



Seeking Care for Long COVID: A Narrative Analysis of Canadian Experiences

Journal of Patient Experience
Volume 10: 1-8
© The Author(s) 2023
Article reuse guidelines:
sagepub.com/journals-permissions
DOI: 10.1177/23743735231151770
journals.sagepub.com/home/jpx


Julia Kaufmann, BSc¹, Odette Gould, PhD¹ ,
and Vett Lloyd, PhD²

Abstract

The goal of this study was to explore the experiences of individuals seeking care for long COVID-19 in the Canadian health-care system. Recorded virtual interviews were carried out with 8 participants and narrative analysis was used to examine the stories produced and identify the central narratives that defined participants' experiences. Care-seeking experiences were characterized by (1) often debilitating multi-system symptoms for which little information about prognosis was available and no effective treatments were provided, (2) compounded by the frustration of trying to convince family, friends, and health care practitioners of the legitimacy of their illness, (3) access to medical care was severely limited by the global pandemic and associated higher thresholds for care, (4) like others suffering from complex, multi-system conditions, people with long COVID are often struggling with a health-care system ill-suited for dealing with long-term and possibly chronic conditions. To make system-level improvements to better serve those with chronic conditions, it is critical that we understand the care-seeking experiences of chronic illness patients, including the unique experiences of those with long COVID.

Keywords

long COVID, care seeking, chronic illness, medical care during a pandemic, burden of care, narrative analysis

Approximately 3.5 million Canadians were infected with COVID-19 by April 2022, with almost 150 000 hospitalizations and over 38 000 deaths (1). Additionally, many were infected and survived, but did not promptly recover. As a new, complex, poorly understood, and multi-system condition, consensus lagged on the diagnostic criteria or even the validity of “long COVID” as a stand-alone condition (2), yet incidence rates of approximately 10% to 30% have been reported (3,4). The present project explored the experiences of accessing care for long COVID in the Canadian healthcare system during the global pandemic.

Generally, healthcare systems are optimized for acute illnesses and injury (5) and the Burden of Treatment Theory (6,7) is a useful framework for understanding the factors related to accessing care for chronic illnesses and identifying the effects of shifting the responsibility of care from health care professionals to patients (8). The theory proposes that the capacity of patients to seek and obtain care is affected by the robustness of their social support system as well as the health care system itself. Interacting with the patients' capacity to obtain healthcare is the work required to manage treatments and access care (eg, gaining disease

knowledge, ongoing assessment of progress and setbacks, coordinating care with multiple providers, etc). Essentially, the Burden of Treatment Theory highlights that high levels of capacity are needed to navigate the healthcare system and its many barriers (7).

Research on the experience of seeking care for non-specific, multi-system chronic illnesses (eg, myalgic encephalomyelitis, fibromyalgia, Lyme disease, chronic pain) has highlighted the issues raised in the Burden of Treatment Theory (7). Lack of knowledge, dismissiveness on the part of medical professionals and others, and the difficulties of obtaining a diagnosis have been raised repeatedly (9–14). Also, multi-system symptoms that are not supported by

¹ Department of Psychology, Mount Allison University, Sackville, NB, Canada

² Department of Biology, Mount Allison University, Sackville, NB, Canada

Corresponding Author:

Odette Gould, Department of Psychology, Mount Allison University, 49A York Street, Sackville, NB E4L 1C7.
Email: ogould@mta.ca



Creative Commons Non Commercial CC BY-NC: This article is distributed under the terms of the Creative Commons Attribution-NonCommercial 4.0 License (<https://creativecommons.org/licenses/by-nc/4.0/>) which permits non-commercial use, reproduction and distribution of the work without further permission provided the original work is attributed as specified on the SAGE and Open Access page (<https://us.sagepub.com/en-us/nam/open-access-at-sage>).

established diagnostic algorithms are difficult for physicians (15,16) and restrictions on time, energy, and power can limit their capacity to provide care to patients with chronic illnesses (8). While some doctors faced with multi-system conditions persistently investigated specific symptoms (which could contribute to the treatment burden on patients (15,16), others disengaged from patients, sometimes dismissing symptoms as being entirely psychological or psychosomatic. This accentuated the stigmas surrounding mental health, while doing nothing to address the legitimate physical components of the condition (17).

Recent work in the United Kingdom (18–21) suggested that the experiences of long COVID patients not only reflected past findings regarding the difficulty of accessing medical care for chronic illnesses but also presented unique challenges. These patients tended to avoid seeking care, due in part to persistent and often confusing symptoms (eg, affecting multiple systems, oscillating) paired with invalidating responses from both healthcare practitioners and members of their social network (18–20). When care was sought, it was often difficult to obtain because of pandemic-related changes to the healthcare system, including temporary closures and reduced services, lack of knowledge from providers, and triage protocols that limited the priority of patients who were not in acute and life-threatening distress (19). Even health care providers experiencing long COVID reported dismissiveness despite their enhanced knowledge, credibility, and access to the healthcare system (21). The consequences of feeling dismissed included seeking a primary care provider who validated their experience (18), self-advocacy, research regarding long COVID, on-going efforts to get referrals, and relying on other sufferers for advice and support (19).

Recognizing the importance of the patient perspective in understanding the functionality of healthcare, (22) in the present study, we carried out interviews with individuals from across Canada who self-identified as having long COVID. Using a narrative analysis approach (23) and an analysis lens inspired by Burden of Treatment Theory, (6–8) our goal was to explore the full picture of participants' healthcare experiences from initial COVID infection onwards.

Method

Participants

We conducted 8 interviews in February and March 2022 and participants were recruited from those who completed the Canada-wide survey (24) titled, *Chronic Complications of COVID-19*. Data for that study were collected in 2020 from a total of 738 participants, with 229 (31%) experiencing prolonged COVID symptoms. Sampling for the present study involved selecting every 25th participant from the previous study and checking to see if they met the following inclusion criteria: (a) had ongoing symptoms for at least 3 weeks after onset, (b) were over the age of 18, and (c) had agreed to be re-contacted for a subsequent study. If the 25th participant

did not meet the inclusion criteria, the following individual on the list was reviewed for inclusion. We aimed for half of the interviews reported in the present study to be from wave one of the pandemic. Twenty invitations to participate were sent out, and 8 individuals agreed (40% response rate).

Materials and Procedure

Participants were provided with a description of the study by email, and informed consent was obtained verbally. Interviews were performed, recorded, and transcribed using Microsoft Teams, by a young female university student visible to the interviewee on camera. Participants were first asked preliminary demographic questions and questions regarding COVID status. The main interview questions included (a) broad questions about experience with the acute COVID infection and subsequent experiences, (b) questions about the facilitators and barriers faced when accessing care for long COVID and (c) an invitation to fill in any parts of their story not covered. Lastly, we asked demographic questions, comorbidities, and where information about COVID was accessed.

Analysis

After the transcriptions were edited for accuracy, the virtual whiteboard software, Miro™ was used. The first 2 authors worked collaboratively, and all coding decisions were made through consensus. We used a narrative analysis approach (23) and analyzed the interviews through the lens of Burden of Treatment Theory (7) with a focus on the concepts of “capacity” and “work” and the connecting factors of barriers and facilitators.

Stories were defined as passages containing an event (“something happened”) along with the accompanying pre-ambles and prologue²³ and the analysis was framed around the following 4 storytelling elements.

1. *Structural features* were the key event of the story, and its stage, characters, and plot.
2. Stories were *categorized* as focusing on capacity, work or other (7). Capacity stories described the storyteller's past and present situation and character/personality. Work included any descriptions of care seeking or information seeking about the illness.
3. *Co-creation and storytelling* elements focused on *how* the story was told, including involving the interviewer in the storytelling process (eg, using humor, providing background information, and phatic elements such as “you know?”).
4. The *social narratives* underpinning each story included the impact of the pandemic on the healthcare system and on society in general, the implied beliefs of the storyteller concerning their illness, and how their illness was perceived by others around them.

By exploring each of these elements independently and in relation to one another, connections and parallels between transcripts stood out and were used to identify overarching narratives exploring how capacity and work related to access to care.

Results

Participant demographic information is shown in Table 1. The mean age of participants was 47 ($SD = 12.9$), 6 of the 8 were female (75%), and a variety of professions, including health care providers, office workers, and contract employees were represented. Three participants had pre-existing conditions that involved regular visits with a medical practitioner (37.5%), all participants had a family doctor, and, on average, participants reported having previously seen health care professionals 2.14 times per year (ranging from once per decade to 4 times a year). Four participants contracted COVID during the first wave in their region (50%), 2 in the second wave (25%), and 2 in 2021 (25%). Only those with an acute infection in the first wave did not have positive COVID tests. Symptoms reported by the participants are presented in Table 2.

After extensive analysis of all the stories, 5 primary narratives were identified and are described below. Numbered excerpts from the interview stories are provided in Table 3.

Narrative 1: My Situation “This Has...”

Each participant provided descriptions of their long COVID experience and many focused on the dramatic differences in their lives *before* and *after* the onset of illness. For example, participant 2 repeatedly highlighted the decrease in their “activity levels” since becoming sick and reluctance to deplete energy needed for work by engaging in previously enjoyed activities to reinforce their argument that they had been deeply affected by the condition (Excerpt 1). Some participants explicitly recognized and acknowledged the work that went into convincing family members, colleagues, and healthcare practitioners of the severity of their condition. This work was particularly challenging early in the pandemic when most news reports focused on hospitalizations, number of people on ventilators, and deaths. In this context, having an illness that affected day-to-day life yet did not seem to warrant attention amid a global pandemic was part of the inherent frustration of the participants’ experiences (Excerpt 2). Describing one’s situation was part of every interview and the

Table 1. Demographic Information.

ID	Age	Gender	Province	Living	Education
01	28	Male	SK	Urban	Some post-secondary
02	55	Female	ON	Urban	Post-secondary degree +
03	41	Female	SK	Rural	Post-secondary degree
04	34	Female	MB	Rural	Post-secondary degree
05	66	Female	ON	Urban	Post-secondary degree +
06	48	Female	BC	Urban	Some post-secondary
07	60	Male	ON	Rural	Post-secondary degree
08	44	Female	NS	Rural	Post-secondary degree

overarching question (ie, social narrative) of whether long COVID really exists was consistently present.

Narrative 2: Identity “I Am...”

The “*I am...*” narrative encompassed the construction of identity in relation to the participants’ illnesses (ie, developing a patient role). For many, this narrative was built through stories of active participation in care, often through self-monitoring and research. The need to push to be heard and supported in the healthcare system was central to the work of care seeking and seemed to be exacerbated within the context of long COVID. Not only was it necessary to advocate for the legitimacy of the illness, but it was also necessary to develop an identity as an active, engaged patient. (Excerpt 3).

Narrative 3: Personal Capacity “I Can...”

This narrative reflected the personal in/capacity of participants to seek health care. Not only did long COVID symptoms make common tasks difficult (eg, getting to

Table 2. Symptoms Reported.

Category	Symptoms
Flu/cold	Headaches, Ear popping Shortness of breath Fever, sweating, sore throat Lung issues, cough Congestion, tight chest, cold
Neurological/cognition	Brain fog/confusion Blurred vision, Loss of smell Intermittent auditory hallucinations Peripheral neuropathy, Numbness & pain in fingers Pain/burning in feet and toes Slurring of speech
Hypotension/cardiac	POTS Dizziness when standing Dysautonomia postural hypertension Tachycardic Hypertension Blood pressure Postural hypertension
Fatigue/Muscular pain	Fatigue Post exertional malaise Muscle & joint pain Weakness
Gastro-Intestinal (GI)	Nauseous Gastrointestinal Stomach problems GERD
Psychological	Depression Anxiety
Other	Blood clotting Hot flashes Rashes

Table 3. Excerpts From Participant Stories.

Narrative	Theme	Story excerpts
Situation	Before versus After	1: <i>my activity levels are definitely down. [...] I'm not somebody who likes to sit around. [...] It's a complaint my mother always had about me, is like, 'would you please just sit down?' And you know-, but my activity levels are definitely down. And I'm kind of nervous and I'm kind of reluctant to try and get back into some of the activities that I really enjoy doing. [...] I'd love to do Pilates, but I'm kind of reluctant to expend that energy because I'm concerned that if I do that then it's going to make it difficult for me to work... (P02)</i>
	Severity of illness	2: <i>I didn't have the really scary symptoms that they talk about the shortness of breath, the coughing, the fever, the stuff that put people in the hospital and on respirators. But I was definitely sick. And there's really kind of frustrating to have people say-, look at me and say, oh, you look great. You look just fine. And I felt so terrible. And you know, I just couldn't seem to get people to understand that. Yeah, I wasn't going to be on a respirator in the hospital, but I felt darn bad. (P02)</i>
Identity	Patient role	3: <i>Once I noticed that this was long COVID and once I noticed in about March that this wasn't going away, I started doing a daily journal. So I was recording um the date, the time, any physical activity. I did the symptoms that were present, notes about those symptoms, scale of 1 to 10, how tired I was scale of 1 to 10, how much that was impacting my work and daily life, medications taken and any extra notes that I needed because I thought at the time and I still haven't like been able to eradicate this thought completely was that if this continues for a long time I want documentation there that I have documented, recorded this and it's not just I'm looking to get some extra supports because I would like them. (P01)</i>
Personal capacity	Prognosis confusion	4: <i>I mean, the most frustrating part about a lot of it was that every time I saw somebody, they're like, "well, that's just COVID." And we're not sure [...] is it going to get better? When is it gonna get better? Nobody really knew. It was just, it's COVID, and that was the answer. [...] It was just you have COVID and we don't know... (P06)</i>
	Online support	5: <i>the one thing I found really helpful was I joined a support group online [interviewer: okay] and that that was like pivotal, that was really instrumental in me starting to be able to find opportunities to do things that could make it better, right? [...] And then you kind of got to talk with other people and see and it's like, oh okay, yeah, those other 16,000 people that are in that group are also feeling dizzy. (P03)</i>
System capacity	Role of primary physician	6: <i>Uhm, my family doctor he tried-, there finally was a long COVID clinic opened up in [my area], but you had to have a positive result to be referred there so they wouldn't take me and I tried to get antibody testing, but the province didn't have that at the time. My doctor tried to get me out of province antibody testing approval, they didn't approve that, so I was kind of just left stranded with my family doctor who is wonderful but didn't really have any answers either. (P04)</i>
	Referrals	7: <i>Usually you go into your family doctor and when they don't initially know what's wrong with you, you get referred onto somebody else. [...] There was a lot of this referral process that was happening and then COVID hit and it's like oh all these people have shut down so that referral process isn't happening. [...] Prior to covid, we were quick to refer people on and you might wait for three or four months to get into somebody, but they would [pause] help you progress further down that medical pipeline and now we don't have that. (P06)</i>
	Psycho-logical symptoms	8: <i>...and, you know, some people are like, 'oh, it's all in your head,' and I'm like, well, okay, well, if it's in my head, get it out. Like, I mean, I don't, I don't really care if it's physical or if it's mental, I just want it to stop. And, you know, like just I want to be better, I want my, you know, my old life back [laughter], sort of right... (P06)</i>
Work	Gratitude	9: <i>I am so so fortunate that my doctor has really been, she's just really really attentive to my case. [...] She's always been very attentive to me when I come to her with concerns and I consider myself really, really fortunate that way (P02)</i>
	Alternative care	10: <i>I saw a naturopathic doctor. These are definitely outside of the, my normal range of approach to management of medical conditions, but there was really nothing from a from a quote-unquote traditional Western medicine standpoint (P05)</i>
	Alternative care	11: <i>I'm just constantly searching for anything that might help me [interviewer: uh-huh], whether it's western medicine or alternative methods, or it's just like a never ending hoping that something will [laughter] help me. (P04)</i>

appointments), but also confusion about these symptoms such as having symptoms disappear and then return, and having new symptoms unexpectedly appear was a barrier to seeking care and often caused frustration. Furthermore, the lack of medical information about long COVID outcomes and prognoses drove participants to shift back and forth

between efforts to find a cure on the one hand and adapting to a potentially life-long disability on the other (Excerpt 4).

Many stories also mentioned research and internet skills and the ability to access and understand information about long COVID as a facilitator to accessing care. Logistical factors including financial resources were also a component

of the capacity narrative, although less commonly discussed. There was substantial heterogeneity in the way interpersonal relations were perceived to impact personal capacity: logistical support was usually described as a facilitator and dismissiveness as a barrier. Moreover, the in-group-out-group dynamic between those with long COVID and those without was also interwoven into many of these narratives: fellow long COVID sufferers often provided informational and emotional support not available elsewhere (Excerpt 5).

Narrative 4: System Capacity “I Think the System...”

Views about the healthcare system’s capacity to provide care was a complex narrative that linked personal capacity to seek care and the work required to seek care. Stronger personal capacity made care-seeking work more likely, but participants felt frustrated with a healthcare system that did not have the information needed to help them, that was slow in testing and adopting new evidence-based interventions, and that did not have the capacity to deal with multi-system conditions with diverse and confusing symptoms. Nonetheless, many participants believed that their primary physician *wanted* to provide care but simply did not have the knowledge to do so (Excerpt 6).

Part of this narrative included descriptions of pre-existing issues (eg, referrals) with the healthcare system which were exacerbated by the pandemic (Excerpt 7). Another issue

was gatekeeping of care: not only was it difficult to access care unless symptoms were life-threatening, but many were told they needed a positive COVID test to access care, even though they contracted the virus before testing was widely available. Finally, while many participants acknowledged that mental illness symptoms could be part of their illness, the perception that a psychological diagnosis was used as reason not to provide medical care was clearly frustrating (Excerpt 8).

Narrative 5: Work “(When) I Tried...”

The final narrative was about seeking medical care. Some experiences were explicitly negative (eg, not being believed) while others were unsatisfactory because of a lack of treatment options (though transparency about knowledge limitations by family physicians was perceived positively by participants). Indeed, participants expressed surprise and gratitude when providers were kind and attentive, even when medical treatment was unavailable or unsuccessful, highlighting relatively low expectations (Excerpt 9). Most participants also told stories of eventually seeking alternative care but aimed to present themselves as “reasonable patients” by highlighting their attempts to access care through normalized routes before branching out to non-traditional avenues (Excerpt 10). For many, as the symptoms continued, the

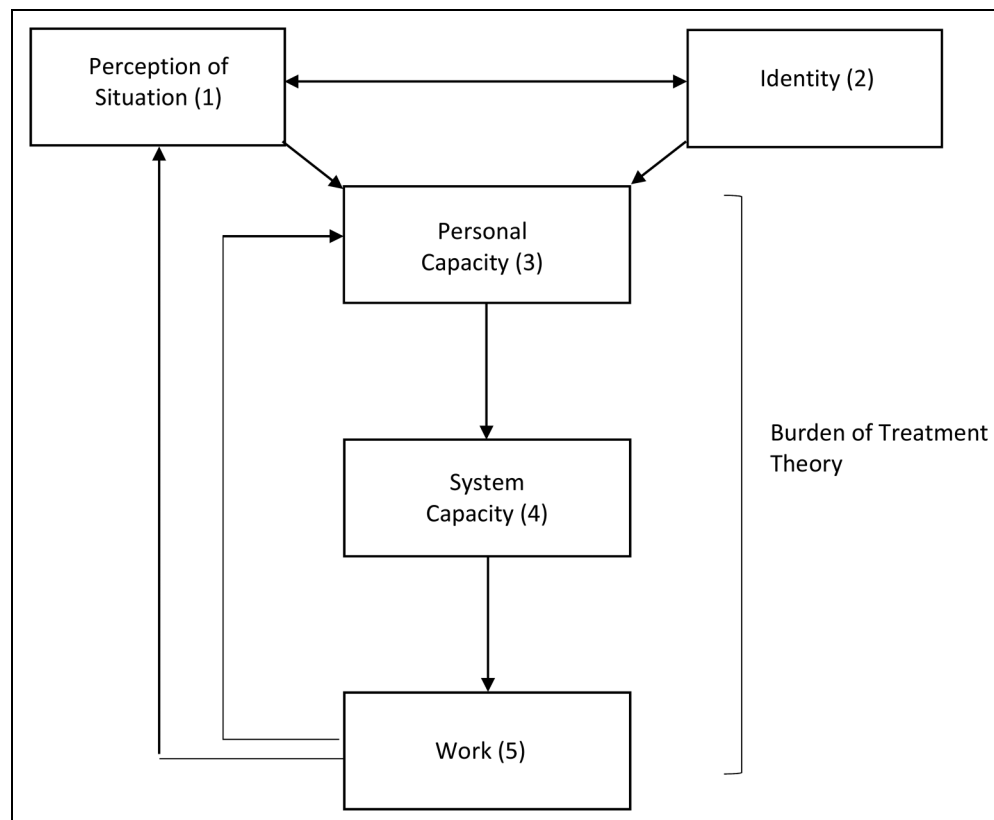


Figure 1. Interconnected narratives.

search for treatments became broader, and less linked to traditional medical treatments (Excerpt 11).

Framework of Narratives

When seen through the framework of Burden of Treatment Theory (7), the 5 narratives we identified highlighted the feedback loops within the process of seeking healthcare. The background to the help-seeking stories included both Situation Description (1) and Identity (2) narratives that together contributed to the Personal Capacity (3) of the participant to seek care. Trying to access care can either result in increased or decreased future capacity, as shown in Figure 1. For example, when participants feel overwhelmed and ineffectual, their capacity to seek care is low. Using Personal Capacity (3) to carry out the Work (5) of help seeking is facilitated or constrained by the characteristics of the Healthcare System (4): if someone has the capacity to go to an appointment but there is no local hospital, they cannot carry out that work. An important insight here was that the experiences of doing the Work (5) of seeking care may affect the Personal Capacity (3) to seek future care. If a health care provider is dismissive of symptoms, the patient's Perception of the situation (1) may decrease willingness to seek future care. Additionally, if doing the Work (5) of tracking down a specialist and obtaining a referral to that person is difficult, there may be insufficient Personal Capacity (3) remaining to follow through with that appointment.

Discussion

This study explored the experiences of people with long COVID trying to access care in Canada. The results replicated and extended other studies within the chronic illness literature and the limited research on accessing care for long COVID conducted in the United Kingdom (18–21). As with other chronic but ill-defined conditions such as Lyme disease (9) and chronic pain (13) our participants were frustrated when trying to convince family members, colleagues, and health care providers of the validity of their illness. As found in the United Kingdom, the self-doubt linked to confusing and diverse symptoms (19,21), fears about not being believed, and hesitant or negative attitudes about the healthcare system (19) all influenced care seeking decisions and care avoidance.

One consequence of having a medical condition that was not initially and universally accepted by the medical establishment was that while all began seeking care within the traditional medical system, many felt pushed into trying alternative treatments because of not receiving the help needed. A related outcome was the frequent adoption of a patient role that required high levels of engagement and self-advocacy. Both actions are congruent with past chronic illness literature (9,10,17,19). Of course, the emphasis on active patient roles in the present data set may be partly explained by a participation bias: most participants found

the original survey through online groups, and those who responded to our interview invitation were likely particularly engaged. It would be of interest in future research to contrast the care-seeking pathways of passive and highly engaged patients.

Key issues were raised in the present paper that are specific to long COVID, and specific to seeking health care during the unprecedented disarray of a global pandemic. Existing issues with system capacity and logistical challenges were exacerbated by the pandemic, leading to delayed care, increased gatekeeping, and higher thresholds for care (21). As in the United Kingdom (19), our participants suggested that non-life-threatening symptoms were a barrier to care because their condition was not seen as a priority. The lack of knowledge about long COVID among participants and the medical community created additional challenges, including the absence of effective treatment, and the finding that some individuals perceived that they were not provided medical care due to mental health diagnoses. Similar observations were made in the United Kingdom for long COVID (18–21), and in Canada for Lyme disease (17). Of note in the present study was the importance given to social media networks and digital support groups as a means of obtaining interpersonal support from others with long COVID (18–21). Participants in the current study often suggested that others experiencing long COVID provided unique support, a finding that is likely to generalize to other complex chronic conditions.

Limitations

The goal of the present study was to explore the experiences of individuals living with long COVID but the experiences described here do not represent the experiences of all Canadians with this condition. Since this project began, there have been several more COVID waves and several long COVID clinics have opened in Canada. With relatively rapid changes in available information and resources, the present research should be read as a snapshot during a particular period. Moreover, the study relied on sampling from previous research which introduces selection and participation bias and may further limit the representativeness of this clearly small sample.

Conclusions

The WHO (5) published a report in 2002 detailing why healthcare systems are challenged by chronic health conditions and means to make them more effective. The current study found parallels to previous literature on chronic illness, and to a large extent, these issues seem to remain unresolved. Many participants had to advocate for care and for the legitimacy of their illness and others with long COVID were an important support and resource. Participants also reported broader frustrations with the healthcare system, including lack of information, slow

adoption of interventions, limited capacity to deal with multi-system conditions, gatekeeping of care based on severity, and minimization and segregation of mental health symptoms and care. Overall, experiences seeking care for long COVID were reportedly unsatisfactory. Despite this, many participants expressed gratitude for attentive and supportive health care providers.

Long COVID is unique in that for many participants it was not clear whether it was acute or chronic and this uncertain trajectory meant participants were unsure whether it was best to focus their limited resources on adapting their lifestyle to accommodate a chronic condition or continuing to strive for access to new diagnostics and treatments. Future research should focus on developing a better understanding of how the healthcare system can change to handle complex chronic illnesses.

Acknowledgment

The authors would like to thank Mya Milner for her assistance in data coding.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This work was supported by the New Brunswick Innovation Foundation (grant number NBIF COV-088).

Ethics Approval

Ethics approval for this study was obtained from the Mount Allison University Research Ethics Board (#102920).


Statement of Human and Animal Rights

All procedures in this study were conducted in accordance with the Mount Allison University Research Ethics Board (#102920) approval protocols.

Statement of Informed Consent

Verbal informed consent was obtained from the participants for their anonymized information to be published in this article.

ORCID iD

Odette Gould  <https://orcid.org/0000-0001-8127-6655>

References

- Public Health Agency of Canada. Detailed preliminary information on cases of COVID-19, 2020-2022: 6-Dimensions (Aggregated data). Government of Canada, Statistics Canada. Accessed September 26, 2022. <https://doi.org/10.25318/1310077401-ENG>.
- Greenhalgh T, Knight M, A'Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care. *Br Med J*. 2020;370(m3026):1-8. <https://doi.org/10.1136/bmj.m3026>.
- Pavli A, Theodoridou M, Maltezou HC. Post-COVID syndrome: incidence, clinical spectrum, and challenges for primary healthcare professionals. *Arch Med Res*. 2021;52(6):575-81. <https://doi.org/10.1016/j.arcmed.2021.03.010>.
- Yoo SM, Liu TC, Motwani Y, et al. Factors associated with post-acute sequelae of SARS-CoV-2 (PASC) after diagnosis of symptomatic COVID-19 in the inpatient and outpatient setting in a diverse cohort. *J Gen Intern Med*. 2022;37(8):1988-95. <https://doi.org/10.1007/s11606-022-07523-3>.
- World Health Organization. *Innovative care for chronic conditions: Building blocks for action: global report*. 2002. World Health Organization. Accessed September 26, 2022. <https://www.who.int/publications/i/item/innovative-care-for-chronic-conditions-building-blocks-for-actions>
- May CR, Montori VM, Mair FS. We need minimally disruptive medicine. *Br Med J*. 2009;339(b2803):485-7. <https://doi.org/10.1136/bmj.b2803>
- May CR, Eton DT, Boehmer K, et al. Rethinking the patient: using burden of treatment theory to understand the changing dynamics of illness. *BMC Health Serv Res*. 2014;14(1):281. <https://doi.org/10.1186/1472-6963-14-281>.
- Sav A, Kendall E, McMillan SS, et al. 'You say treatment, I say hard work': treatment burden among people with chronic illness and their carers in Australia. *Health Soc Care Community*. 2013;21(6):665-74. <https://doi.org/10.1111/hsc.12052>.
- Boudreau CR, Lloyd VK, Gould ON. Motivations and experiences of Canadians seeking treatment for Lyme disease outside of the conventional Canadian health-care system. *J Patient Exp*. 2018;5(2):120-6. <https://doi.org/10.1177/2374373517736385>.
- Egeli NA, Crooks VA, Matheson D, Ursa M, Marchant E. Patients' views: improving care for people with fibromyalgia. *J Clin Nurs*. 2008;17(11c):3y562-369. 2008. doi:10.1111/j.1365-2702.2008.02505.x
- Geraghty KJ, Blease C. Myalgic encephalomyelitis/chronic fatigue syndrome and the biopsychosocial model: a review of patient harm and distress in the medical encounter. *Disabil Rehabil*. 2019;41(25):3092-102. <https://doi.org/10.1080/09638288.2018.1481149>.
- Ghavidel-Parsa B, Amir Maafi A, Aarabi Y, et al. Correlation of invalidation with symptom severity and health status in fibromyalgia. *Rheumatology (Oxford)*. 2015;54(3):482-6. 2015. <https://doi.org/10.1093/rheumatology/keu355>.
- Upshur CC, Bacigalupe G, Luckmann R. "They don't want anything to do with you": patient views of primary care management of chronic pain. *Pain Med*. 2010;11(12):1791-8. <https://doi.org/10.1111/j.1526-4637.2010.00960.x>.
- Wright PJ, Dawson RM, Corbett CF. Social construction of biopsychosocial and medical experiences of women with polycystic ovary syndrome. *J Adv Nurs*. 2020;76(7):1728-36. <https://doi.org/10.1111/jan.14371>.
- Wileman L. Medically unexplained symptoms and the problem of power in the primary care consultation: a qualitative study. *Fam Pract*. 2002;19(2):178-82. <https://doi.org/10.1093/fampra/19.2.178>.
- Yon K, Nettleton S, Walters K, Lamaheewa K, Buszewicz M. Junior doctors' experiences of managing patients with medically unexplained symptoms: a qualitative study. *BMJ Open*. 2015;5(12):e009593. <https://doi.org/10.1136/bmjopen-2015-009593>.

17. Gaudet EM, Gould ON, Lloyd V. Parenting when children have Lyme disease: fear, frustration, advocacy. *Healthcare (Basel)*. 2019;7(3):95. <https://doi.org/10.3390/healthcare7030095>.
18. Kingstone T, Taylor AK, O'Donnell CA, Atherton H, Blane DN, Chew-Graham CA. Finding the "right" GP: a qualitative study of the experiences of people with long-COVID. *BJGP Open*. 2020;4(5):bjgpopen20X101143. <https://doi.org/10.3399/bjgpopen20X101143>.
19. Ladds E, Rushforth A, Wieringa S, et al. Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Serv Res*. 2020;20(1):1144. <https://doi.org/10.1186/s12913-020-06001-y>.
20. Ladds E, Rushforth A, Wieringa S, et al. Developing services for long COVID: lessons from a study of wounded healers. *Clin Med*. 2021;21(1):59-65. 2021; <https://doi.org/10.7861/clinmed.2020-0962>.
21. Taylor AK, Kingstone T, Briggs TA, et al. "Reluctant pioneer": a qualitative study of doctors' experiences as patients with long COVID. *Health Expect*. 2021;24(3):833-42. 2021. <https://doi.org/10.1111/hex.13223>.
22. Alwan NA, Attree E, Blair JM, et al. From doctors as patients: a manifesto for tackling persisting symptoms of covid-19. *Br Med J*. 2020;370(8260):m3565. <https://doi.org/10.1136/bmj.m3565>
23. Wong G, Breheny M. Narrative analysis in health psychology: a guide for analysis. *Health Psychol Behav Med*. 2018;6(1):245-61. <https://doi.org/10.1080/21642850.2018.1515017>.
24. Lloyd VK, Singh-Ranger G, Wills M. 2022. *Long COVID in Canada-A longitudinal study*. Manuscript in preparation.