
2023

Living with COVID-19 in the community during the first wave of the pandemic: Lessons from patients for healthcare providers and policy makers

Linda Rozmovits

Michelle Marcinow
Trillium Health Partners

Ilja Ormel
St. Mary's Research Centre

Terence Tang
Trillium Health Partners

Elizabeth Mansfield
Trillium Health Partners

See next page for additional authors

Follow this and additional works at: <https://pxjournal.org/journal>



Part of the [Health Services Research Commons](#)

Recommended Citation

Rozmovits L, Marcinow M, Ormel I, Tang T, Mansfield E, Kuluski K, Marwaha S, Law S. Living with COVID-19 in the community during the first wave of the pandemic: Lessons from patients for healthcare providers and policy makers. *Patient Experience Journal*. 2023; 10(1):115-123. doi: 10.35680/2372-0247.1714.

This Research is brought to you for free and open access by Patient Experience Journal. It has been accepted for inclusion in Patient Experience Journal by an authorized editor of Patient Experience Journal.

Living with COVID-19 in the community during the first wave of the pandemic: Lessons from patients for healthcare providers and policy makers

Cover Page Footnote

This article is associated with the Policy & Measurement lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_PolicyMeasure

Authors

Linda Rozmovits, Michelle Marcinow, Ilja Ormel, Terence Tang, Elizabeth Mansfield, Kerry Kuluski, Seema Marwaha, and Susan Law Dr

Living with COVID-19 in the community during the first wave of the pandemic: Lessons from patients for healthcare providers and policy makers

Linda Rozmovits, *Independent qualitative health researcher, linda_rozmovits@sympatico.ca*

Michelle Marcinow, *Trillium Health Partners, michelle.marcinow@thp.ca*

Ilja Ormel, *St. Mary's Research Centre, ilja.ormel.comtl@ssss.gouv.qc.ca*

Terence Tang, *Trillium Health Partners, terence.tang@thp.ca*

Elizabeth Mansfield, *Trillium Health Partners, Elizabeth.mansfield@thp.ca*

Kerry Kuluski, *Trillium Health Partners, kerry.kuluski@thp.ca*

Seema Marwaha, *Unity Health, seema.marwaha@unityhealth.to*

Dr. Susan Law, *University of Toronto, susan.law@utoronto.ca*

Abstract

This qualitative descriptive study explores patients' experiences of living with COVID-19, in the community, during the early stages of the pandemic. Between October 2020 and April 2021, fifteen semi-structured, video-recorded interviews were conducted, via Zoom, with participants in five Canadian provinces. Participants self-identified as having had a confirmed or suspected case of COVID-19. The constant comparative method was used to produce a thematic analysis of findings. Key findings include 1) PCR tests were not widely available in Canada, during the first wave, so many participants lacked a confirmed diagnosis and, subsequently, encountered challenges accessing specialist medical care; 2) Rapidly changing protocols around testing also impacted return to work as employers' requirements were sometimes misaligned with public health guidelines; 3) Participants often found public health measures to be illogical, inconsistent, or sub-optimally implemented, and frequently perceived them as politically motivated rather than evidence-based; 4) some individuals with persistent symptoms had difficulty gaining acknowledgement and support for what is now more widely acknowledged to be long-COVID; and 5) The view that healthcare providers need a more nuanced approach to patients who lack a confirmed diagnosis or present with hard-to-explain symptoms was widely shared. There is the need for greater responsiveness to the lived experiences of patients with COVID-19, especially those with persistent symptoms, in developing clinical pathways and social supports.

Keywords

COVID-19, lived experience, pandemic, qualitative methods, health system response

Introduction

Between January 2020 and December 2021, nearly 2 million Canadians contracted COVID-19 and more than 28,000 people died in Canada.¹ Understandably, overburdened hospitals and exhausted healthcare workers were at the forefront of the academic and public conversation, as the discussion often centred on how to encourage compliance with public health measures in order to protect health systems and healthcare workers from collapse.²⁻⁸ But while the focus on hospitals is, thus, unsurprising, more than 90% of people affected by COVID-19 in Canada, during that period, coped with their illness in the community,⁹ often with only remote access to primary care and generic guidance from public health. In addition, many of those affected early in the pandemic were unable to access a PCR test, (widely considered the

most reliable indicator of infection), and therefore, lack a confirmed diagnosis, complicating subsequent encounters with care providers and, sometimes, limiting their access to supports such as workers' compensation¹⁰ or specialist medical care.¹¹

Much of the literature on patients' experiences of COVID-19, to date, has focused on hospitalized patients,¹²⁻²³ sub-populations such as pregnant women²⁴⁻²⁶ or the elderly,²⁷ or those with specific co-morbidities such as cancer.²⁸ Thus, many of the day-to-day realities of coping with this emergent and rapidly evolving disease in the community, such as accessing testing, interactions with public health, finding resources related to self-management, and coping with employment while affected by COVID-19, remain largely unexplored from the patient perspective.

This study of the experiences of individuals living with COVID-19 in the community, in the early stages of the pandemic, offers insights into how clinical practice and public health policy responded to their needs and might better respond to similar events in the future.

Methods

Study design and setting

This qualitative descriptive study²⁹ used one-to-one semi-structured interviews to explore community-based patients' experiences of COVID-19 during the first wave of the pandemic. Discussions were wide-ranging and touched on: onset of illness, symptoms, care sought and received, perceptions of public health interventions, support needs, and ongoing physical and psychosocial impacts of the disease. The interview guide appears as Appendix 1. Interviews were conducted with participants who self-reported confirmed or suspected COVID-19 in five Canadian provinces (Alberta, British Columbia, Quebec, Ontario and New Brunswick), and took place via Zoom in compliance with social distancing requirements.

This work is part of the ongoing Health Experiences Research Canada³⁰ (HERC) program of research into patient and caregiver experience. HERC is affiliated with DIPEX International,³¹ an association of qualitative researchers in 13 countries, using established methodology^{32,33} to improve understanding of the lived experience of health and illness globally. This study laid the foundation for further work on patients' experiences of COVID-19, currently underway.³⁴

Recruitment

A convenience sample of N=15, was recruited through professional networks and advertisement via a Canadian online support group for individuals with COVID-19. Eight participants were referred through professional networks, five through an online support group and two through a qualitative study of COVID-19 and pregnancy at an affiliated academic hospital in Ontario. Three additional individuals provided consent to be contacted but, ultimately, did not participate. Participants had to be 18 years of age or older, not in hospital, able to speak English or French and willing and able to independently participate in a recorded interview. Participants self-identified as having a confirmed or suspected case of COVID-19.

Sample

Twelve women and three men ranging from 24 to 65 years of age participated in interviews. Ten participants had a diagnosis confirmed by PCR test, one by antibody test and one suspected by their doctor. Three were unconfirmed. Ten participants said they had recovered from their illness while five described themselves as living with persistent symptoms consistent with the current WHO definition of

long-COVID.³⁵ Demographic information was collected, by questionnaire during the interview and is presented in Appendix, Table 1.

Consent and Ethics

All participants received a consent form detailing the study. They had the opportunity to review the form, ask questions and discuss any concerns with a member of the study team prior to consenting. Consent was confirmed verbally and documented directly before interviews. Consent for the eventual preparation of a short film featuring excerpts from the interviews was obtained separately. This study was approved by the Research Ethics Board at Trillium Health Partners.

Data Collection

Interviews were conducted from October 2020 to April 2021, using a semi-structured interview guide that invited participants to narrate their experience without interruption before the interviewer posed open-ended follow-up questions. Interviews averaged 70 minutes in length, were digitally video recorded, and professionally transcribed.

Data analysis

Transcripts were reviewed for accuracy. A coding framework was developed in discussion with the study team incorporating both *a priori* categories embedded in the interview guide and concepts emerging from interviews. Open, axial, and selective coding were used to articulate a thematically organized narrative account of findings. The constant comparative method³⁶ was used to test the integrity of the coding framework and searches for disconfirming evidence were undertaken to evaluate the hypotheses generated by our findings.³⁷ A qualitative descriptive approach informed the analysis^{38,39} HyperResearch software⁴⁰ was used to facilitate data coding and management.

Findings

Participants described a wide range of experiences but four themes emerged as predominant:

Challenges related to PCR testing; engagement with public health measures; lack of acknowledgment of long-COVID; and the need for more responsiveness to patients' experiences.

Challenges related to PCR testing

While some participants were able to access a PCR test soon after the onset of symptoms (e.g. those working in a health care setting and pregnant women), others were unable to do so, either because the tests were not yet widely available or they were considered a low priority for testing based on the relative severity of their symptoms or for other reasons that were not made clear to them. Processes and criteria for accessing a COVID-19 test

varied by location, but extremely long waits were common. Several participants described themselves as having stood in line for hours only to find that tests had run out, or to be refused testing when they got to the head of the line.

I called up my doctor ... and she said "Try and go to one of these assessment clinics to see if you can get seen." So, I ... went to the assessment clinic and there was a line-up and they just said "We're not taking anybody else today." Then the next morning I jumped in the car really early, went to one in [another municipality] and waited outside in the cold, shivering ... I don't even know if it was cold, but I was freezing and I was just there and bundled up and feeling awful ... waited for like two hours in this line-up. So, I got to the doctor at the front who basically said, "Go home and tough it out." I don't think it makes sense for us to test you or really take a look." [P08]

Uncertainty about their COVID status meant that some participants were unable to access specialist care or were unsure whether their symptoms were linked to COVID or some other undiagnosed condition. Both of these situations were described as causing both practical difficulty and substantial anxiety:

I never had the proof of a positive test which ... has allowed medical professionals to dismiss me ... I had to go back to the hospital and insist about six times that I needed to see a cardiologist when I was dealing with the pericarditis and all of the tachycardia ... [P02]

Antibody tests were available ... privately in September. So, I went in for that and I was positive ... Strangely it felt like a relief ... because the alternative is, "Holy crap, I've been sick for six months and we have no idea what it was." [P08]

The way PCR testing was used in the context of employment created challenges for several participants. One received conflicting information from her employer and public health about isolation requirements. Two others were unable to return to work due to repeatedly testing positive after recovery. In one case a participant underwent ten PCR tests over 49 days until she had two consecutive negative tests and was able to return to work. Another individual, who was working from home, felt so harassed by her employer, (whose requirements were misaligned with public health guidelines), that she eventually resigned. She was tested five times and abandoned three other attempts to get tested due to excessive wait times.

They did not update their policies based on WHO or [provincial] public health regulations ... So I had to get tested multiple times ... I was in line for 3 – 4 hours each time, [and] ... after three months they were still showing positive. So I just emailed them back saying "Hey, this is a very traumatizing experience for me ... my boss keeps sending me very aggressive

emails asking "Are you using your work day time to get retested?" The only concern was do not use corporate time to do that. [P14]

Participants' experience of public health measures and processes

Participants' perceptions of public health measures varied by jurisdiction. Some participants felt that their provincial health officers had "done a great job calming everyone down and trying to ensure that they did follow protocols," [P04] and that they had demonstrated effective "leadership and communication." [P07] Other participants found public health measures in their province to be inconsistent, illogical, and confusing, especially with regard to management of public spaces:

In the first phase ... the government was great. But the second stage ... I don't believe that their guidelines have been as consistent ... [or] logical ... less than 1 or 2% of cases came from gyms. And they've blanketed gyms ... meanwhile schools had a higher rate of COVID outbreaks. [P03]

It seems very clear they're no longer following the advice of their ... medical and scientific experts ... If the government keeps on the path that it's on, it's going to become like the US ... So that's terrifying. [P05]

Participants' experience of contact tracing and follow-up from public health was similarly variable. While some were contacted promptly after diagnosis, others waited for days and took it upon themselves to reach out to others they might have infected. Others were told that someone from public health would call them to let them know when they could come out of isolation but never received such a call. This participant describes how she only confirmed that it was safe for her to leave isolation, when public health happened to call for another reason:

I kept calling them and they just kept saying ... wait for somebody to call me, they don't know anything ... And then after three weeks ... they called me to ask ... what my symptoms were or something. And they're like, "OK great, thanks." And I was like, "Can I go now? ... I'm stuck at my home." And they're like, "Yeah, if it's been 14 days since you've been checked for symptoms." [P01].

Several participants felt that the representatives they spoke with were inadequately trained or seemed overwhelmed by the job. One participant described the public health workers she spoke with on the phone as "super uninformed." [P01] Others described follow-up calls with public health as excessively long, rigidly scripted and repetitious:

A conversation that could have been 20 minutes, ended up being 45 minutes ... She would lose her train of thought and then ask questions all over the place and then document the

information I provided to her incorrectly ... I think she definitely needed more training. [P03]

You have an assigned person for your case, but God forbid, if that person ... is not available ... and another person is taking over ... Day 15 or day 16, a lady called and said "Hey, I cannot read the handwriting, tell me how it started?" I said "No, no, no ... I'm not repeating that. Call me back whenever you had a chance to read the whole profile." [P14]

Lack of acknowledgement of long-COVID

Several participants were experiencing symptoms such as extreme fatigue after minimal exertion, tachycardia, shortness of breath, and brain fog months after the onset of the illness. Some of these individuals experienced challenges in getting support from healthcare providers. Most described themselves as struggling to gain acknowledgement as individuals living with long-COVID.

This participant recalled how she felt abandoned by public health once she was no longer infectious:

Even though I was having relapses and I really wasn't feeling better, that's when I felt like there was no communication and no support ... public health doesn't follow up on long haulers, because you're no longer infectious and they're only concerned about containing the spread ... I felt a little bit abandoned, I think. [P07]

A second expressed frustration at the failure of public health to acknowledge the substantial number of people now living with persistent symptoms:

I don't think [the messaging from public health has] been very accurate, because it has zero representation of anyone who isn't dead or recovered. There is nothing in between ... 2% die and you make a whole big hoo-ha about that. But the 10 to 15% of people who are still sick nine months later get zero acknowledgement. [P04]

A third participant explained how she was beginning to doubt herself until she discovered an online support group:

I felt like I was crazy because I had all of these symptoms that wouldn't go away and I couldn't work, no matter how hard I tried and my brain was so foggy. And my physician really didn't have anything to offer ... I was questioning my sanity. Am I just making this up, am I just depressed? ... And so joining the ... group was huge, because I discovered that I wasn't alone and there were so many people worldwide that were experiencing the same thing. [P07]

Need for more responsiveness to patients' experiences

While participants acknowledged that healthcare providers were doing their best in a difficult situation, several wished

that some of the providers they encountered had been more responsive to their experience. They were distressed when doctors minimized or dismissed their symptoms, especially because these could appear suddenly, be intermittent, and were often not explained by routine clinical evaluations.

One participant had gone to an emergency department with severe shortness of breath. She described her encounter with a medical resident who dismissed her symptoms as anxiety:

When she told me it's in my head and she told me that it was anxiety ... I ... asked her, how does she define anxiety? How does she know that I have anxiety? ... She had no answers. And I was very clear, I said "I do not suffer from anxiety. I am very well aware of what is going on. I want to understand how you can say it's in my head?" And she couldn't ... But when I had her supervisor walk in the room and say to me, before anything else ... "I can't prove it, but what you have is real." ... Knowing that a doctor believed everything, especially after ... what she had said, that meant everything. [P06]

Another participant was living with multiple persistent symptoms and had been unable to access a PCR test early in the pandemic. She explained why her GP's inflexible approach and skepticism about her having had COVID, because she had no proof, was unhelpful:

I think the doctor told me they have five minutes and one issue. This is not a five-minute, one issue problem ... I get that you don't want to scare people and you don't want to blow things out of proportion. But to categorically tell somebody they didn't have something when they couldn't possibly know that either, doesn't seem like a particularly good way of caring for people. [P04]

Discussion

This study explores patients' experiences of living with COVID-19 in the community during the early stages of the pandemic when it was difficult to access testing or primary care and many of those affected lacked a definitive diagnosis. Participants encountered a number of common challenges. Some had difficulty accessing PCR tests and encountered challenges related to what followed from having or not having particular results, especially with regard to employment and accessing specialist medical care. Many participants found it challenging to comply with public health measures that sometimes seemed illogical, inconsistent, or sub-optimally implemented, and with which employers' requirements were sometimes misaligned. For individuals with persistent symptoms, difficulty gaining support for long-COVID, and a sense that healthcare practitioners needed a different approach to patients who lack a confirmed diagnosis or present with hard-to-explain symptoms, was widely shared.

Implications for policy and practice

Our findings offer insights for policy makers and healthcare practitioners. At public health level, they highlight the importance of consistent, evidence-based messaging both within and across jurisdictions, and the need for local regulations (such as requirements from individual employers) to be up-to-date and aligned with those issued by public health. Second, our findings demonstrate that members of the public notice, and distrust, public health measures that are inconsistent or appear to be politically motivated rather than evidence based. Third, our findings suggest the need for more robust public health processes as illustrated by participants' often challenging experiences of testing, contact tracing and follow-up.

Our findings also underscore the need for healthcare providers to take patients' accounts of their symptoms seriously, even when they lack a confirmed diagnosis or fall outside conventionally-defined clinical scenarios. Long-COVID is now widely acknowledged thanks, in large part, to the efforts of affected individuals, internationally, harnessing the power of social media.⁴¹ But, as our evidence indicates, many people living with the condition struggled to gain acknowledgement earlier in the pandemic. Their experiences provide an opportunity to reflect on conventional medical approaches to hard-to-explain symptoms⁴² and the importance of viewing patients as partners in defining disease and in developing new pathways to care.⁴³⁻³⁶

Similarly, as case numbers became uncountably high due to the Omicron variant, we saw a move away from positive PCR tests as the gateway to support and services because the tests were no longer routinely available to the general public. Omicron has forced us to view patient self-reports of COVID infection in a different light. Whether the insights emerging from patients' experiences of COVID-19 during the first wave will lead care providers and policy makers to place a higher value on patients' experiences in future remains to be seen.

Limitations

Healthcare in Canada is provincially funded and administered and experience varied across jurisdictions. It was not the aim of this study to compare experience between jurisdictions as this would not be possible with a small qualitative study. Rather, we highlight commonalities of patients' experiences across jurisdictions because we believe it is in these elements of shared experience that insights for healthcare providers and policy makers lie. Moreover, given the rapidly evolving nature of the pandemic, this study offers only a snapshot of patients' experiences during the first wave rather than a more

comprehensive account of what has followed. Some of the issues raised by our participants are now being addressed to varying degrees in different jurisdictions.

This is a pilot study based on a convenience sample which was limited in terms of age range and gender distribution. Having a larger number of older and male participants would likely have brought additional findings to light. The sample is also limited in terms of its socio-economic and cultural mix. As the pandemic has disproportionately affected people of colour and those living on low incomes,^{47,48} it is highly likely that a more diverse sample would have brought many additional challenges to light, including those related to inadequate or overcrowded housing, multi-generational households, food insecurity, precarious employment and the risks faced by essential workers.

Conclusion

The experiences of non-hospitalized individuals with COVID-19 during the first wave of the pandemic provide valuable insights for policy makers and care providers. Specifically, they underline the importance of clear and consistent messaging, evidence-based policy, and effective communication with the public. They further underline the importance of a meaningful therapeutic alliance between patients and care providers so that patients' experiences are fully taken into account, especially when they challenge conventional approaches to care.

Ethical Approval

Ethical approval for this study was obtained from the Trillium Health Partners Research Ethics Board (ID #1003), Mississauga, Ontario, Canada.

Statement of Human and Animal Rights

All of the procedures in this study were conducted in accordance with the Trillium Health Partners Research Ethics Board (ID #1003) approved protocols.

Statement of Informed Consent

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

References

1. Public Health Agency of Canada. Epidemiological summary of COVID-19 cases in Canada. Government of Canada. Published April 19, 2020. <https://health-infobase.canada.ca/covid-19/epidemiological-summary-covid-19-cases.html>

2. Bavel JJV, Baicker K, Boggio PS, et al. Using social and behavioural science to support COVID-19 pandemic response. *Nature Human Behaviour*. 2020;4(1):460-471. doi:10.1038/s41562-020-0884-z
3. Weible CM, Nohrstedt D, Cairney P, et al. COVID-19 and the policy sciences: initial reactions and perspectives. *Policy Sciences*. 2020;53. doi:10.1007/s11077-020-09381-4
4. West R, Michie S, Rubin GJ, Amlôt R. Applying principles of behaviour change to reduce SARS-CoV-2 transmission. *Nature Human Behaviour*. 2020;4. doi:10.1038/s41562-020-0887-9
5. Harper CA, Satchell LP, Fido D, Latzman RD. Functional Fear Predicts Public Health Compliance in the COVID-19 Pandemic. *International Journal of Mental Health and Addiction*. Published online April 27, 2020. doi:10.1007/s11469-020-00281-5
6. Deslatte A. To shop or shelter? Issue framing effects and social-distancing preferences in the COVID-19 pandemic. *Journal of Behavioral Public Administration*. 2020;3(1). doi:10.30636/jbpa.31.158
7. Im H, Ahn C, Wang P, Chen C. An Early Examination: Psychological, Health, and Economic Correlates and Determinants of Social Distancing Amidst COVID-19. *Frontiers in Psychology*. 2021;12. doi:10.3389/fpsyg.2021.589579
8. Briscese G, Lacetera N, Macis M, Tonin M. Compliance with COVID-19 Social-Distancing Measures in Italy: The Role of Expectations and Duration. *SSRN Electronic Journal*. Published online 2020. doi:10.2139/ssrn.3568295
9. Public Health Agency of Canada. Epidemiological summary of COVID-19 cases in Canada. Government of Canada. Published April 19, 2020. <https://health-infobase.canada.ca/covid-19/epidemiological-summary-covid-19-cases.html>
10. Sask. WCB requires positive PCR test to file COVID-19 claim. *leaderpost*. Accessed April 26, 2022. <https://leaderpost.com/news/saskatchewan/sask-wcb-requires-positive-pcr-test-to-file-covid-19-claim>
11. “They’re absolutely ignoring us”: COVID-19 long-haulers plead for help from federal and provincial governments | CBC News. CBC. <https://www.cbc.ca/news/canada/covid-long-haulers-seek-help-1.5881170>. Accessed April 5, 2021.
12. Aliyu S, Travers JL, Norful AA, Clarke M, Schroeder K. The Lived Experience of Being Diagnosed With COVID-19 Among Black Patients: A Qualitative Study. *Journal of Patient Experience*. 2021;8:237437352199696. doi:10.1177/2374373521996963
13. Hsiao CT, Sun JJ, Chiang YH, Chen HL, Liu TY. Experience of patients with COVID - 19 in hospital isolation in Taiwan. *Nursing & Health Sciences*. 2021 Dec;23(4):888-97.
14. Jamili S, Ebrahimipour H, Adel A, et al. Experience of patients hospitalized with COVID-19: A qualitative study of a pandemic disease in Iran. *Health Expectations: An International Journal of Public Participation in Health Care and Health Policy*. Published online July 5, 2021. doi:10.1111/hex.13280
15. Karimi L, Makvandi S, Rahimi-Bashar F, Vahedian-Azimi A, Sahebkar A. The Experiences of Recovered COVID-19 Patients in Baqiyatallah Hospital: A Qualitative Study. In Guest PC, ed. *Identification of Biomarkers, New Treatments, and Vaccines for COVID-19*. Cham: Springer; 2021.
16. Kürtüncü M, Kurt A, Arslan N. The Experiences of COVID-19 Patients in Intensive Care Units: A Qualitative Study. *OMEGA - Journal of Death and Dying*. Published online June 12, 2021:003022282110241. doi:10.1177/00302228211024120
17. Liu W, Liu J. Living with COVID-19: a phenomenological study of hospitalised patients involved in family cluster transmission. *BMJ Open*. 2021;11(2):e046128. doi:10.1136/bmjopen-2020-046128
18. Mukhtar NB, Abdullahi A, Abba MA, Mohammed J. Views and experiences of discharged COVID-19 patients in Kano, Nigeria a qualitative study. *Pan African Medical Journal*. 2020;37. doi:10.11604/pamj.suppl.2020.37.1.26609
19. Norouzadeh R, Abbasinia M, Tayebi Z, et al. Experiences of Patients With COVID-19 Admitted to the Intensive Care Units: A Qualitative Study. *Journal of Patient Experience*. 2021;8:237437352110073. doi:10.1177/23743735211007359
20. Pei H, Wu Q, Xie Y, Deng J, Jiang L, Gan X. A Qualitative Investigation of the Psychological Experiences of COVID-19 Patients Receiving Inpatient Care in Isolation. *Clinical Nursing Research*. 2021;30(7):1113-1120. doi:10.1177/10547738211024807
21. Shaban RZ, Nahidi S, Sotomayor-Castillo C, Li C, Gilroy N, O'Sullivan MV, Sorrell TC, White E, Hackett K, Bag S. SARS-CoV-2 infection and COVID-19: The lived experience and perceptions of patients in isolation and care in an Australian healthcare setting. *American Journal of Infection Control*. 2020 Dec 1;48(12):1445-50.
22. Son HM, Choi WH, Hwang YH, Yang HR. The Lived Experiences of COVID-19 Patients in South Korea: A Qualitative Study. *International Journal of Environmental Research and Public Health*. 2021;18(14):7419. doi:10.3390/ijerph18147419
23. Sun N, Wei L, Wang H, et al. Qualitative Study of the Psychological Experience of COVID-19 Patients during Hospitalization. *Journal of Affective Disorders*. 2020;278. doi:10.1016/j.jad.2020.08.040
24. Juan J, Gil MM, Rong Z, Zhang Y, Yang H, Poon LC. Effect of coronavirus disease 2019 (COVID - 19) on maternal, perinatal and neonatal outcome: systematic

- review. *Ultrasound in Obstetrics & Gynecology*. 2020 Jul;56(1):15-27.
25. Bradley D, Blaine A, Shah N, Mehrotra A, Gupta R, Wolfberg A. Patient Experience of Obstetric Care During the COVID-19 Pandemic: Preliminary Results From a Recurring National Survey. *Journal of Patient Experience*. 2020;7(5):653-656. doi:10.1177/2374373520964045
 26. Mollard E, Wittmaack A. Experiences of Women Who Gave Birth in US Hospitals During the COVID-19 Pandemic. *Journal of Patient Experience*. 2021;8:237437352098149. doi:10.1177/2374373520981492
 27. Neumann-Podczaska A, Al-Saad SR, Karbowski LM, Chojnicki M, Tobis S, Wieczorowska-Tobis K. COVID 19 - Clinical Picture in the Elderly Population: A Qualitative Systematic Review. *Aging and disease*. 2020;11(4):988. doi:10.14336/ad.2020.0620
 28. van de Haar J, Hoes LR, Coles CE, et al. Caring for patients with cancer in the COVID-19 era. *Nature Medicine*. 2020;26(5):665-671. doi:10.1038/s41591-020-0874-8
 29. Sandelowski M. Whatever happened to qualitative description? *Research in nursing & health*. 2000 Aug;23(4):334-40.
 30. Home. Health Experiences. <https://healthexperiences.ca>
 31. Home. Dipex International. <https://dipexinternational.org>
 32. Herxheimer A, McPherson A, Miller R, Shepperd S, Yaphe J, Ziebland S. Database of patients' experiences (DIPEX): a multi-media approach to sharing experiences and information. *The Lancet*. 2000;355(9214):1540-1543. doi:10.1016/s0140-6736(00)02174-7
 33. The Research. <https://healthtalk.org/uploads/files/HERGresearch.pdf>
 34. Living with long-COVID: Patient experience to inform policy makers and care providers. Study funded by Canadian Institutes of Health Research
 35. A clinical case definition of post COVID-19 condition by a Delphi consensus, 6 October 2021. www.who.int. https://www.who.int/publications/i/item/WHO-2019-nCoV-Post_COVID-19_condition-Clinical_case_definition-2021.1
 36. Strauss A, Corbin J. *Basics of qualitative research*. Thousand Oaks, CA: SAGE; 1998.
 37. Booth A, Carroll C, Illott I, Low LL, Cooper K. Desperately seeking dissonance: identifying the disconfirming case in qualitative evidence synthesis. *Qualitative health research*. 2013 Jan;23(1):126-41.
 38. Sandelowski M. Whatever happened to qualitative description? *Research in nursing & health*. 2000 Aug;23(4):334-40.
 39. Sandelowski M. What's in a name? Qualitative description revisited. *Research in nursing & health*. 2010 Feb;33(1):77-84.
 40. HyperResearch version 4.5.2, Researchware, Randolph, MA.
 41. Callard F, Perego E. How and why patients made Long Covid. *Social science & medicine*. 2021 Jan 1;268:113426.
 42. Davidson SL, Menkes DB. Long covid: reshaping conversations about medically unexplained symptoms. *BMJ*. Published online July 28, 2021:n1859. doi:10.1136/bmj.n1859
 43. Long COVID: let patients help define long-lasting COVID symptoms. *Nature*. 2020;586(7828):170-170. doi:10.1038/d41586-020-02796-2
 44. Gorna R, MacDermott N, Rayner C, et al. Long COVID guidelines need to reflect lived experience. *The Lancet*. 2021;397(10273):455-457. doi:10.1016/s0140-6736(20)32705-7
 45. McCorkell L, S. Assaf G, E. Davis H, Wei H, Akrami A. Patient-Led Research Collaborative: embedding patients in the Long COVID narrative. *PAIN Reports*. 2021;6(1):e913. doi:10.1097/pr9.0000000000000913
 46. Ladds E, Rushforth A, Wieringa S, et al. Developing services for long COVID: lessons from a study of wounded healers. *Clinical Medicine*. 2021;21(1):59-65. doi:10.7861/clinmed.2020-0962
 47. Xia Y, Ma H, Moloney G, et al. Geographic concentration of SARS-CoV-2 cases by social determinants of health in metropolitan areas in Canada: a cross-sectional study. *Canadian Medical Association Journal*. 2022;194(6):E195-E204. doi:10.1503/cmaj.211249
 48. Government of Canada SC. COVID-19 in Canada: A One-year Update on Social and Economic Impacts. www150.statcan.gc.ca. Published March 11, 2021. <https://www150.statcan.gc.ca/n1/pub/11-631-x/11-631-x2021001eng.htm>

Appendix

Table 1. Detailed Interview Guide (Jan. 18, 2021)

Part one: Discovery

1. When did you first suspect you might have COVID-19?
 - When did you start to feel unwell?
 - What signs or symptoms did you notice?
 - How certain/uncertain were you about what whether this might be COVID-19? Did you think it might be something else?
 - If your symptoms were very mild or you did not have symptoms, what led you to think you might have COVID-19?
2. Did you reach out for medical attention?
 - Did you call a helpline?
 - Did you reach out to your family doctor/local clinic/public health/other?
 - Did you go to hospital?
 - How quickly did you get a response?
 - What did they say/do/offer you?
3. Were you formally tested for COVID-19?
 - How quickly were you able to get tested?
 - Where were you tested?
 - How long did you have to wait?
 - What was the result of the test?
 - If the result was negative, was there any discussion about the possibility that it might be COVID-19 anyway?
4. Were you formally diagnosed with COVID-19?
 - Who made the diagnosis? When was this?
 - What did they actually say when they told you it was COVID-19?
 - Did they ask about other health conditions you might have? Did you mention any other health conditions?
5. Once you received the diagnosis, how concerned were you?
 - Very concerned because ... (e.g. felt at risk of serious illness or death; loss of employment/income; risk to others because of exposure to you; general uncertainty about the disease; lack of social support)
 - Somewhat concerned because ... (issues as above but concern mitigated by other factors)
 - Not very concerned because ... (didn't think they were likely to get very sick; had good social support; had job/income security)
 - What was your biggest concern?

Part two: Experience of the illness and treatment

6. Where were you during your illness?
 - In hospital? At home? Somewhere else?
 - If in hospital explore hospital experience below. (Treatment)
 - If at home, (or in someone else's home) were you able to isolate yourself from others? How did you manage this?
7. Physical experience of COVID-19
 - What symptoms did you experience? (dry cough, fever, loss of sense of smell and taste, difficulty breathing, extreme fatigue, other?)
 - How long did symptoms last?
 - Did they change over time?
 - Which symptoms were most difficult for you? How did you manage them?
 - Did your symptoms impact any other health conditions you already had?
8. Treatment
 - Did you receive any treatment for COVID-19? (Active treatment? Stay at home and wait it out?)
 - What options were you offered?
 - How much information were you offered/did you have about treatment options?
 - Were you able to discuss treatment options with your doctor/other care provider?
 - Did you do your own research about treatment options? (Where did you look? What did you find? Were you able to discuss what you found with your care providers?)
 - How easy/difficult was it deciding what to do?
 - How well did the treatment work?

9a. Hospitalization (if applicable)

- How did you end up in hospital?
- How long were you there?
- What treatment did you receive?
- Was the treatment effective?
- Did you have any side effects of treatment?
- What about the emotional side of being in hospital? What was that like for you? (Relieved to be in hospital? Frightened? Unsure about what was happening? etc.)
- When you were discharged from hospital, what information were you given about what to do next?

9b. Self-care and isolation (if applicable)

- What was it like isolating with COVID-19?
- Was there anyone looking after you? E.g. making meals for you.
- Were you in contact with any healthcare providers or anyone from public health? Was this helpful? If not in contact, would contact have been helpful?
- What was it like during isolation, both physically and emotionally/psychologically?
- How did you pass the time?
- What was the toughest thing about being in isolation?

10. What or who were your main sources of support during your illness?

- Family members, friends, neighbours/ healthcare providers/online community/others?
- Did you have enough support? If not, why was this the case? (People were afraid of the disease/don't have a good support network/not comfortable asking for help/I'm usually the care provider not the one needing care) etc.
- What other forms of support would have been most helpful to you?

Part three: Impacts of COVID-19, reflections and advice to others

11. Did COVID-19 have an impact on you or your life that you consider significant?

- Was there a financial impact or impact on your working life?
- Did it have an impact on your homelife?
- Did it impact any of your relationships with family members, friends or others?
- Did it impact your sense of yourself in any way (feeling vulnerable, realizing you are stronger than you thought, finding out who your real supporters are? etc.)

12. Given your experience with COVID-19 how do you feel about the way the pandemic has been handled by governments and public health agencies?

- What do you think about the public health advice we have been receiving? (re: masks, social distancing, avoiding non-essential travel etc.)
- What do you think about the policies and regulations that have been put in place? (closure of businesses, curfews, quarantine regulations, restrictions on travel)
- Are there other policies, regulations or forms of enforcement that you would like to see?

13. Final thoughts and advice to others

- What has been the big takeaway for you from this experience?
- What advice would you offer to others--both those who have or haven't had--COVID-19?
- What advice would you offer to healthcare providers about dealing with COVID-19 patients?
- If you could speak to government or public health officials, what would you say to them?

14. Is there anything else about this experience that's been important to you that we haven't talked about?