

# Understanding the Early Impacts of the COVID-19 Pandemic on Brain Injury Associations Across Canada: A Qualitative Study

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Ana Paula Salazar, PhD<sup>1,2</sup>, Sophie Lecours, PhD<sup>2</sup>, Lisa Engel, PhD<sup>3,4</sup>,  
Monique A. M. Gignac, PhD<sup>4,5</sup>, Shlomit Rotenberg, PhD<sup>5</sup>, Sareh Zarshenas, PhD<sup>5</sup>,  
Michelle McDonald, BA<sup>6</sup>, and Carolina Bottari, PhD<sup>1,2</sup>

## Abstract

The COVID-19 pandemic has increased challenges for people living with brain injury and community associations to support this vulnerable population. This study aimed to gain an in-depth understanding of the challenges faced by brain injury survivors during the first year of the pandemic and how community brain injury associations adapted their services to respond to these needs. Findings from seven focus-group with 31 representatives of Canadian brain injury associations revealed 4 main themes: (1) Addressing evolving client needs; (2) Keeping clients safe; (3) Challenges and opportunities navigating the digital world; and (4) Sustaining brain injury associations in the face of uncertainties and disruptions. To comply with public health measures, associations reported pivoting their service delivery online, despite recognizing the difficulties this could create for many brain injury survivors in accessing and using technology. Our findings also highlight concrete directions for not-profit organizations providing instrumental help with activities, acting as a liaison and interpreter of public health guidelines, and in connecting with clients using technology while handling potential cognitive and technological challenges. Addressing these issues has the potential to protect people living with brain injury and community associations from external threats, like pandemics, in the future.

## Keywords

COVID-19, brain injuries, community support, vulnerable populations, public health

### What do we already know about this topic?

The COVID-19 pandemic disproportionately affected people living with brain injury.

### How does your research contribute to the field?

Our research contributes by showing the challenges and adaptations brain injury associations made to assist clients with basic needs, technological issues, and compliance with public health guidelines during the COVID-19 pandemic.

### What are your research's implications towards theory, practice, or policy?

Given the challenges faced by brain injury associations and the disparities experienced by brain injury survivors during the COVID-19 pandemic, public health officials must apply an equity and fairness lens to future emergency responses.

## Introduction

The COVID-19 pandemic disproportionately affected people living with disabilities.<sup>1,2</sup> The impacts of the pandemic on this population included increased social isolation, financial uncertainty, anxiety, and overall stress, which can compound the often lower quality of life reported by those living with a brain injury in Canada<sup>3</sup> and other countries.<sup>4,5</sup> This has been

attributed to pre-existing health and social disparities,<sup>1</sup> as well as a lack of disability-inclusive preparedness.<sup>1,2</sup>

Studies have shown that people living with disabilities had difficulty accessing information and support services during the pandemic.<sup>6,7</sup> Safety measures implemented at the onset of the pandemic reduced the risk of infection transmission but also created new challenges and disparities for



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people living with brain injury including increased isolation, fear, and anxiety.<sup>8</sup> In Canada, federal and provincial governments began implementing lockdown measures in mid-March 2020 including border restrictions, limited gatherings, school and non-essential business closures, mandatory working from home, and temporary suspension of non-essential health and public services.<sup>9</sup>

During this period, most of the support services and public health information were disseminated through online technologies and remote services.<sup>10</sup> However, even prior to COVID-19, 20% of people with disabilities in Canada did not use the Internet due to a lack of devices, no Internet services available, a need for adaptation or specialized software, and a lack of accessibility on several websites.<sup>11</sup> In fact, the digital-divide has been noted among people living with disabilities due to lower income and greater poverty,<sup>12</sup> which results in less economic capacity to access technology, including hardware and internet services.<sup>13</sup> Added to this, reduced cognitive and communication abilities among people living with disabilities can make it more challenging to learn and navigate new technologies and online environments. Thus, while the internet became a key source of information and support for many people worldwide, it widened pre-existing inequalities in access to technology for people living with disabilities,<sup>14</sup> including those living with brain injury.<sup>15</sup>

A recent report has shown that difficulties in accessing needed information and support services increased mental health challenges for people living with brain injury.<sup>8</sup> In Canada, many people living with chronic brain injury rely on the information, support, and services provided through non-profit community brain injury associations. A 2022 pan-Canadian survey showed that, even though brain injury associations encountered financial difficulties, they quickly transitioned their support programs to online delivery and developed new programs to continue providing services to clients, while complying with protective measures.<sup>16</sup> Brain injury associations are part of the Canadian non-profit sector, which has also faced considerable challenges and many continue to report being in a precarious situation, often due to revenue declines and increased demand surpassing capacity.<sup>17</sup> Despite knowing that the pandemic has challenged brain injury associations,<sup>16</sup> little is known about the extent and type of changes that were undertaken by community

associations in response to the pandemic. Specifically, their perceived challenges, successes, and outcomes. Therefore, the aims of this study were to gain in-depth knowledge about the early effects of the COVID-19 pandemic from the perspective of staff and volunteers of community associations on people living with brain injury and community brain injury services in Canada, as well as to understand how community associations responded to changes happening during this period of the pandemic to meet the needs of people living with brain injury.

## Methods

### Study Design

This qualitative descriptive study<sup>18</sup> is part of a community-based participatory research project that started at the beginning of the pandemic. We conducted semi-structured online focus groups to gather broad perspectives from staff and/or volunteer representatives from Canadian community brain injury associations. We were interested in learning about the challenges that community brain injury associations encountered and the adaptations they made at both individual (staff, clients) and organizational levels (financial strategies, mission changes). We used the Consolidated Criteria for reporting qualitative research (COREQ) reporting guidelines to ensure that the methods used to achieve our findings were well-detailed.<sup>19</sup>

Informed consent was obtained from all participants. Associations received \$100 (CAD) incentive for their representative's participation. This study was approved by the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (2022-1424) Ethics Committee.

### Participants

We identified 70 brain injury associations across Canada from a list of associations available at the Brain Injury Canada website (<https://braininjurycanada.ca/en/brain-injury-associations>; note: currently there are no known brain injury associations operating in the 3 Canadian northern territories). Participants were recruited by convenience, by the co-investigators (executive directors) of the study, as they

<sup>1</sup>School of Rehabilitation, Université de Montréal, Montréal, QC, Canada

<sup>2</sup>Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal, Institut universitaire sur la réadaptation en déficience physique de Montréal du CIUSSS du Centre-Sud-de-l'Île-de-Montréal, Montréal, QC, Canada

<sup>3</sup>Department of Occupational Therapy, College of Rehabilitation Sciences, University of Manitoba, Winnipeg, MB, Canada

<sup>4</sup>Institute for Work & Health, Toronto, ON, Canada

<sup>5</sup>Dalla Lana School of Public Health, University of Toronto, Toronto, ON, Canada

<sup>6</sup>Brain Injury Canada, Ottawa, ON, Canada

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### Corresponding Author:

Carolina Bottari, Center for Interdisciplinary Research in Rehabilitation of Greater Montreal (CRIR), Institut universitaire sur la réadaptation en déficience physique de Montréal (IURDPM), 6363, Chemin Hudson, Montréal, QC H3S 1M9, Canada.

Email: [carolina.bottari@umontreal.ca](mailto:carolina.bottari@umontreal.ca)

knew who to contact in the associations. One representative from each association received a personalized email with a formal invitation to participate in the study. People were eligible to participate if they (1) were a volunteer or staff representative of a brain injury association who could speak about the staffing, clients (i.e., people living with brain injury, their families, and caregivers), public health, and other organizational challenges and adaptations experienced during the pandemic; (2) had knowledge about the pre- and during-COVID-19 needs and challenges of their associations and clients, as well as about the associations' response actions and plans to address needs and challenges; (3) had access to a stable internet connection, and (4) had the ability to communicate in English or French. Associations were included if they served the brain injury population with a formal or self-reported diagnosis. They were excluded if they were not "community-based," that is, their program was part of the healthcare system, if they were fee-for-service, and/or focused on outpatient rehabilitation. From the list of associations, two were excluded because their funding came primarily from health authorities, and one because its service was focused on outpatient rehabilitation. Twenty-nine associations did not respond to the invitation email, even after receiving two reminder emails.

### Data Collection

Our all-female team consists of six interdisciplinary researchers, seven executive directors of Canadian brain injury community associations, one postdoctoral researcher with expertise in rehabilitation and brain injury care, and one research assistant with expertise in neuropsychology and community services.

Since this is a pan-Canadian study performed during the COVID-19 pandemic, seven 2-hour online focus groups were conducted using a secured Zoom link between October 2021 and May 2022, with 4 to 7 participants in each group (mean=6). Three focus-groups were conducted in simultaneous English and French and four were conducted in English only. The bilingual groups had one or two bilingual researchers who took notes and translated into French or English the essence of the answers for the whole group or individually using Zoom's chat feature. In addition, the questions discussed during the focus groups were presented in both languages on a shared screen during the meeting. Online focus groups have several advantages including (1) enhanced participation and outreach (pan-Canadian participation); (2) facilitation of audio recording; (3) screen-sharing and instant messaging options; and (4) low cost.<sup>20-22</sup>

Two groups were facilitated by a researcher (LE) with expertise in moderating focus groups. Five were facilitated by co-investigators from brain injury associations (executive directors) to decrease hierarchy and maximize supportive information sharing. Facilitators who volunteered to moderate

the focus groups were trained by LE, AS, and SL. Four researchers (CB, AS, SL, SR) participated as note-takers during the focus groups. Facilitators followed a focus-group guide that was developed, and pilot-tested by co-investigators from brain injury associations. The guide (Supplemental Appendix 1) had open-ended questions about brain injury association experiences during the first year of the COVID-19 pandemic (March 2020 to March 2021) and facilitators used probes to elicit additional information and enhance clarity of responses. Questions were sent by email to participants at least one week prior to the focus-group meeting (in English and French). To provide context and to remind the participants about events and legislation that were in place during the first year of the pandemic, at the beginning of each focus group, facilitators talked about things happening during this specific period. For example, during the first year of the pandemic vaccines were not available, the guidelines by the World Health Organization and other international organizations were constantly changing, many people were only beginning to use Zoom and other online communication platforms, and Canadian provinces had different public health measures in place. Facilitators also introduced themselves and reminded the participants of the aims of the project.

We collected background information about the participating brain injury associations during the self-introductions of focus-group members (eg, location of associations, number of clients they serve, and association size based on the number of staff). Participants also responded to a short online demographic questionnaire developed and pretested by the research team (Supplemental Appendix 2). They received a personalized email with information about the questionnaire, including the time to complete it and a link to a REDCap<sup>®</sup> (Research Electronic Data Capture System) questionnaire.

To enhance the trustworthiness of data collection, summary notes were presented at the end of each session by the moderator and note taker, and participants were invited to provide feedback, clarify information, or refine the summary statements.

### Data Analysis

We analyzed the data using qualitative thematic analysis methods outlined by Miles et al.<sup>18</sup> We chose to use a data-driven process, that is, an inductive approach since it offers the opportunity to summarize and identify patterns across qualitative data without using a specific conceptual or theoretical framework.<sup>23</sup> First, all audio records were transcribed. Statements in French were translated into English by a bilingual researcher (SL), and all data were anonymized. Then, two researchers (AS, SL) familiarized themselves with the data by reading the transcripts in detail. The same researchers completed initial coding to identify units of meaning and summarize information in small data chunks. Once agreement on initial codes was obtained through discussion, the list

of codes and topics was reviewed, discussed, and enhanced by other members of the research team to the point where no additional issues were identified, and the codebook stabilized. All transcripts were then coded, and the codes were grouped into categories in an iterative process. Continued discussion with team members (including researchers and executive directors) was performed in several stages to group codes into categories (ie, topics) and generate potential initial themes. The themes and subthemes presented only include codes that reached data saturation. Data coding and analysis were performed using NVivo 10.0 (QSR International Pty Ltd. NVivo qualitative data analysis software. 10 ed; 2012).

## Findings

Out of the 38 staff or volunteers from brain injury associations who showed interest in participating in the study, 31 individuals participated in this study. Demographic data including the clocation of the associations, and the number of staff and clients prior to the pandemic is shown in Table 1.

Four main themes were developed, including nine subthemes, which illustrated how the COVID-19 pandemic affected community associations, as depicted in Table 2. A discussion of each of the themes and subthemes is presented below.

### Theme 1: Addressing Evolving Client Needs

Early in the pandemic, brain injury associations changed their provision of services to public health crisis interventions to respond to the needs of clients which were rapidly changing.

**1.1 Basic needs insecurities.** Participants observed an increase in basic needs insecurities (ie, food, housing, and health services) among their clients as food banks had reduced their operations and had fewer supplies (see Table 2). Clients were also hesitant to go to grocery stores.

Associations concentrated their efforts on food assistance early on, which was a new support service for many associations. This was provided in the form of grocery gift cards, frozen meal deliveries, take-out lunches, and accompaniment to grocery stores. New services to address urgent financial, housing, and health needs were also provided by completing forms, booking appointments, finding transportation, accompanying clients to medical appointments, and picking up or dropping off documents at doctors' and lawyers' offices.

"We're still open and able to help people because housing, financial, and health crisis went through the roof, so just being able to provide all those supports [was important]." (Participant 9)

**1.2 Mental health challenges.** The pandemic also intensified mental health challenges for brain injury survivors. According to associations' representatives, clients experienced depression and anxiety, specifically related to fear of contracting COVID-19.

**Table 1.** Characteristics of Respondents and Associations (n=31).

Variables	Frequency (%)
Respondent's role in the association	
Executive director	24 (77)
Frontline worker	2 (7)
Coordinator of programs	5 (16)
Years of involvement in community brain injury association	
<10	16 (52)
10-20	10 (32)
>20	5 (16)
Association's location in Canada	
Nova Scotia	1 (3)
Newfoundland and Labrador	1 (3)
Quebec	4 (13)
Ontario	12 (39)
Manitoba	1 (3)
Saskatchewan	1 (3)
Alberta	3 (10)
British Columbia	8 (26)
Number of full-time staff prior to the pandemic	
0-5	19 (61)
5-10	4 (13)
11-20	5 (16)
>20	3 (10)
Number of part-time staff prior to the pandemic <sup>a</sup>	
0-5	25 (81)
5-10	6 (19)
Number of volunteers prior to the pandemic (n=25) <sup>b</sup>	
0-25	13 (52)
26-50	6 (24)
51-75	1 (4)
>75	5 (20)
Number of clients served prior to the pandemic (n=28) <sup>c</sup>	
0-150	6 (21)
151-300	8 (29)
>300	14 (50)

<sup>a</sup>Five associations reported the layoff of staff after the onset of the pandemic.

<sup>b</sup>Six participants answered "I do not know" for the number of volunteers prior to the pandemic.

<sup>c</sup>Three associations did not report the number of clients served by their associations prior to the pandemic.

"... a lot of fear and anxiety from our clients. One of the themes that kind of ran through it was, especially those that lived on their own, that when they were isolated from any supports within their natural support system..." (Participant 13)

Additionally, they experienced stress, confusion, and fatigue related to increased information processing requirements.

"The biggest effect that it had on the people we serve is that constant state of flooding, that information processing, that increased isolation which led to depression, I mean we had increased rates of suicide." (Participant 9)



**Table 2.** Themes, Subthemes, and Quotations.

Theme	Subtheme	Example quotations
1. Addressing evolving client needs	1.1 Basic needs insecurities	<p>"The effect of the pandemic really was on an individual's self-care and that's talking about isolation, access to food. Some people were having difficulty getting to previous programs that provided them with food." (Participant 21)</p> <p>"We had staff ordering groceries and having them delivered to our members, we had staff dropping off grocery cards, we had staff picking up and dropping off documents to doctors' and lawyers' offices, really taking the time to identify what the priority was, because there were so many things happening at once and making sure those basic needs were met first, and then kind of going from there." (Participant 16)</p>
	1.2 Mental health challenges	"The biggest challenge that we noticed was with the isolation, and fear, just because of the pandemic and being locked down. There was a lot of fear and just being afraid of the future, not knowing what was happening, and being alone to deal with that" (Participant 10)
	1.3 Adapting services	"... the pandemic, as for anyone, has been very hard on our clients, as they are very vulnerable. So, we had to change the way that we responded to their needs because their needs did change during the pandemic. We had to work a bit harder to reach out to these clients as we were no longer seeing them in person from week to week at our support groups and outings. So, we had to think of creative ways to reach out to the clients. We did this through implementing the wellness checks. We also implemented a buddy program, which involves pairing a volunteer up with a brain injury survivor, and they would contact them however they saw fit, whether that be through Zoom or a phone call, and just check in and see how they're doing and coping with the pandemic and what we, as an association, could do to better serve them." (Participant 4)
2. Keeping clients safe		<p>"It was so confusing, the information that we were receiving from the government. We're on, we're off, we're on, we're off, we're moving ahead, we're stepping back, so that really confused a lot of our clients." (Participant 10)</p> <p>"We had a lot of conversations over the last 2 years with the clients, with our clients, explaining, you know, what Covid is, and what the risks are, and, you know, healthy fear versus unrealistic fear, so that one was big, but we were super grateful for our counseling program at that time because then we could offer that remotely, or over the phone, to help them unpack that one a little bit." (Participant 12)</p>
3. Challenges and opportunities in navigating the digital world	3.1 Addressing the information and technology divide	"We worked with individuals who needed the education, bringing them a device, teaching them, setting it up for them. A lot of times we helped [them] navigate, like setting up home internet, and the securities for their home internet and those devices. And we offered ongoing ad hoc services. So, if one person really did not know how to use Zoom, then we work with them to help them sort out how to use Zoom. If somebody wasn't sure how to set up an email, answer or type emails, use talk-to-text technology, or things like that, we would help with that. So basically, wherever or whatever people needed we did... ." (Participant 24)
	3.2 Challenges and opportunities for brain injury associations	"Access for advocacy was so much easier because of the virtual. I was able to get meetings with actual MPs [members of parliament] and not just their policy staff. I found that, because of the virtual nature, they could take that half an hour and meet with me [ . . . ]. I found that really beneficial that we were able to get into people's ears and luckily that sounds like it's going to keep on going. [ . . . ] It used to be that you have to come to CI_P3 to meet with them or you'd have to meet with your MP in your writing, but now I was having access to MPs from across the country . . . ." (Participant 1)
4. Sustaining brain injury associations in the face of uncertainties and disruptions	4.1 Complying with public health guidelines	"Every time we called [public health authorities] to know a little bit what was going on, they had no clue either what's going on or what we had the right to do and didn't have the right to do. And they spent a lot of time arguing if we were essential or not for the population." (Participant 6)
	4.2 Supporting staff mental health	<p>"Some of our staff actually requested to be laid off because they didn't want to do frontline work anymore, so there is just a lot going on in that period." (Participant 12)</p> <p>"If you needed a mental health day, you took a mental health day. If you needed a mental health afternoon, that's what you needed to do to be able to do your job." (Participant 1)</p>
	4.3 Financial sustainability	<p>"Our main fundraising [activity] is a golf tournament. That's what generates our true income, and that didn't happen that year. So, yes, then, we just realized that we just have to do what we have to do, and we did it anyways. . . . we just carried on... ." (Participant 1)</p> <p>"... there was quite a bit of funding like COVID relief supports and things like that which were great, . . . but also when you're already trying to plan so much and have to apply for extra funding, and make sure you're meeting that specific criteria of funding on top of our all the other criteria for funding and have limited flexibility. . . it was a lot of. . . extra bureaucratic processes." (Participant 9)</p>
	4.4 Increasing networking between associations and community partners	"When you've got that direct connection [with a partner], when you've got that ability to communicate with the person and just say, "Hey, this is what's going on," that makes a huge difference. I think that's one of the successes that we saw in the pandemic. The investment in relationships makes a difference in those critical times. And yet, we're not funded to collaborate in a lot of ways." (Participant 25)

Their pre-existing life circumstances intensified the feeling of social isolation further restricted by COVID-related health policies, as explained by one participant:

"When the bubble mandate came out, like stick to your bubble, we noticed that a lot of our clients didn't have a bubble. And asking other people to come into their bubble - . . . those other people were already in a bubble. That was quite depressing, and

it highlighted for some of our individuals that they didn't have that, so their bubble consisted of themselves which was not good." (Participant 12)

Brain injury associations across Canada adapted their service delivery to address these needs by pivoting their services to remote delivery, over the phone, online, and, in some cases outdoor activities.

**1.3 Adapting services.** Associations implemented new ways of delivering services to ensure service/program continuation. Many pre-existing services usually delivered in person were pivoted to at a distance, that is, on the phone, online, or outdoors when allowed by public health authorities. Examples of outdoor activities and socially distanced services, such as distance visits, drumming sessions, meetings in parks, and door-step deliveries were mentioned by one participant:

“But that [meeting outside] was an interesting thing. [. . .] They gathered in the park in small groups. We scheduled somebody to come, a musician to play, this musician had written songs that we were using to help people create a dance [. . .] we had sort of a concert and dance session in the park in small groups.” (Participant 2)

Associations also shifted from group interventions to a more individualized type of support tailored to clients’ specific needs such as counseling services and case management, as mentioned by one participant: “. . . helping [clients] was more on an individual basis. Our executive director at the time would help people individually with any concerns over the public health guidelines [for example] . . .” (Participant 20)

This increased the ties between brain injury associations and clients and allowed them to take into consideration everyone’s specific needs.

“Basically, we didn’t do face-to-face meetings anymore, so [. . .] what changed was that we did a one-to-one call. We normally do social integration through the group, but we called people individually, so it increased the link with members, it was a follow-up that was hyper-individualized, so we knew a lot more about their personal lives. . .” (Participant 3)

In addition, associations expanded support and services to address mental health challenges, reduce isolation, check well-being, and identify needs. One participant stated:

“We did a lot of porch visits, wellness checks, where you were delivering a meal and checking to make sure that the clients were doing okay. . .” (Participant 2)

## Theme 2: Keeping Clients Safe

Another new role for community brain injury associations that arose during the pandemic was serving as a conduit of public health information for clients. Participants reported that clients living with brain injury were experiencing significant difficulties in understanding and adhering to COVID-19 public health recommendations, such as wearing masks properly and/or respecting physical distancing, thus increasing their risk of contracting COVID-19, and sometimes creating additional anxiety and fear (see Table 2).

COVID and public health-related information was often complex and not always written in language easily accessible to people with disabilities. Moreover, information was

frequently changing as understanding of the health impacts and COVID-19 disease grew. One participant said: “we’re hearing from people that the public health guidelines were causing a lot of confusion at the start because they’re not written in plain language, they’re written in some very medical technical language. There’s also confusion about the origins of COVID, there’s so much misinformation” (Participant 1).

Brain injury associations worked to identify, update, and translate COVID-related information and guidelines into plain language. They also provided clients with education about COVID-19 and sent reminders about the importance of adhering to public health restrictions:

“When I did the support groups I would just kind of provide (when I called or texted or emailed) [clients] with the reminders. I would remind them that you have to wear a mask, there’s going to be social distancing, and self-screen before going - things like that. And then the whole time at the meeting it was kind of the same. . . it was like gentle reminders all throughout the meeting. . . they just kept forgetting.” (Participant 7)

In some cases, misinformation coming from social media influenced clients’ behaviors and increased their infection risk as these clients questioned the validity of public health guidelines and refused to comply with them. Associations encouraged safe behavior and compliance with measures while trying to respect beliefs and degrees of adherence to measures.

“We would talk about science, we would use graphs that were provided by the regional public health, we’d try and clarify what is a YouTube source, Facebook source, versus the official CDC or Canadian, or the regional public health information. . . We talked about science evolving and what we thought at the beginning of the pandemic is changing and that doesn’t mean the science is wrong, but science is changing and so you learn from that and move on. . .” (Participant 21)

## Theme 3: Challenges and Opportunities in Navigating the Digital World

The urgent need for online delivery of services was new for most associations, resulting in both challenges and new opportunities for both clients and associations (see Table 2).

**3.1 Addressing the information and technology divide.** During the pandemic, internet-based technologies and remote services allowed associations to continue responding to client needs while respecting public health guidelines. However, cognitive impairments secondary to brain injury along with low levels of digital skills and digital literacy made it difficult for them to transition to a virtual format. Also, the limited financial resources of this population meant reduced access to adequate software, hardware, or broadband internet limited their access to the Internet.

It was, however, seen as a “high priority [for associations] to keep people connected.” (Participant 24). Associations “spent time putting together teaching materials that were aphasia friendly” (Participant 17) and provided clients with “technology devices and education, weekly chats, about how to use technology. . .” (Participant 21). Some also paid for phone cards and internet services “so they [clients] could attend appointments and virtual programming. . .” (Participant 24)

“We worked with individuals who needed the education, bringing them a device, teaching them, setting it up for them. A lot of times we helped [them] navigate. . . So, if one person really did not know how to use Zoom, then we [would] help them sort out how to use Zoom. If somebody wasn’t sure how to set up an email, or answer or type emails, use talk-to-text technology, things like that, we would help with that.” (Participant 24)

**3.2 Challenges and opportunities for brain injury associations.** During the transition to online services, associations that had offered online services prior to the pandemic were in a better position and adapted to online delivery more readily. For other associations, the transition was more complicated and time-consuming. Remote work was even harder for staff who were themselves brain injury survivors.

To account for the pivot to online services, brain injury associations increased their staffing by hiring paid collaborators and recruiting volunteers on an ad hoc basis (eg, COVID-navigator, tech trainer, online event facilitator, speaker).

Online communication and virtual services/programs allowed associations to extend the geographic boundaries of services, specifically to small communities and rural areas, thanks to which attendance for services increased and participants reported feeling less isolated. For those clients with online communication issues, brain injury associations offered “low tech” solutions, such as support groups and individualized support services over the telephone, and outdoor socially distanced services, like porch visits, deliveries, or small walking groups.

#### **Theme 4: Sustaining Brain Injury Associations in the Face of Uncertainties and Disruptions**

Uncertainties and disruptions in services arose as a direct result of the pandemic. Participants commended the resilience of their staff and volunteers during the evolving changes in public health measures and increases in demand for services.

**4.1 Complying with public health guidelines.** The first year of the pandemic was a difficult period for brain injury associations to make decisions and change services in their efforts to maintain their role and meet client demands. This was, in part, related to limited and sometimes unclear public health guidance. Non-essential work was suspended, but guidelines were unclear as to whether health non-profit organizations

were recognized by the government as essential service providers. One participant mentioned:

“Every time we called them [public health authorities] to know a little bit what was going on they had no clue either what’s going on or what we had the right to do and didn’t have the right to do and they spent a lot of time arguing if you were essential or not for the population and I guess every organization should be essential for their clients [ . . . ] no matter what.” (Participant 6)

**4.2 Supporting staff mental health.** Managing staff mental health became a priority during the pandemic, including managing anxiety, fatigue, isolation, and fear.

To support staff’s well-being and work-life balance, associations implemented wellness days, where staff were given paid time off work, reduced work hours, and introduced flexible time to facilitate remote work.

“If you needed a mental health day, you took a mental health day. If you needed a mental health afternoon, that’s what you needed to do to be able to do your job. And we kept the flexible work hours. . .” (Participant 1)

**4.3 Financial sustainability.** Even prior to the pandemic, financial precariousness was a major issue for many brain injury associations. Loss of traditional revenue sources such as fundraising events, new COVID-related expenses, and limited flexibility of new government funding opportunities threatened financial viability and increased organizational pressures.

“[The pandemic] impacted the organization through a loss of funding as well, so that was a pretty significant challenge [ . . . ] due to the reduction from our funder, but also the lack of opportunity to fundraise, and so that has impacts on clients. . .” (Participant 11)

Associations applied for COVID-19 funds released by the Canadian government, pivoted fundraising activities to online and/or hybrid options, and redirected funds to new purposes as noted by one participant: “. . . instead of spending the money, I guess, on group activities, we were trying to route it in crisis intervention and basic needs and services.” (Participant 1)

**4.4 Increasing networking between associations and community partners.** To survive the challenges presented by the COVID-19 pandemic, brain injury associations increased collaborations amongst themselves and with other community partners and service providers. These new partnerships allowed for faster and more effective responses to crisis situations to protect the most vulnerable populations (Table 2).

“. . . When you need to make decisions quickly, you need to be able to trust each other, and where there was trust there was some quick action [ . . . ] It really made a difference when we had those established relationships with different organizations, with different community stakeholders.” (Participant 31)

## Discussion

This is one of the first studies to highlight the new challenges brought by the COVID-19 pandemic to people living with brain injury and to community brain injury associations that are tasked with helping to meet the health and wellness needs of the people they serve. Findings revealed that associations across Canada were very proactive, rapidly changing the way they delivered services. They pivoted to online supports, and implemented a wide range of adapted services, particularly to address public health information provision and instrumental support for people living with brain injury, which sometimes went beyond the original scope of their mandates. This is notable given that they were operating under financial and human resource constraints both before the pandemic and even more pronounced during the pandemic.

The results presented here emphasize how community brain injury associations became and remained vital in addressing public health issues for a particular segment of the Canadian population. The COVID-19 pandemic has worsened chronic physical, cognitive, mental, and behavioral sequelae for people living with a brain injury due to disruption in healthcare services during the pandemic.<sup>8,15</sup> A survey study of 45 key representatives from brain injury associations across Canada echoes these findings with participants noting that social isolation, loneliness, boredom, anxiety, and depression were frequent psychosocial challenges experienced by people living with brain injury during the COVID-19 pandemic.<sup>16</sup> This vulnerable population also experienced increased challenges related to personal finances, social support, and daily living during the pandemic.<sup>4,5</sup> Indeed, our results show that clients' specific needs related to basic finances, food, and housing increased during the first year of the pandemic. These findings are consistent with emerging literature on the experiences of people with disabilities<sup>6,24-26</sup> and disability organizations based in other countries highlighting the unequal impact of COVID-19 on people living with disabilities.<sup>6,27,28</sup> The pandemic has shown the increasing development and use of technology. With protective measures in place, like other non-profit organizations, brain injury associations across Canada started to offer support services online, which increased outreach to clients but also highlighted disparities related to technological accessibility.<sup>29,30</sup> Our findings showed that some clients living with brain injury have difficulty accessing the online programming available at the onset of the pandemic. Brain injury associations worked to reduce the digital divide among individuals with disabilities by providing their clients with devices and teaching materials, as well as financial support to buy devices or pay for internet plans. For those with poor internet connection, they offered support services over the telephone. Given that online programming offered by associations has been a good alternative to reach and support people suffering from brain injury during the pandemic, it is important to ensure that this population

receives adequate training and has the necessary resources to have equal access to support services in the event of a future public health crisis.

Similar to other non-profit organizations around the world, associations across Canada provided a vital support to their clients during the pandemic, often filling in the gaps in mainstream service provision while lacking recognition as essential service providers.<sup>27</sup> Since the onset of the pandemic, associations provided extra support services to address the technological issues experienced by clients which created challenges for associations as staff and volunteers had to increase their workload to develop new resources.<sup>30</sup> Participants reported increased stress and well-being challenges among staff in trying to meet the service and support the new and emerging needs of clients. This points to the importance of mental health for the sustainability of organizations and the need to "help the helpers" as well as clients. Brain injury associations and other not-for-profit groups need to attend to the mental health of their own workers and volunteers as a critical aspect of sustainability in addition to financial resources.

COVID-19 also revealed increased operational challenges for many associations during the first year of the pandemic.<sup>27</sup> In fact, our findings suggested additional gaps for brain injury associations, particularly around workforce capacity and financial resources. To mitigate against high rates of staff turnover, which has been reported as challenging in other Canadian sectors,<sup>31</sup> non-profit associations need greater attention to capacity and ways to protect against burnout. Brain injury associations participating in the present study acknowledged the time and emotional investment that was required from their staff during the first year of the pandemic. At the same time, many associations are small and rely considerably on volunteer engagement. More attention to strategies that may be helpful to small community associations is needed, especially in times of crisis.

The COVID-19 pandemic also threatened the financial viability of brain injury associations like other non-profit associations across Canada.<sup>32</sup> Corroborating with our findings, many community associations in different countries also reported losing income due to the disruption of fundraising activities.<sup>27</sup> In Canada, federal and provincial governments released COVID-19 emergency funds that helped to keep associations viable. However, our results show that associations had difficulty accessing the funds which led to new administrative burdens. Looking to the future, more advocacy efforts are needed to work with governments to address the need for and access to emergency funds that would improve accessibility and adequate funding for brain injury and other disability groups. Associations should also develop a strategic financial plan to help them face the impacts of future pandemics.<sup>33</sup>

Finally, the COVID-19 pandemic highlighted the need for disability-inclusive preparedness.<sup>2,34,35</sup> Policymakers, public health authorities, service providers, and researchers need a



proactive collaboration with people living with disabilities, their support network, and advocates to ensure the development of disability-inclusive solutions to overcome barriers encountered during health crises.<sup>10,27</sup> This would enable community associations to be better prepared and empowered to play a more prominent role in the ongoing support of people living with disabilities.<sup>27</sup> Our study provides evidence for the value of brain injury associations in providing emergency response at the community level that is tailored to the diverse needs of people living with brain injury, their families, and caregivers.

## Limitations and Future Research

While this study shows the impact of the COVID-19 pandemic on community brain injury associations across Canada and provides in-depth knowledge of their actions in response to the pandemic, it has some limitations that need to be highlighted. First, although we had a wide representation of brain injury associations across Canada and reached saturation in our data, the provinces were not represented in proportion to their total number of associations (Table 1). Second, when participants were asked (question 1—Supplemental Appendix 1) about the reality of the association (large, small, more aging people, men/women, LGBTQSA2+, indigenous, etc.) they did not provide enough information about their clientele. Therefore, further studies are needed to investigate whether associations offer personalized services to specific groups of people living with brain injury, such as the indigenous population and the LGBTQSA2+ community, as well as the effects of the pandemic on these subgroups. Third, our findings are from the lens of key representatives of brain injury associations, so the challenges experienced by brain injury survivors, their families, and caregivers are reported by them. Future research needs to gather the perspectives of people living with brain injuries, their families, health care professionals, and other stakeholders in Canada. Finally, the lingering effects of the pandemic and the uniqueness of people living with brain injury need to be considered in future research to address the emerging needs of this population. Going forward, additional community-based participatory research including vulnerable populations is needed to better support their clients in times of crisis.

## Conclusion

Our findings show the challenges faced by community associations across Canada as well as by people living with brain injury during the first year of the COVID-19 pandemic. We highlight the critical role played by these associations specifically in addressing the emerging needs of clients, ensuring their safety, and distilling public health information. Associations also worked to reduce the digital divide by finding ways to use technology with a brain-injured population, and the sustainability of brain injury associations. Various brain injury associations have created new management strategies to sustain themselves and meet these new and evolving needs. These findings are useful not only to brain

injury associations in thinking about pandemic preparedness, but also provide guidance to other not-for-profit groups in planning for the future.

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## Author Contributions

CB and LE are the principal investigators on the grant obtained to run this study. AS, SL, LE, MAMG, SR, SZ, MM, and CB, were involved in the study design and development of focus-group questions. AS and SL analyzed the data. AS, SL, LE, MAMG, SR, SZ, MM, and CB critically discussed the results. AS wrote the initial draft of the manuscript. SL and CB provided feedback on the first draft of the manuscript. All authors made edits and contributions to the final draft and approved the final version of this manuscript.

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## Ethics Approval

The study was approved by the Centre for Interdisciplinary Research in Rehabilitation of Greater Montreal (2022-1424) Ethics Committee.

## Consent to Participate

All participants provided informed consent to participate prior to completing the survey. All methods were carried out in accordance with relevant guidelines and regulations.

## ORCID iDs

Ana Paula Salazar  <https://orcid.org/0000-0001-7106-1167>

Lisa Engel  <https://orcid.org/0000-0002-3208-9850>

## Supplemental Material

Supplemental material for this article is available online.

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