptoms: post-exertional malaise:
		I feel ill and my original [COVID-19] symptoms return after exercise. (P16)
		I do get fatigue and worsened symptoms including sore throat, stuffy nose, headache, aching, fatigue, dizziness after doing cognitive tasks for a long period, such as writing and reading. (P17)
		Now I feel ill and ache and hurt all of the day, everyday. Sometimes, I can't explain why I feel ill, I just feel ill from the inside out. (P18)
		[I get] post-exertional malaise after even small activities. (P19)
		[The] post-exertional malaise is debilitating. (P20)
		[The] post-exertional malaise is very hard to judge, and I am constantly stressed about triggering it and making my day-to-day fatigue worse. (P21)
		Physical exertion is my worst trigger, but my symptoms also flare up from mental and emotional exertion. (P22)
		The worst was mental exertion, like having a conversation with a friend for a few hours. (P23)
		Emotional and mental stress can cause a crash just as much as doing something physical. (P24)
		Common symptoms: breathing challenges
		I feel constantly breathless. [...] I often have an expiratory wheeze. I feel that I cannot fully exhale, inhalation feels pretty fully but unfulfilling. (P25)
		I get breathless talking to people, moving around or exerting myself (e.g., washing, dressing). I am ok when I am resting quietly. (P20)
		I would say thankfully shortness of breath has not been a concerning symptom for me. (P26)
		Just to bend down, or move about, I am so out of breath. Sometimes its scary because I feel I won't be able to catch my breath. (P27)
		Breathing in feels like taking that first deep breath if very cold air in the winter. It's very painful. But it's not just one breath, it's every breath. (P28)
		This [breathing challenges] seems to come in cycles where it suddenly gets worse and hard to access breath like I used to be able to, like can't breathe into abdomen at all and diaphragm isn't working properly. (P29)
		I definitely feel as if I have forgotten how to breathe. (P30)

**Table 2** (continued)

Theme	Subthemes	Example quotes
	Symptoms vary in presentation and intensity	<p>It's unpredictable. One day I can be energetic and the next, exhausted. (P31)</p> <p>Most [symptoms] I continue to have. Most are debilitating, painful, or bizarre. They are often cyclical fading and getting worse again while others take their place doing the same. (P01)</p> <p>My breathing has improved over 11 months, but it was very limited and breathless during and post-acute COVID. (P32)</p> <p>Mental health has improved the last few months as physically I feel better. Still dealing with pains, shortness of breath, inflammation, numbness. (P33)</p> <p>Shortness of breath has improved over 40 weeks but slowly and still extremely impacts my daily life. (P34)</p> <p>There is no pattern. Some days it is mild and on others it is severe. Some days the after-effects of exercise are immediate but sometimes it happens after 2 days. The coming and going of symptoms matches this pattern too. (P35)</p> <p>It comes in waves, good and bad days. The bad days are getting fewer but still they continue to happen. (P36)</p> <p>You need another response to 'how long does it last?' of 'it varies'. Physical exertion leads to worsening symptoms usually after 24–48 h, and can last all day, emotional exertion such as stress leads to immediate symptoms which tend to fade quickly. (P11)</p> <p>Relapsing and remitting symptoms worse if too much done. (37)</p> <p>The severity of ongoing symptoms varies from day to day. (38)</p>
The effects of long COVID are pervasive	Modified sense of self	<p>I was a happy, healthy, fit person prior to developing this virus. My life has been turned upside down and I have no idea if I will ever get better. (P26)</p> <p>I don't know this person I have become since COVID-19. (P39)</p> <p>I now consider myself disabled in many ways. (P22)</p> <p>Long Covid has totally consumed my life. I was once an athlete, [...] and lived a full, healthy, active life, now I am out of breath during a fast-paced conversation at times. (40)</p> <p>Before I got COVID, I had immaculate health. [...] I led a full, rich life with friends and work. [...] This virus has stolen all of this from me. This is not a life; this is a waking nightmare. (P41)</p>

Table 2 (continued)

Theme	Subthemes	Example quotes
		<p>I feel trapped in this half-life. [...] This half-life is totally frustrating and feels like a real trap. [...] I do feel my quality of life is dreadfully impacted and reduced, limited beyond endurance really. So, worrying with no one having answers or understanding what it is that is going on with my body to make me so vulnerable. (P42)</p> <p>I am having mental health difficulties as a result of the ongoing and unpredictable nature of the illness. (P21)</p> <p>I feel like a mere shadow of the person I was before COVID-19 and that is very saddening. (P43)</p> <p>Before COVID I would have said I was in excellent health and had a good quality of life. What this has left me with is an existence. All of the things I used to enjoy I cannot do. (P44)</p> <p>I feel like my body is broken. (P45)</p> <p>[Long COVID] has ruined my life completely. (P46)</p> <p>To avoid days of relapse, I literally do almost nothing. This is not who I am, and not what my primary relationship was based on. [It is] very depressing at times. (P12)</p> <p>I cannot enjoy any time with my family and friends anymore, and even if I could, I get so tired I would have a window of about 20 min. (P47)</p> <p>Housework has not been completed as usual. Many things are put aside as the energy is not there to complete them. (P48)</p> <p>I can barely leave my house. I get up to use the restroom and lay back down. It's almost impossible to shop and cook dinner for my children. I have no interest in anything. I don't want to talk to people, nor do I have the energy. [...] I'm miserable. (P49)</p> <p>I either lay down or sit 99.9% of the time. When going to bathroom, I use the walls to assist. (P50)</p> <p>I cannot actively participate in extracurricular activities, sports, or outings with friends due to my illness. (P19)</p> <p>I only work 4 days per week, but post-exertional malaise affects me all the time when I am not working, which is affecting quality of life. My home life and jobs [i.e., chores] are left undone and spiraling out of control. (P51)</p> <p>I fear the loss of income as I've been off work for 3 months and am now subject to occupational health adviser reports to my employer with the risk of dismissal due to ill health. (P38)</p>
	Changed capacity to manage roles and responsibilities	
	Changed capacity to work	



**Table 2** (continued)

Theme	Subthemes	Example quotes
Physical activity is difficult and, in some cases, not possible		During the first four weeks of my illness, I slowly improved. I was able to return to work normally during [date]. My main symptom at that point was insomnia. On the evening of [date], I went for a short jog. [The next day], I woke up to severe fatigue and neurological symptoms that have not improved at all. I am unable to read or write complex things (I am a writer, so this is normally an easy task for me). I am exhausted throughout the day but unable to sleep. I am experiencing pins-and-needles sensations in my hands, feet and scalp. My hair has started to fall out. I feel "fizziness" inside of my body, and periodic waves that feel as if I am being washed in poison. (P41)
		[I did a] phased return to work due to the fatigue felt after exertion. This started by requiring 18 h of sleep and only being able to do one task such as brushing teeth at a time before needing a rest, to now 4 weeks later being able to work for half a day and then requiring a 3 h nap after work. (P52)
		I have had to cut my working hours in half as it is too exhausting working full time. [...] I don't think I will be able to keep my job. I'm barely getting by doing the minimum. (P49)
		My job requires a mix of sitting, standing and walking. I get much more breathless and tired than I normally would. I'm still not up to full shifts and I do NOTHING else on days I work. (P24)
		In the last 8 weeks I've been extremely fatigued, as previous to this, I was bullied back to working fulltime I managed being in pain and rested and did nothing on my days off, but it took its toll and I have been off work for 8 weeks recovering. (P18)
		I did return to work part-time. Since the most recent lockdown, I have had to be signed off work as I cannot work and look after my kids as that led to a relapse. (53)
		To go from always moving, playing with children, walking everywhere, swimming, spinning, golf etc.to sitting down for 16 h a day is devastating. (P54)
		I tried to go for a 20 min walk round the block, timed myself so not to do too much, it took me three days to recover enough to move about my small flat comfortably after that, so I got nervous about going out again. Now I just stay inside, scared that even the smallest amount of exercise is going to push me back into being in bed, immobile again. It is terrifying to have been physically active before and now finding myself so incapable of what was totally not anything I would have thought about before. (P42)

**Table 2** (continued)

Theme	Subthemes	Example quotes
		<p>I have improved from lying a lot to being able to sit a lot more in past week. I've been able to reintroduce exercise and managed up to 5 min aerobic exercise on 3 days. But couldn't manage more than 5 min. [I am] hoping to continue to expand this as I continue to feel better. I also reintroduced a core strengthening exercise routine this week and spent about 20 min on this on about 5 days. (P55)</p> <p>I went from being a fit runner to only being able to tolerate very slow walks. (P56)</p> <p>Before COVID, I exercised 4–5 times a week. Now I only allow myself a 10–15 min slow-paced walk, [and that is only] if I have had adequate sleep. [I do this], maybe 1–2 times a week so it doesn't flare up my symptoms of insomnia and fatigue. (P57)</p> <p>I have been trying to pace my exercise, so I am yet to push it too hard. However, in the first 8 weeks, any walk more than 2 miles resulted in me spending the rest of the day on the sofa resting. In the last few weeks, I have been able to walk 3 miles and/or do Pilates and not need the same amount of recovery. However, my previous pre-COVID exercise was a min of 30 min of exercise every day, including weightlifting and 20–60 mile bike rides. (P58)</p> <p>Before long COVID, I cycled maybe 5 h a week, played tennis for 2–4 h, could jog, walk for miles etc. And now I have to think hard about every activity. Will it result in post-exertional malaise, which can put me out of action for days? (P16)</p> <p>I can summon energy to engage in greater activity, but often I will feel tired during, after, or 24 h later. I am sometimes fearful of walking even a short distance alone because I may tire and not be able to get back home. The fear of exhaustion is debilitating in itself. And I was enormously active before all this began. (P59)</p> <p>I have attempted to even do minimal exercise as usually it's something I love doing but everything I try I end up with terrible flu like symptoms and I'm bedridden for up to a week before I get back to my baseline. (P26)</p> <p>Before COVID-19, I was an endurance athlete, marathons and half ironman working out 6 days a week and at least 10 h a week. I do not do any exercise at all, just some easy walking. I am severely limited in my ability to live the life I used to. (P44)</p> <p>I normally hike and bike all summer; and downhill, cross country and skate ski as well as snowshoe all winter. [...] I am able to walk 1 km only without relapse for days with shortness of breath, muscle pain and debilitating fatigue. This is not my life. (P12)</p>

**Table 2** (continued)

Theme	Subthemes	Example quotes
Asking for help when few are listening, and little is working	Support received	<p>For the first 9 months of long COVID, the fact that nobody knew anything about long COVID, how to treat it and whether it would be chronic increased a sense of hopelessness which definitely affected my mental health and quality of life. (P60)</p> <p>I have been trying to get help, but when every test comes back normal, I have been told there is nothing to be done. With so many of us suffering someone has to help us. Please help us I beg you. (P61)</p> <p>My medical support has be mediocre on average. I've done most of the education. All while in pain and/or faint. My original doctor was neglectful and shocking in her dismissive words. (P01)</p> <p>I'm lucky. I have been believed. Too many are told it's all anxiety and given Ativan. (P62)</p> <p>I have had excellent care. My family doctor called me on a daily basis during the acute phase. She prescribed medications as needed and contacted a COVID specialist on various occasions. I was referred to a physiotherapist focuses on breathing. This has been so helpful. I was referred to the post COVID clinic unfortunately there is a long wait list but I do feel very supported. (P63)</p> <p>I was denied medical care during the acute illness and was told my only option was the ER. After I did not get any better for a month, I started hounding doctors to see me. [...] Very frustrating and demeaning experience. I am a scientist and brought papers with me to have them dismissed that "we don't know how to help you guys." (P09)</p> <p>Most of the stress comes from [my] doctor not acknowledging that there is a pre-COVID me and this new life post virus is not normal. (P64)</p> <p>I have found that my local GP practice is poor in trying to help with long COVID, and reluctance to consider the symptoms may be long COVID. (P65)</p> <p>I didn't receive support for long COVID from my general practitioner. (P66)</p>
	Few, if any, treatments work	<p>Traditional medicine has been of no help. Relief to some extent from breathing physio, elimination of alcohol from diet, and Symbicort (though no asthma). (P05)</p> <p>I have been taking 10 mg of cetirizine and 1,000 mg of Quercetin for 2 weeks now (self-prescribed) and have noticed a difference in the fatigue, brain fog and lung congestion (though all still remain). (P58)</p> <p>Steroid inhalers and Ventolin made me worse. Two short courses of oral steroids improved symptoms while using. (P25)</p>

**Table 2** (continued)

Theme	Subthemes	Example quotes
		[My doctor] put me on low dose Metoprolol to help lower heart rate. So far, it has helped and I regained most energy and experience minimal setbacks after working and found improvement in shortness of breath and cough. Cut back dose and about to try to get off pill altogether in next week if heart rate cooperates (started mid-Jan). (P67)
		Some people have benefitted from a very restricted 'low histamine' diet which isn't sustainable but seems to have worked in getting the body/immune system out of this loop of fighting itself. I'm planning to explore this with my nutritionist. (P68)
		I have been doing breathing exercises daily for 8 weeks but I can't my peak flow above 300. [I] was on a rescue inhaler only for years. Since COVID I went up to three inhalers. Then went for respiratory testing. Now on Symbicort. 8 puffs/day for four weeks now and very little improvement. (P69)

not needing to be physically active or that their symptoms were improving and they were (very) slowly re-integrating into some of their prior activities.

#### **Changed capacity to manage roles and responsibilities**

Participants indicated they could no longer take care of their home, families, and in some cases, themselves because of their symptoms. For many participants, their current functional capacity stood in stark contrast to their life before COVID-19. Participants also described that despite social opportunities being limited due to physical distancing restrictions, they are still unable to manage engaging in, or thinking about, being social. Being unable to manage their day-to-day life was described by participants as extremely upsetting and distressing.

#### **Changed capacity to work**

Most participants within this sample wrote that they were not working or had greatly reduced the hours within their workweek to help manage their long COVID symptoms. For those participants who were not currently working, concerns over lost income and/or being dismissed were prevalent. For those participants who were working, many described phased returns to work (that were gentle and progressed slowly), needing modified schedules, working from bed or the couch, being depleted after work and on their days off, or the setbacks they were facing along the way.

#### **Physical activity is difficult, and in some cases, not possible**

This theme captures when participants wrote about changing their physical activity behavior as a result of post-exertional malaise or symptoms during physical activity. Participants expressed a sense of loss over their pre-COVID physical activity behavior. Some participants expressed deep-seated fears of engaging in more physical activity in case it worsened their symptoms and caused further setbacks, which was underlined by a sense of deteriorating trust in their own bodies. While some participants described reintroducing physical activity, the slow, adapted nature of their 'new' movement routine was described as standing in stark contrast to their prior capacity.

#### **Asking for help when few are listening, and little is working**

This theme captures when participants described the support (or lack thereof) they received from the healthcare system. Participants expressed a desire to be heard and taken seriously and to be helped. Further, participants described what they had done/tried to minimize symptoms, whether under guidance from their healthcare team or alternative sources.

## Support received

While some participants in this sample felt supported by their healthcare provider, this was viewed as the exception rather than the norm. Indeed, the vast majority of participants recounted being ignored or dismissed by their primary healthcare providers. This left most participants feeling defeated, helpless, invisible, or frustrated. However, participants described still needing care, and many continued to advocate for themselves, despite their symptoms. Participants used the space within the open-ended items in this sub-study to ask, and in some cases, beg for help.

## Few, if any, treatments work

Participants described what they have done (or are doing) to minimize their symptoms. Unfortunately, many described their symptoms as persisting regardless of their attempts to find treatment(s). While some participants were of the opinion that pharmacological (e.g., medication) and non-pharmacological options (e.g., diet, physiotherapy) could offer minor relief from symptoms, for others, no treatment(s) had yet offered a reprieve.

## Discussion

The purpose of this sub-study was to better understand and explore individuals' experiences with long COVID and commonly reported symptoms using qualitative data collected from open-ended survey items contained within a larger survey [7]. Findings support initial research, which took place during or shortly after the first wave of the pandemic in the United Kingdom with individuals affected by long COVID who were predominantly healthcare professionals [23–27]. Results align with the vexing experience of navigating an 'invisible' and poorly understood illness that disrupts nearly all aspects of daily living and reduces quality of life that have been described previously [23–27]. Thus, this study reaffirms a small evidence base, extending these earlier findings with a larger sample from predominantly developed countries who have been living with long COVID for more than 10 months. This study and those it builds upon [21, 23–27] call for continued efforts to better understand and improve care for individuals with long COVID.

Participants in this sample described their new capacity as being discordant with their physical, occupational, and social obligations. This dissonance manifested as feelings of deep loss, sadness, and frustration. Mourning over one's pre-illness identity and ability to participate in roles, responsibilities, and leisure pursuits has been reported previously with individuals affected by long COVID [27] and other chronic conditions, including fibromyalgia and

myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) [35–38]. Participants also offered insights into how they have altered their day-to-day life to account for their reduced capacities and possible continued deterioration. For example, some participants described sacrificing social activities to keep up at work; others had to leave work altogether or were fearful of termination; whereas others chose to engage in one task per day or to take breaks after every activity. These findings align with the recent conceptualization of long COVID as characterized by health-related challenges or episodic disability [39, 40]. Looking ahead, exploring if and how individuals adapt to their post-illness body will be necessary. For example, post-exertional malaise can greatly limit the ability to engage in activities that could otherwise help prevent low mood and feelings of isolation [41]. When combined with severe functional limitations and the burden of educating others, there can be serious adverse impacts on mental health [41, 42]. A deeper exploration of common symptoms, including post-exertional malaise, and their physical and psychological consequences, could disentangle the effects of long COVID from the secondary impacts on mental health—ultimately informing interventions and supportive care strategies. For example, mixed-methods approaches may afford participants the opportunity to clarify which symptoms and side effects they consider to be central features of long COVID and which they consider to be secondary consequences.

There were multiple and varied ways participants described self-managing their condition, from consuming medical information and advocating for themselves to adhering to treatments that do not always offer relief. Participants also shared the additional challenge they faced in self-managing their condition within a system that challenged or contested their diagnosis. This sentiment of navigating one's condition amidst doubts about authenticity has been reported in individuals with ME/CFS [43–47]. ME/CFS can occur after an infectious illness such as mononucleosis [48], but it remains a highly stigmatized health condition where patients are vulnerable to epistemic injustice in healthcare encounters [45]. The feelings of dismissal from healthcare providers expressed by participants in this sample, the conceptual ambiguity of both ME/CFS and long COVID, and the nature of symptoms, which are numerous and hard to describe, may result in low credibility being given to the patient testimonial [45]. The recent recognition of long COVID as an outcome of COVID-19 infection (for example, through being given a clinical case definition by the World Health Organization [32]) may help further legitimize the illness. Considering that long COVID may lead to ME/CFS for some patients [49], an important next step is educating primary healthcare providers, who are the front line for patients, to recognize and validate their patients' experiences. Beyond this, equipping healthcare providers with evidence-based guidelines

and referral pathways is necessary to better support a growing patient population as they adapt to long COVID.

Finally, there is a critical need to identify appropriate interventions and treatments for those affected by long COVID, which may be best accomplished by including patients as partners in intervention development, implementation, and evaluation. Anecdotally, some individuals with long COVID are responding well to self-management, including activity pacing over extended time periods. Given that typical rehabilitation timeframes are often 2–3 months, and existing rehabilitation approaches (such as pulmonary rehabilitation) are unlikely to be suitable for the majority of people with long COVID, given the distinct clinical presentations [50], novel approaches will be necessary. For example, people with long COVID can have different clusters of symptoms, including predominantly respiratory symptoms or predominantly fatigue-related symptoms [49]. In patients with predominantly fatigue-related symptoms, pulmonary rehabilitation does not target and may exacerbate fatigue. Multidisciplinary, tailored interventions that leverage peer support may be most effective and should adhere to the recommended quality standards of being evidence-based, accessible, and of minimal burden [24, 25]. Rehabilitation specialists who have expertise and experience working with people who have been discredited in the past (e.g., fibromyalgia, ME/CFS, or other chronic conditions resulting in drastically changed capacity or disability) may be best placed to work with patients to design appropriate and effective interventions. Appropriate training of all professionals working with people with long COVID may enhance continuity of care and offer prolonged support for this cohort (as opposed to the often-disconnected care pathways). Engaging with patients and learning from their experiences represent a valuable first step toward improving training and care.

### Considerations

First, as acknowledged in the larger study [7], online questionnaires are subject to selection bias. Thus, the extent to which the sample described herein is representative of the population of people living with long COVID is unknown. Second, this sample primarily self-identified as White women residing in North America or Europe. Capturing the perspectives of people from different backgrounds (especially those from historically marginalized and underrepresented groups) is critical to fully understanding long COVID and its potential range of impacts. Relatedly, this survey was only available in English, meaning the perspectives of non-English speakers were not included, and nearly 40% of the sample was from the United Kingdom despite seeking to explore the experiences of individuals with long COVID residing elsewhere. Thus, there remains a need to explore long COVID experience among individuals with

long COVID beyond the United Kingdom and industrialized countries more broadly. Third, participants did not need to have a definitive COVID-19 diagnosis. Fourth, this was an anonymous survey, and therefore, the confirmed or suspected infection with SARS-CoV-2 was self-reported. Despite rigorous data cleaning and the severity of self-reported symptoms as previously reported [7], it is possible that some of the participants do not represent the population of interest. Methods of verification of laboratory-confirmed or probable SARS-CoV-2 infection should be considered and reported in future studies. Fifth, this sub-study collected and analyzed open-ended responses to items presented after closed-ended questions measuring specific outcomes or on specific topics. While it is possible that the open-ended item stems were leading, efforts were made to minimize this. For example, the item stems prompted participants to reflect on their broader experiences and use the space if they had additional insights to share and/or to clarify their responses to closed-ended items. Participants were also reminded that their response to open-ended items was completely optional. Sixth, given the nature of the online survey, there was no opportunity to use probes to gain deeper insights, which limits our understanding of the participants' lived experiences. Nevertheless, the authors felt that the benefits of using online open-ended items (i.e., collating a large number of firsthand accounts, low participant burden, anonymity) outweighed these considerations and aligned with the pragmatic approach adopted wherein a balance was sought between advancing conceptualizations of long COVID, and sharing evidence to support this population in real-time.

### Conclusion

Given the uncertain nature, and recency of long COVID, exploring individuals' lived experiences is paramount. Findings supplement a relatively small evidence base and reiterate that long COVID is complex and distressing for those affected. The varied relapsing–remitting symptoms, unknown prognosis, and deep sense of loss over one's prior identity suggest interventions are needed to support this population. Further, results underscore the challenges individuals affected by long COVID face when advocating for themselves and adapting to their illness during the pandemic and amidst healthcare systems that are understaffed, at times disbelieving or unarmed (as of yet) with comprehensive treatment guidelines. More research is needed to identify and address the pathophysiology, capture the consequences of long COVID, implement strategies to support those affected, and ultimately better help this cohort navigate the process of adapting to long COVID.

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## Declarations

**Conflict of interest** JDM is a physiotherapist and owner of Breath Well Physio (Alberta, Canada) and has been treating people living with long COVID in private practice since July 2020. JDM and RT run a virtual program for people living with long COVID in Alberta, Canada, in collaboration with Synaptic Health (Registered Charity No. 830838280RR001). JDM delivered a paid course for rehabilitation professionals working with people with long COVID in April 2021. The authors have no other conflict of interest to disclose.

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