

# The impact of the COVID-19 pandemic on the well-being of individuals with persistent postconcussive symptoms: A qualitative study

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## Abstract

**Background:** In response to the COVID-19 pandemic, public health measures were implemented that closed essential businesses, mandated social distancing, and imposed substantial changes to the routine care experienced by patients with mild traumatic brain injury (mTBI) and persistent postconcussive symptoms (PPCS). Patients with PPCS often rely on a comprehensive care team, requiring in-person treatments and consistent care. Little information exists regarding how access to these services have been affected by public health measures and what outcome the measures have had on the recovery of patients with PPCS.

**Objective:** To explore the impact of the restriction of in-person treatments, shifts to virtual care, and global public health measures on the recovery and psychological well-being of patients with PPCS.

**Design:** Qualitative interviews were recorded, transcribed, and analyzed using a reflexive thematic analysis approach to identify the main impacts of the public health measures on participants with PPCS.

**Setting:** Participant interviews were completed remotely via telephone or video-calling software during province-wide shutdowns.

**Participants:** 20 individuals with PPCS who attended the institution's Brain Injury Program consented to participate.

**Interventions:** Not applicable.

**Results:** The impacts of the public health measures emerged most prominently in three main categories: (1) day-to-day lived experiences, (2) personal health status, and (3) health service experiences and barriers.

**Conclusions:** This in-depth investigation of the lived experiences of patients with PPCS outlines how the COVID-19 public health measures negatively affected their care and well-being. The analysis identified that through increasing social support systems, providing better access to standard or remote treatment, and developing more effective telehealth strategies, this population could be better supported in the event of future public health measures.

## INTRODUCTION

Mild traumatic brain injury (mTBI) poses a public health challenge to a significant portion of the population, as an estimated 492-653/100,000 Canadians experience an mTBI annually, and this prevalence increases by 2% each year.<sup>1,2</sup> Most individuals will recover within

10-14 days, but up to 30% will have persistent symptoms beyond 3 months, defined as persistent postconcussive symptoms (PPCS).<sup>3-5</sup> Concussion (PPCS) and mTBI are used synonymously throughout this paper. PPCS are characterized by headache, dizziness, fatigue, mental health challenges, and cognitive deficits, among other chronic impairments.<sup>3,4</sup>

The Ontario Neurotrauma Foundation guidelines for patients with PPCS following a mTBI recommend a comprehensive multidisciplinary rehabilitation approach to treatment.<sup>6</sup>

Access to the treatment regimens and day-to-day recovery of individuals recovering from mTBI has been curtailed following the public health restrictions implemented across Canada in response to COVID-19. Because rehabilitation of individuals with PPCS requires a diverse team of health care professionals, restricted access to these resources may have detrimental effects on the patient's recovery.<sup>7</sup> For example, access to mental health services is imperative. Mood disorders, most prominently depression and anxiety, are found at significantly higher incidences in those with mTBI compared to healthy controls.<sup>8-10</sup> In fact, experiencing depression becomes over three times more likely after an mTBI,<sup>9</sup> and approximately 29%-53% of patients may also experience anxiety postinjury.<sup>10,11</sup> Physiotherapy is another commonly accessed treatment by patients with PPCS, as preliminary evidence supports rehabilitation programs including progressive exercise and fitness training (aerobic, anaerobic, and coordination exercises), vestibular and cervical based treatments, and manual therapy interventions to reduce symptomology and improve functional outcomes.<sup>5,12</sup> Barriers to receiving these treatments, as well as other health care resources and supports routinely used by patients with PPCS, may detrimentally affect their physiological and psychological well-being and recovery.<sup>13</sup>

Requirements for social distancing during the COVID-19 pandemic have further isolated many patients with PPCS. To maintain public safety, COVID-19 measures required isolation in a way that was not experienced previously; limiting social integration and potentially affecting mental and physical well-being.<sup>14</sup> Patients with PPCS are especially vulnerable, as they may already struggle with isolation due to aversive symptoms such as pain, sound sensitivity, light sensitivity, and fatigue. The impact of these symptoms is reflected by the design of rehabilitation programs for patients with PPCS, which often address physical deficits and psychosocial needs and promote community re-integration.<sup>15,16</sup> For patients with PPCS who already struggle with social connections and community integration, the COVID-19 pandemic may contribute further to isolation.

The primary objective of this study was to gain an in-depth understanding of the impact of the COVID-19 pandemic on patients living with PPCS and how their treatment and recovery were influenced. To gather evidence regarding the changes in health care, day-to-day life, and well-being of these individuals, a qualitative design was used with a reflexive thematic approach to the analysis of the data.

## MATERIALS AND METHODS

Data were collected from individuals with PPCS participating in a large tertiary care center's Brain Injury Program (CBIP) using semistructured telephone or online video interviews because of public health restrictions. The data were collected during the pandemic while strict social distancing and COVID-19 restrictions were in place, which provided accurate detail on the experiences of each individual's lives within the most extreme measures of the pandemic.

### Recruitment

Eligible participants had to have previously provided consent to be contacted for future research opportunities as part of the local clinic registry. Participants were referred to the CBIP by primary care providers, neurologists, critical care physicians, and other medical specialists. The catchment area of CBIP is approximately 2 million people, serving all of central and southern Alberta and the southeastern portion of British Columbia. Acceptance of referral is based on the following criteria: the individual experienced an acquired brain injury, is aged 16 years or older, and lived within the designated catchment area. Patients asked to participate in the study met the diagnostic criteria for mTBI and PPCS based on the World Health Organization definition and International Classification of Diseases, Tenth Revision postconcussion syndrome criteria (where postconcussion syndrome represents the previous terminology used for PPCS).<sup>4,5,17</sup> The diagnosis of mTBI and PPCS was made by a physical medicine and rehabilitation physician before each participant's involvement in the study. Information sheets were shared with interested participants. Informed consent was collected remotely from participants via explicit oral consent or through Qualtrics online survey software (Qualtrics 2019). Process consent was used on the day of the interview, reconfirming the date, time, and agreement to participate.<sup>18</sup> This study was approved by the Conjoint Human Research Ethics Board.

### Data collection

In-depth interviews were conducted by employing a participatory approach, which allowed a thorough exploration of the experiences of the participant's pandemic-related restrictions. This framework also allowed for the topics deemed meaningful by participants to be discussed. A semistructured interview guide developed in partnership with researchers and individuals with lived experience across multiple neuroscience and psychiatric clinics was used to explore each participant's personal accounts of living through the pandemic, social distancing, and experiences accessing virtual health care

**COVID-19 Screening:**

- Have you been tested for and/or diagnosed with COVID-19?
- Has a member of your family been diagnosed with COVID-19?
- Have you presented with any COVID-19 related symptoms?
- Have you been recommended by a public health authority to self-isolate?

**Interview Question Guide:**

- Tell me about the kind of help you or your family member(s) had before the coronavirus pandemic?
- Tell me about the kinds of social activities or day programs you or your family member(s) had before the coronavirus pandemic?
- Tell me about the types of changes that have been hardest for you or your family since the pandemic started?
- What kinds of things have you or your family done to help cope with the changes, positive or negative?
- Can you tell me about changes that might be helpful or that you like since the pandemic started?
- Tell me about how 'virtual' doctor appointments are going for you or your family member(s)?
- What kinds of things would be helpful for you during social distancing?

**FIGURE 1** Semistructured interview questions that were included in the topic guide and asked to guide discussion in each participant. This began with questions screening for past and present exposure to COVID-19 (either personally or with someone close to them), followed by discussion prompts regarding the participant's lived experiences during the pandemic

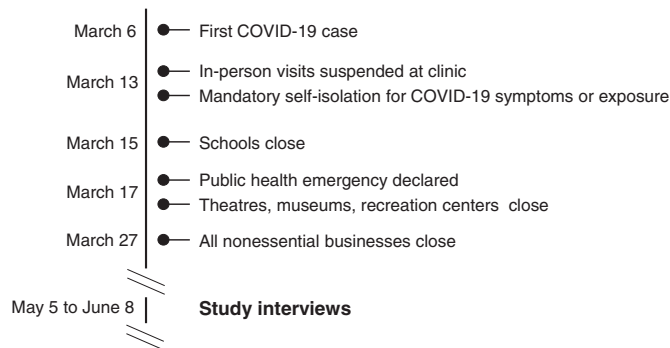
services (Figure 1). All recruitment and data collection were completed by C.J. and M.M. - research assistants possessing experience working with individuals with mTBI and PPCS. Before the recruitment telephone call, participants were unaware of who the interviewers were. The initial recruitment telephone call entailed an introduction to the research assistant, an explanation of the study, and consent. Upon conclusion of the first call, a date was arranged for a second phone or video call. The second call involved a repeat introduction and explanation, process content, and the interview.

A target of 20 participant interviews was established to provide enough thick description to reach theoretical saturation. Each in-depth interview's audio was recorded and anonymous field notes were simultaneously taken in a dedicated field journal. Immediately following the interview, reflexive field notes were written. Participants' demographic data were collected from the CBIP REDCap database (7.6.9 Vanderbilt University).

Using publicly available data from Alberta Health Services (Alberta's sole public health care system, which oversees the CBIP), the city where this study was conducted, government of Alberta, and the local Herald newspaper (Canada), a timeline of the provincial public health actions taken in response to COVID-19 was created (Figure 2).

## Analyses

Following each interview audio recordings were uploaded and sent to a secure professional transcribing



**FIGURE 2** Timeline of when the pandemic restrictions were introduced, the public health guidelines that were enacted following this, and when our interviews were conducted within this time of public health restrictions. This timeline takes place in the first half of the year 2020

service and transcribed verbatim. Returned transcripts were verified and anonymized by C.J. and M.M. Management of the data and the qualitative analysis were both completed using NVivo 12 (QSR International, 2018), a qualitative analysis software tool. To ensure the achievement of theoretical saturation, analysis of transcribed interviews occurred simultaneously to the conducting of new participant interviews in order to allow the exploration of emerging themes in future interviews.

Reflexive thematic analysis, a method that recognizes and categorizes emerging and consistent themes from a data set, was used to analyze the transcriptions.<sup>19</sup> The approach was reflexive and iterative in nature through many revisions of coding, identifying themes, naming, expanding themes, and converting these patterns into a written form.<sup>20</sup> Further it relies on actively applying theoretical ideas and learned knowledge to the ideas present in the data. The thematic analysis was carried out following the framework identified from Braun and Clarke, which involved familiarizing with the data, creating the first iteration of codes, investigating the data for themes, revising the themes identified, designating names for the themes, and then writing the results.<sup>19</sup> Upon the emergence of differences regarding themes or analysis methods, disagreements were settled through team discussions. Themes and subthemes were then shared with participants of the study, to ensure trustworthiness of the data and establish a qualitative rigor through member checking.<sup>21</sup>

## RESULTS

### Participant demographics

A total of 34 individuals diagnosed with an mTBI and PPCS who attended the CBIP were approached for participation, and 20 agreed to participate. One

**TABLE 1** Characteristics of the interviewed persons with persistent postconcussion syndrome

Characteristic	Value	
Age (mean, SD)	39 years, 10.3	
Female gender	15 (75%)	
Time since injury	1–2 years	7 (35%)
	>2 years, <3 years	9 (45%)
	>3 years	4 (20%)

Note: Twenty individuals with brain injury were interviewed for the study. Each participant was over the age of 18, met the criteria for mild traumatic brain injury and persistent postconcussive symptoms, and all had their injury more than 1 year prior.

interview was completed through Zoom, the others were conducted over the telephone. Interviews ranged in duration from 16 m:40s to 01 h:33 m:04 s (mean length = 36 m:30s). All 20 interviews were completed between May 5, 2020, and June 8, 2020.

The age, gender, and time since each participant's injury are shown in Table 1. Although the time since their head injury varies, all participants included were actively receiving treatment for PPCS before the pandemic and at the time of the study. From the date of the declaration of the public health emergency to the date of their interview (Figure 2), no participants reported a diagnosis of COVID-19 for themselves or anyone in their household; eight participants reported symptoms consistent with COVID-19, two were tested (negative result); and six of the participants self-isolated (two by personal choice due to symptoms and vulnerable family members, and four as prescribed by their physicians due to travel and/or COVID-19 related symptoms).

## Thematic analysis: Experiences of the COVID-19 pandemic

Coding and synthesis were completed by C.J. and M.M. and directed by P.R. (Principal Investigator and qualitative methods expert). Qualitative analysis revealed three overall themes encompassing six distinct subthemes that illustrated how the COVID-19 pandemic has affected the lives and experiences of patients with PPCS (Table 2). The thematic analysis is explored next, and Tables 3, 4, and 5 provide supporting quotations for each theme. To improve readability, minor grammar and spelling changes were made.

### Impact on day-to-day lived experiences

#### Managing activities and daily living

Participants noted significant difficulty in maintaining their typical schedule and routine, especially with

**TABLE 2** Experiences of the COVID-19 pandemic sorted into themes

Theme	Subthemes
Impact on day-to-day lived experiences	Managing activities and daily living
	Managing isolation induced by COVID-19 restrictions
Impact on personal health status	Physical symptoms affected by pandemic
	Increase in mental health needs affected by pandemic
Impact on health service experiences	Accessibility to services and resources
	Remote care: Barriers and facilitators

Note: The three main themes of experiences identified after analysis of the interview transcripts. Each main theme is further subdivided into two subthemes that more accurately categorize the lived experiences.

working from home and/or limiting community outings. These disruptions to typical routine and schedule seemed to cause significant challenges in various areas of day-to-day activity (Table 3; Subtheme 3.1a). As a requirement of working from home and social activities being conducted online, there were increased levels of screen time reported. Many participants felt it was difficult to manage, as the increase in screen time was required for work or activity but exacerbated symptoms of PPCS (Table 3; Subtheme 3.1b).

Many participants indicated additional challenges during the period of mandated social distancing including a significant decrease in physical activity, which was often noted as an integral part of their recovery routine. Along with difficulties maintaining exercise, participants noted changes to social activity and financial difficulties (Table 3; Subtheme 3.1c).

#### Managing isolation induced by COVID-19 restrictions

Many patients with PPCS feel isolated from friends, family, and community because of symptom exacerbation in these environments. Because of this, many of the participants felt they were already familiar with experiencing social isolation (Table 3; Subtheme 3.2a). The COVID-19 pandemic forced society to social distance and isolate, and participants with PPCS now felt others were able to relate to the feelings of isolation (Table 3; Subtheme 3.2b). In fact, participants experiencing significant social isolation before the pandemic felt improved social connections and improved quality time with immediate family because of this (Table 3; Subtheme 3.2c).

**TABLE 3** Impact of COVID-19 pandemic on day-to-day lived experiences: Theme 1 quotations

Theme	Subtheme	Specific Topics	Example Quotations
3. Day-to-Day Lived Experiences	3.1 Managing Activities and Daily Living	3.1a Disruptions to Normal Routine and Schedule	<p>“With getting my first concussion, ADHD became more prominent in my life. And so, I’ve been learning how to adapt to have ADHD and losing my schedule and my routine was really rough. I would definitely use getting up for school and having to go do things as a way to wake up in the morning. And now I do not wake up in the morning-” (Participant 530)</p> <p>“I would agree that having a provided structure, or a prescribed structure would make it easier to kind of . . . It’s, hmm. It’s- it’s sort of been like, it’s been difficult to prioritize my needs.” (Participant 519)</p> <p>“Because, like, with the bad memory and stuff, you are staying in every day, and you can get other stuff done, but, like, you do not realize that it’s really affected your routine. So, I started having issues, you know, remembering my meds. Like, one time I accidentally did not take them for 4 days, and I did not know. You know? So, um, getting outside was, like, kind of crucial to separating days.” (Participant 509)</p>
		3.1b Managing Screen Time	<p>“So yeah, that’s also a stressor, is the fact that I need to be on my computer almost 24/7. And I definitely, like I do not read very well and I have tracking issues. And I’m usually pretty good with tracking on the computer. But that’s when I get breaks. And so now that I’m staring at a computer, lines start to merge, especially if I’m looking at Excel files, so that I need to take extra time. (Participant 530)</p> <p>“Yeah, and all your socializing is, you know, with family and friends is done through the computer.” (Participant 519)</p> <p>“I mean, that’s the thing too, it’s, like, hard. I already have to be on the computer way too much, and so for me to be on the computer more it’s - I’ve been feeling very angry lately, um, the last, like, month and I’m not an angry person, so I do not know, like what’s causing that. I mean, I’m sure it could be a lot of different variables, but uh, I do not know if it’s because I’ve also been having a lot of screen time that that’s uh, adding to the frustration.” (Participant 524)</p>
	3.1c Additional Challenges of Daily Living	<p>“I have not really figured out how to work exercise into the schedule. Yeah, I think we could come up with a better routine. We could come up with a routine. That routine could include physical activity. I think physical activity would make everything better.” (Participant 519)</p> <p>“Yeah, and I think, I mean in terms of how that plays into my head injury, that’s actually really important because maintaining the level of physical activity then I’ve been able to return to, um, is (a) really important for me and my mental health, but (b) an important process of my recovery. So if I just, if I did not keep up those activities, then I would expect that I would see a resurgence in symptoms. So yeah, I think it’s important to make whatever adaptations, um, I needed to make in order to stay active.” (Participant 527)</p> <p>“So, my brain injury, I guess, was starting to get better just before, um, they decided to put all these restrictions in place. And I was starting to see friends more and able to have, like, longer conversations and socialize. And then it was like, [Expletive].’ (laughs) ‘Now I cannot see people anymore.’ Yeah (laughs).” (Participant 514)</p>	

(Continues)

TABLE 3 (Continued)

Theme	Subtheme	Specific Topics	Example Quotations
			“Well, one thing it’s really affected, um, our business. So, money’s been really tight. So, you know, I arranged to defer as many payments as I could. But of course, I mean, you are still going to owe the interest on, you know, the car payments and the mortgage and everything. So, that’s going to come back and bite you ... in the end, but you have to do what you can do in the meantime. And yeah, so, financial concerns and, uh, of course, car payments are due to start back next month and our business is not restored. (Participant 510)
	3.2 Managing Isolation Induced by COVID-19 Restrictions	3.2a Positive Coping Strategies to Managing Social Isolation	“At the beginning, it wasn’t stressful for me because in many ways, uh, along with other concussion people I’ve connected with in the community, it felt that, well, we have been training for this for the last several months. And in many ways it made it easier. I felt more mentally prepared for the pandemic in the sense that I had already experienced being stuck at home but not being able to do anything.” (Participant 517)
		3.2b Others Relating to their Regular Feelings of Isolation	“Like I said for us it’s par for the course. It’s what we do every day. But, like for sick people, we are doing great, because we deal with this all the time. But for people who do not, it’s an added anxiety.” (Participant 534)
		3.2c Increased Time with Immediate Family Leading to Important Social Connections	“I’ve become a hermit (laughs) [since my concussion]. I think everybody else is feeling like a hermit now because they are in my world that way.” (Participant 501)
			“I would say right now I’m getting more stimulus social-wise with just direct family than I received in the past. Before I was pretty much alone all day.” (Participant 501)
			“Well, on the plus side, my daughter and I’ve been able to spend a lot more time together and we have had more time for our pets.” (Participant 510)
			“So we have been using our workout room, too, more now, and actually, my wife and my daughter and I are all doing this together now. So we have been able to find things to keep doing together.” (Participant 502)

Note: Key quotations provided by participants that guided the identification of theme 1 and the subthemes. Specific topics were included to enhance understanding and support to the claims made in the body of the text, allowing reference to be drawn from the transcript. Quotations have had minor adjustments to improve readability.

## Impact on personal health status

### Physical symptoms affected by pandemic

Due to the abrupt stop to many of their regular treatments, participants described various elements of recovery regression. This seemed to manifest in areas of increased headache, physical pain, and worsened dizziness (Table 4; Subtheme 4.1).

### Increase in mental health needs affected by pandemic

Numerous participants described an increase in mental health challenges and a decrease in support. This most often was a reflection of the abrupt stop in regular mental health treatment for depression, anxiety, or other

mental health concerns. Limited access to treatment and/or less in-person social support significantly affected the participants’ mental health (Table 4; Subtheme 4.2). Some participants described feeling anxiety about the pandemic in general, mainly for those with additional underlying medical issues that would make them or other family members more at risk. Additionally, some participants described anxiety around the future and the unknown.

## Impact on health service experiences

### Accessibility to services and resources

The pandemic and associated public health measures have had a clear impact on the health service experience of patients with PPCS. Participants reported that

**TABLE 4** Impact of COVID-19 Pandemic on Personal Health Status: Theme 2 Quotations

Theme	Subtheme	Example Quotations
4. Personal Health Status	4.1 Physical Symptoms Affected by Pandemic	<p><i>“My headaches have returned, so I have not had another injection for that because of this kind of starting up.” (Participant 503)</i></p> <p><i>“I’ve noticed the increase in pain in my back and my neck that was previously pretty well managed after my accident. And then the increase in headaches, too.” (Participant 503)</i></p> <p><i>“Yeah, so with my ongoing concussion symptoms, they are triggered by, I guess, requirements for concentration, multitasking, screen time, um, typical things I guess you would expect that would be more challenging when you have head injury symptoms.” (Participant 527)</i></p> <p><i>“But for sure, on the vestibular side, because like we live in an apartment, I’ve only been walking, like, you know, at most 15 ft. So, when we started doing the walks, you know, just half a block you are kind of like all over the place. And I was like, “Wow,” you know. “I did not expect this.” (Participant 509)</i></p>
	4.2 Increase in Mental Health Needs Affected by Pandemic	<p><i>“I would say mentally I’m suffering on that end.” (Participant 501)</i></p> <p><i>“Um, sleep, mood and motivators, for sure, have been disrupted. Yeah. It’s just really stressful.” (Participant 530)</i></p> <p><i>“I do not know, it’s hard . . . It’s been so long. I’m always like . . . I definitely know that mood swings have been more intense, like a lot of ups and downs.” (Participant 517)</i></p> <p><i>“There was a little while where I felt my depression get really, really bad. So I had to kind of let that one, oh man . . . I let it get bad. And then I let myself wallow in it for a little bit to try and feel better ‘cause I could not use my typical distractions.” (Participant 530)</i></p> <p><i>“I was going to a group meeting once a month where we go and we talk about issues . . . it’s all brain injury people and that had to discontinue since- I do not even know if it can continue. I hope they do when it starts up again. That is very positive for me because . . . I do not want it to sound bad, but it’s nice to see that there are worse people off than me. And that they all have similar situations as me. Everybody’s got their own issues (laughs), but it’s somehow relieving when you are at the meetings because you just see, uh, “Okay, they got the same thing,” or he or she has the same idea of what I’m doing, and it’s not a whine session, it’s just great to sometimes just talk it out with other people than family, because you do not want to talk about it at home all the time, right? (Participant 501)</i></p> <p><i>“I have concerns about that too. I mean, I’m not the youngest guy, and, uh (laughs), I just do not know . . . My family basically, um, do not want me going anywhere if I do not have to anyways medically.” (Participant 501)</i></p> <p><i>“I’m probably going to do a follow-up with my GP, but even then, like, I’m asthmatic, so I’m kind of not- I’m a little bit reluctant to actually go in.” (Participant 502)</i></p> <p><i>“I find the social media has been really triggering for my anxiety.” (Participant 503)</i></p> <p><i>“I was previously seeing a chiropractor two to three times a month and I was seeing a psychologist related to anxiety from my traumatic brain injury twice a month. Um, and then, I wasn’t able to see the chiropractor at all from mid-March and my psychology appointments have also decreased. And then, I also typically see my neurologist whenever my headaches return, but I have not really felt comfortable to make an appointment just because I do not want to go to the hospital. Because I have asthma, as well. I’m quite fearful of the virus. And so going to a hospital just felt like, it increased my anxiety a lot which was something I had to work with my psychologist on. So it just did not feel right to me to get in touch for an appointment.” (Participant 503)</i></p> <p><i>“Yeah, and also like just the new type of paranoia regarding visiting other people that’s (laughs) settling in the psyche all over. So, every time we want to go somewhere, if we go to my parents’ place it’s like, ‘Are we going to expose them?’ because we went to the shop, we went to Superstore, Walmart, whatever, uh, maybe picked up something and we could pass it to them, and if we are going to friends, it’s like, ‘Yeah, who could’ve visited before we are going to them or did they visit before they are coming to us.’ So there’s this paranoia.” (Participant 507)</i></p>

Note: Key quotations provided by participants that guided the identification of theme 2 and the subthemes. Quotations have had minor adjustments to improve readability.

their regular treatment protocols involved seeing a variety of service providers for a multitude of symptoms. The main impact to this population seemed to be the abrupt stop in treatments. The three key treatments that were affected most often included physiotherapy, mental health services, and musculoskeletal or nerve injections. Participants reported these treatments to be essential services for their recovery and felt that the

abrupt halt of these services negatively affected their recovery (Table 5; Subtheme 5.1).

## Remote care: Barriers and facilitators

Public health measures were implemented quickly, but some health service providers such as family

**TABLE 5** Impact of COVID-19 pandemic on health service experiences

Theme	Subtheme	Example Quotationss
5. Health Care Support	5.1 Accessibility to Services and Resources	<i>“But then, not having physiotherapy for, like, the headaches, and not getting the actual physical treatment, sucks sucks sucks.” (Participant 509)</i>
		<i>“Well, the physiotherapy clinics had shut down, so I did not have any treatment for about 2 months, which was really hard ‘cause I get chronic headaches, so just from the tense muscles and stuff.” (Participant 510)</i>
		<i>“I was supposed to have the injections repeated and then all the restrictions came down, so, uh... So, after all of the COVID stuff happened, I have not heard back from the brain injury clinic since then.” (Participant 510)</i>
		<i>“So I mean it’s not like critical that I talk to a therapist, but it would have been really nice. So I think there is need for maybe a little bit more recognition of services that are going to be more highly utilized during a pandemic and that people may have difficulty accessing as a result of increased demand. I mean, I’ve probably tried, like four or five different people.” (Participant 527)</i>
		<i>“I still have hyperacusis and sensitivity to noise but that’s gotten better, you know. I tried building up my walks. I’ve been asking for like progressions on my vestibular stuff. I mean it’s... I still have a road ahead of me, I understand that, but I mean, since COVID, like, I do not know. It feels like I’m back doing it on my own.” (Participant 531)</i>
	5.2a Remote Care: Barriers	<i>“She offers virtual appointments, but I’m not really interested in that. I kind of want to do the one-on-one kind of thing,” (Participant 504)</i>
		<i>“I definitely prefer going in. I miss going in. It was like her office feels like a very safe space for me and, not that my home does not, but it’s just like, her offices just have a different feeling for me. It’s like somewhere I know is very, very safe, whereas at home I just do not feel like I get as deeply into my sessions.” (Participant 503)</i>
		<i>“I do not like the video. Over the phone for doctors, that’s been just fine because the doctors have known me and seen me. But for the physio, no, it’s definitely not as effective.” (Participant 514)</i>
		<i>“Um, counseling, I mean, I just think it moves at a slower pace. I was actually talking to her about that. I just think it takes a lot longer. I think it’s not as effective. It’s still somewhat effective, but not as effective as in-person sessions, and I think to build rapport and connection, and uh, vulnerability takes a lot. It just moves at a slower pace than in-person does. But, I mean, it’s still somewhat effective.” (Participant 524)</i>
		<i>“The great thing is, like, it’s super great that I do not have to navigate to get to the numerous doctor’s appointments when they are over the phone.” (Participant 509)</i>
5.2b Remote Care: Facilitators	<i>“It’s not a bad thing, because, you know, our health care service, like, you are kind of getting more of your doctors now.” (Participant 509)</i>	
	<i>“So, it’s nice to have, I guess it’s like, you speak to a neurologist and it’s like having a prelim over the phone. And then you get to go meet them in person, and then you know, it’s going to be easier. ‘Cause it’s harder to talk and communicate yourself, right?” (Participant 509)</i>	
	<i>“Our family physician has been doing home visits and he knows us really well. So, I just call and make an appointment and then he calls me and does an assessment over the phone and then provides prescription refills.” (Participant 516)</i>	
	<i>“I still think that the virtual system should not totally disappear as I believe there are ways it can be quite advantageous in giving medical professionals a more full diagnosis by seeing their patients environments and assisting them by suggesting things they can use in their home or things they can look into to getting them by until they can actually come in to see a medical professional.” (Participant 531)</i>	

Note: Key quotations provided by participants that guided the identification of theme 3 and the subthemes. Quotations have had minor adjustments to improve readability.

physicians, physiotherapists, and mental health providers were able to offer virtual services via telephone or video conferencing. Overall, the participants appreciated the attempt to maintain service levels, but preferred face-to-face appointments, suggesting in-person

appointments were more effective (Table 5; Subtheme 5.2a). However, participants felt some aspects of virtual treatment were advantageous including less travel time, increased dedicated time with the health care provider, virtual management of prescription medication,



and being less rushed to get to appointments (Table 5; Subtheme 5.2b).

## DISCUSSION

To our knowledge, this study was the first of its kind to provide preliminary insight into the impact of the COVID-19 pandemic on the health and well-being of patients with PPCS. Many adverse effects of the public health measures were identified; most notably difficulties managing activities of daily living, an exacerbation of PPCS, and the impact of limited or impeded access to health care services. Not only does this study identify the direct effects of the pandemic measures on this cohort but also provides valuable insight into the basic needs, services, and resources a patient with PPCS requires to recover - a topic poorly supported by past literature.<sup>22</sup> As little is known regarding the trajectory of the COVID-19 pandemic, insight into how to better support and care for this patient population may prove valuable in the event of future public health measures.

### Impact on day-to-day lived experiences

During the implemented restrictions, participants found continuing with daily routine and activities of daily living particularly challenging. First, transition from in-person work to virtual often exacerbated their PPCS. This transition required work to be completed via computer use only. Participants noted that the extended screen time was quite challenging and exacerbated symptoms, such as photophobia, headaches, and fatigue.<sup>23,24</sup> Additionally, before the pandemic most participants were recovering or working alone at home during the day. Throughout the restrictions, family members and coinhabitants transitioned to being present at home, contributing to new challenges such as a noisier and busier environment and potential interpersonal conflict. Challenges performing mental tasks and concentrating are typical symptoms of PPCS, and in one study almost 90% of patients diagnosed with PPCS reported poor concentration.<sup>4,17,24</sup> The interviewees explained that these symptoms became especially hard to manage when trying to complete their own work while simultaneously balancing external roles including childcare, home-schooling, and sharing workspaces with other family members and partners, which was worsened during COVID-19 restrictions.

For many participants, the requirements of social distancing guidelines to spend more time at home resulted in drastic lifestyle modifications and contributed to social isolation. Although very important to containing the spread of COVID-19, these measures reduced participant access to their typical support networks, creating seclusion. Interestingly, for other

participants the pandemic restrictions did not drastically change their experience of social isolation but instead perpetuated what was already ongoing before the pandemic. This finding highlights the degree to which these patients have experienced social isolation from their injury and the extent to which they have developed their own isolation coping strategies. This finding is supported by previous literature that found patients with PPCS often have difficulty with community integration and seeking social supports.<sup>16</sup> In a study investigating blog posts of 58 athletes during mTBI recovery, many referenced their struggles with social isolation and losing friends because of skepticism about symptoms and inability to empathize.<sup>25</sup> Participants here noted they felt less isolated and marginalized during the COVID-19 pandemic, as the restrictions helped them feel they belonged to a greater community sharing a similar experience. This, combined with increasing interactions with friends and family through in-home access to social networks were found to mitigate feelings of social isolation. It is important to note that although this was the experience of many participants, others felt even more socially isolated than ever before because of the restrictions. Although limited research exists on patients with PPCS experiencing social isolation, promoting community reintegration and strengthening social ties have been found to be important not only for rehabilitation of patients with mTBI but also for overall satisfaction of life and well-being.<sup>15,16,26</sup>

As the world transitions to a digital environment, now may be the best opportunity to introduce virtual social support groups to mitigate isolation in patients with PPCS. In other patient populations, online computer-mediated support groups have been found to significantly reduce feelings of social isolation and loneliness, improve positive coping strategies, and reduce negative feelings and ideations.<sup>27-29</sup> Further, for those with PPCS who avoid transportation to prevent provocation of symptoms, online health services allow access to care that overcomes geographical barriers.<sup>28,30</sup> However, this may be complicated in patients with PPCS as symptoms such as light sensitivity may complicate engagement in online sessions, and little evidence of the use of online support groups in the PPCS population exists. Therefore, more studies are needed to determine the structure and delivery of online interventions to mitigate social isolation in patients with PPCS.

Physical activity was also found to be important to this population's recovery, as almost every participant mentioned its role in their routine. Health benefits of regular physical activity are endless, and many PPCS may be mediated by regular exercise routines.<sup>31</sup> Animal models have suggested that although exercise immediately after head injury is dangerous, exercise later in the recovery trajectory has the potential to improve symptomology and cognitive function.<sup>32</sup> Being

removed from physical activity for lengthy periods may contribute to worsening of PPCS such as fatigue and mental health.<sup>33</sup> In a preliminary study that included 12 participants with PPCS, a controlled aerobic exercise program was used to effectively treat 11 of the 12 participants and facilitate a reduction in their symptoms as well as a successful transition back to work and sport.<sup>34</sup> For participants in this study, access to exercise facilities, sports teams, and exercise practitioners stopped during restrictions; this significantly affected their well-being and recovery.

## Impact on personal health status

Among the specific symptoms of PPCS aggravated by the COVID-19 pandemic, mental health difficulties were the most often discussed. This is not surprising, as mental health conditions, particularly depression, anxiety, and emotional lability, are prominent features of PPCS.<sup>4,17,35</sup> Past situations have illustrated that during a pandemic, substantial psychological damage inflicted from fear, panic, and related stress will likely be greater in incidence than cases of infections.<sup>36</sup> In a study of 1210 Chinese citizens, over 50% reported a psychological impact that they graded as moderate or severe since the COVID-19 pandemic has started.<sup>37,38</sup> Owing to the presence of preexisting mental health conditions in patients with PPCS, this population is at a heightened risk of worsening, relapsing, or experiencing new episodes of their symptoms.<sup>39-41</sup> Therefore, during this time more than ever, it is clear that special attention must be directed to ensuring mental health services are available and those at greater risk have access to services. Despite this, multiple participants reported an inability to access mental health resources or inability to contact their usual practitioners due to pandemic barriers.

Secondary to declines in mental health were the exacerbation of challenging physical symptoms. Due to many concussions involving acceleration-deceleration of the head, the cervical spine and its joints and soft tissue are vulnerable and commonly injured concurrently.<sup>42,43</sup> Physical therapy is used to assist in treating this aspect of the injury, alleviating symptoms such as neck and back pain, tense muscles leading to headaches, and oculomotor or vestibular disturbances.<sup>43</sup> Most participants did not have access to virtual physical therapy through the restrictions, and those who did indicated that they felt it was not effective nor was it offered at suitably frequent intervals. Additionally, allied health treatments such as physiotherapy, vestibular therapy, massage, chiropractic, and others requiring a “hands-on” approach were not felt to transition well to virtual care. As a result, participants expressed that improvement was needed in both the quality and frequency of physical therapy. In the future, alternative methods for

providing this treatment may need to be explored for patients with PPCS, as they serve as an integral adjunct to regular care and recovery.

## Impact on health service experiences

Despite the many barriers created by COVID-19, the main challenge of accessing care experienced was the abrupt halt in treatments. Patients with mTBI have significantly lower quality of life scores than those of individuals without injury, and these scores further decrease in the presence of PPCS, correlated with symptom severity.<sup>44,45</sup> Treatment is therefore necessary to help manage these symptoms to improve health outcomes, improve quality of life, and prevent future strain on the health care system from exacerbations. The three key treatments affected during COVID-19 restrictions included mental health services, physiotherapy, and musculoskeletal and nerve injections. Although the impact of not receiving treatments varied depending on the participant’s level of function, all participants felt these treatments were essential to recovery. Previous research has indicated access to mental health services and exercise physiology (including progressive exercise and fitness training, vestibular therapy, musculoskeletal physiotherapy, and manual therapy interventions) are important treatments that aid in recovery following mTBI.<sup>5,8-10,12,13,46</sup> Therefore, if similar restrictions occur because of future pandemics or other widespread emergencies, special consideration of ways to maintain access to these services for patients with PPCS should be considered or effective alternatives established.

Telemedicine has the opportunity to alleviate some of the strains from treatment halts, but throughout this study only allied health services were offered virtually. Although virtual treatment is not seen as being as effective as in-person treatment, participants felt the availability of virtual treatment was better than no treatment. In fact, participants felt some aspects of virtual treatment were positive, including less travel time, decrease in busy schedule, increased quality time and check-ins with their health care providers, and virtual management of prescription medication. A proactive approach to telehealth medicine that incorporates these services into the regular course of treatments will increase accessibility and frequency of visits, promoting better outcomes for various health care challenges in this population.<sup>47</sup> This hybrid approach may have the benefit of decreasing travel fatigue, decreasing in-person appointments, and potentially decrease the burden on clinic space and wait times. Telehealth services could also provide a supplementary means of outreach and information dissemination. Access to regular, high-quality telehealth services would be of benefit to patients with PPCS to mitigate many symptoms, whether during a pandemic or not.

## LIMITATIONS

The main limitation of the study is that it was conducted in patients with PPCS recruited from a specialized brain injury clinic, reflecting a selection bias. These data were also collected during the first wave of the COVID-19 pandemic, and experiences may have varied with longer exposure to restrictions during second and third waves of the pandemic in Canada. Nonetheless, the themes that emerged from the interviews provide valuable insight and do seem to align with many of the difficulties commonly experienced by patients with PPCS.<sup>6</sup> In future work it may be valuable to understand the specific experiences related to extended virtual care provision in a larger cohort to further inform virtual service design.

## CONCLUSION

This study outlines how the COVID-19 public health measures affected the everyday lived experiences, personal health status, and ability to access necessary health services of patients with PPCS. The findings offer insight into how to better support this population in the event of future public health restrictions, as well as what supports have been missing in their general care. As routines changed drastically, immense challenges in maintaining day-to-day tasks arose, such as physical activity, work, and home responsibilities. Although the few participants who had access to virtual treatments did not find them to be particularly effective, constructive feedback emerged as to how to improve future directions for this modality of care - most notably requests for better access to virtual mental health services. Many participants also considered physical treatments to be essential services and hoped access would be available in future public health measures. Despite shortcomings, some benefit was found with telehealth, demonstrating the potential to incorporate telemedicine into the regular course of treatment for patients with PPCS. This may reduce the demand on the patient's time, increase access to essential services, ease their burden during recovery, and alleviate strain on the public health system. Overall, this study illustrates the vulnerability of patients with PPCS, and more research is required to determine the necessary care required to support and treat them.


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## DISCLOSURE

No competing financial interests exist, and no funding was received for this project.

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