



RESEARCH ARTICLE

# Exploring experiences and changes in daily and social activities among individuals with spinal cord injury during the COVID-19 pandemic: A longitudinal study

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## ABSTRACT

**Objectives:** To explore experiences and changes in daily and social activities among individuals living with spinal cord injuries over the first 9 months of the COVID-19 pandemic.

**Materials and methods:** In this longitudinal qualitative study, data were collected by conducting semi-structured interviews with participants at four time points (June 2020, July 2020, August 2020, January 2021). Data were analyzed longitudinally using a recurrent cross-sectional approach.

**Results:** The 22 participants had a mean age of 54 years, 13 were male. We identified three main themes: 1) 'Dealing with the emotional impact of pandemic-related restrictions' explored feelings of frustration, sources of anxiety, and the importance of adopting a positive mindset; 2) 'Changing daily routines' described aspects of normal routines that changed and ways of adapting to those changes; and 3) 'Revisiting social engagement' conveyed the struggles caused by a lack of social engagement and coping strategies to overcome them.

**Conclusion:** This study explicates the changes experienced by the SCI community during various points of the COVID-19 pandemic. Participants discussed feelings of frustration, anxiety, and gratitude. They described changes, challenges, and strategies used when navigating life during the pandemic. These findings can facilitate future research to address the challenges faced by this population.

**Keywords:** spinal cord injury, COVID-19, pandemic, experiences, changes, longitudinal

## Introduction

The COVID-19 pandemic has had a profound global impact. To restrict the spread of the virus, countries implemented various safety protocols, including physical distancing policies, mask mandates, and travel restrictions<sup>1</sup>. As a result of these restrictions, people experienced widespread changes to daily life and community participation, including access to transport, employment, schooling, and social engagement<sup>2,3</sup>. For example, the COVID-19 pandemic restrictions have resulted in significant declines in physical activity, leisure, socialization, and education<sup>4-6</sup>.

In the early stages of the COVID-19 pandemic response, global health organizations, such as the World Health Organization and the United Nations Foundation, provided comprehensive guidelines to countries on outbreak management and health service delivery. These guidelines included infection control practices, risk communication, travel advice, and strategies to mitigate health system collapse<sup>7</sup>. In addition to global recommendations, multiple precautionary measures were implemented in Canada. In the province of British Columbia, an initial four-phase plan to restart the province safely was introduced in mid-May of 2020<sup>8</sup>. The first phase (mid-May to mid-June 2020) included mandatory 6-foot physical distancing guidelines, postponing non-urgent medical surgeries, closing of non-essential services, and imposing quarantining requirements to decelerate the spread of COVID-19. During this phase, cases of COVID-19 were primarily reported among older adult populations<sup>9</sup>. The second phase (mid-June to mid-July 2020) permitted small social gatherings, resumption of non-essential surgeries, and the re-opening of provincial parks and non-essential businesses to the public with strict safety operation plans in place. The third phase (mid-July to September 2020) allowed for further re-opening of service-based businesses including movie theatres, spas and salons, and hotels under strict safety operations. During the second and third phases, new cases of COVID-19 shifted to being predominantly reported among young adult populations<sup>9</sup>. The intent of Phase 4 (September 2020 onward) was to allow public gatherings of large groups and international tourism, however, a halt to the phases occurred at this time with the reimplementation of mask mandates in public indoor settings and quarantine requirements for travel due to an increase in COVID-19 cases in the province.

People with disabilities, such as spinal cord injury (SCI) have been greatly impacted by pandemic restrictions. Among individuals with mobility disabilities, a study found that restrictions negatively impacted relationships with family and friends, access to groceries, transportation, and employment<sup>10</sup>. The COVID-19 pandemic may have also introduced new issues for this population, such as increased health risks and ambiguity about the future. For example, individuals with SCI may have had limited access to medical care, which contributed to problems with essential self-management activities (e.g., pain management)<sup>11</sup>. Additionally, individuals had to cope with the uncertainty of constantly evolving COVID-19 safety regulations. It has not been all negative, however, as individuals with SCI have appreciated and benefitted

from the increased adoption of online medical appointments and shift to virtual work<sup>12</sup>. Recognizing the unique pandemic-related experiences of individuals with SCI, we previously conducted a cross-sectional study exploring their COVID-19-related lived experiences<sup>12</sup>. The results of that paper highlighted three themes: Experiencing changes to mobility and daily life described the impact of regulations on everyday life and usual routines, particularly relating to mobility; Struggling with new challenges explored various negative ramifications and experiences associated with the pandemic; and being resilient in the face of a new normal conveyed how participants exhibited resilience despite challenges<sup>12</sup>.

As the COVID-19 pandemic is ongoing and dynamic, it is important to continue to monitor and explore participants' experiences longitudinally. Therefore, the objective of this study was to explore experiences and changes in daily and social activities among individuals living with SCI over the first 9 months of the COVID-19 pandemic. Greater understanding of their experiences can also inform future public health strategies for related events.

## Materials and methods

Data were collected as part of a larger, longitudinal mixed-methods project capturing the impact of the COVID-19 restrictions on individuals with various disabilities, families, and older adults<sup>13</sup>. This qualitative descriptive study longitudinally explores the experiences and changes in daily and social activities among individuals with SCI during the COVID-19 pandemic<sup>14</sup>. Ethical approval was obtained from the Vancouver Coastal Health Research Institute and the University of British Columbia's (UBC) Behavioral Research Ethics Board (H20-01109). All participants provided written consent. Qualitative findings were reported in accordance with the Standards for Reporting Qualitative Research guidelines<sup>15</sup>.

### PARTICIPANTS

In order to be included in the study, participants needed to be (1) Canadian, (2)  $\geq 19$  years of age, (3) comfortable with written and spoken English, (4) able to gain access to technology and the internet, and (5) living with a SCI. Individuals were excluded, after a brief screening interview, if they had moderate to severe cognitive impairments that inhibited internet use. Participants were recruited via (1) online postings at the International Collaboration on Repair Discovery and through Vancouver Coastal health e-blasts, (2) a list of previous research participants who have consented to being contacted for future studies, (3) using study researchers' social media pages, and (4) via word of mouth. Eligible participants who expressed interest were sent further information and provided their written informed consent electronically.

### DATA COLLECTION

A total of 22 participants were recruited for this study between 1st April – 31st May 2020 (Table 1). Data were collected by conducting semi-structured interviews at four time points (T1: June 2020; T2: July 2020; T3: August 2020; T4: January 2021) using the videoconferencing platform, Zoom. Participants were recruited at a 100%

retention rate across all four time points. Three interview guides were created: one for T1, one for T2-T3, and one for T4. Each interview explored experiences and changes related to topics such as daily activities, socializing, and coping strategies. Example interview questions included:

What is a typical day like for you right now?

How, if at all, has COVID affected what a typical day is like for you?

What activities are you doing to connect with others?

Is there something that you think is unique about your life that has influenced your COVID experience?

All interviewers were extensively trained by the lead investigators of this study (WBM and WCM) and interviewed the same participants across all four time points to facilitate rapport and ask relevant follow-up questions. The interviews were recorded using UBC secure Zoom accounts and on a voice recorder. All interviews were transcribed verbatim and any identifying information was replaced with pseudonyms to ensure participant anonymity and confidentiality. All data were stored in password-protected files on a secure UBC server. Participants received an honorarium of \$30.00 after each interview.

#### DATA ANALYSES

Data were analyzed longitudinally using a recurrent cross-sectional approach outlined by Grosseohme and Lipstein<sup>16</sup>. Coding was conducted after data collection was completed for all participants for all four time points. First, a codebook was developed from the coding of the data from T1 and applied to the subsequent data at timepoints T2, T3, and T4. Codes were added to the

codebook throughout the analysis of the four timepoints following an iterative process. Second, the codes were grouped together to generate sub-themes and themes. Last, the sub-themes and themes were compared at each time point, highlighting the differences and similarities between each theme. Furthermore, time-ordered sequential matrices were generated to understand the chronological flow of participants' overall changes in daily experiences and social activities at four distinct time points throughout the COVID-19 pandemic. Theoretical sufficiency was achieved with the 22 interviews at each timepoint<sup>17</sup>.

Two main trustworthiness strategies were employed including reflexivity and the involvement of multiple researchers. Researchers (GS, ES, and RM) involved in the longitudinal qualitative analysis coded and analyzed transcripts at each time point independently, along with engaging in regular meetings with the principal investigator (WBM) to debrief, reflect, and reach consensus on the data and study findings. To promote reflexivity interviewers recorded notes and memos about the interviews and their interactions with participants. Data collection and initial analysis were conducted by the three co-authors (GS, ES, and RM) who all have extensive experience in qualitative data collection and analysis. GS is a male with an academic background that focuses on researching mobile health apps for individuals living with SCI, ES is a male with an academic background in kinesiology exploring the means to improve wellbeing and quality of life, and RM is a female with an academic background in neuroscience and psychology with a focus on traumatic brain injury.

#### Results

The demographic information of the 22 participants is outlined in Table 1; they had a mean age of 54 years, and 13 were male.

**Table 1.** Demographic data of study participants (N=22)

Demographic Factor		X ± SD or n (%)
Age	Years	53.77 ± 11.07
Sex	Male	12 (55)
	Female	9 (41)
	Prefer not to answer	1 (4)
Gender	Man	12 (55)
	Woman	9 (41)
	Prefer not to answer	1 (4)
Household Income	Less than \$15,000	2 (9)
	\$15,000 to \$44,999	5 (23)
	\$45,000 to \$74,999	6 (27)
	Greater than \$75,000	3 (14)
	Prefer not to answer	6 (27)
Employment Status	Employed	8 (36)
	Disability assistance	7 (32)
	Unemployed	1 (4)
	Retired	5 (23)
	Other	1 (4)
COVID-19 Employment Impact	Shifted to working from home	4 (44)
	Reduced work hours	2 (22)
	Laid off	1 (11)
	No change	2 (22)
Time living with disability	Since birth	2 (9)
	Since childhood	1 (4)
	Since adolescence	4 (18)

Demographic Factor		X ± SD or n (%)
	Since adulthood	6 (27)
	Later in life	9 (41)
Provide care	Yes	2 (9)
Receive care	Yes	8 (36)
Injury type	Complete	7 (32)
	Incomplete	14 (64)
	Prefer not to answer	1 (4)
Diagnosis	Paraplegia	10 (45)
	Tetraplegia	6 (27)
	Other (e.g., spina bifida)	6 (27)
Ambulatory status	Ambulatory	3 (14)
	Non-ambulatory	16 (73)
	Other	3 (14)
Co-morbidities	Anxiety	6 (27)
	Chronic pain	11 (50)
	Depression	5 (23)
	High blood pressure	3 (14)
Assistive Device(s)	Power wheelchair	8 (36)
	Manual wheelchair	16 (73)
	Scooter	2 (9)
	Walker	7 (32)
	Other	3 (14)
	None	1 (4)
Tested positive for COVID-19	Yes	0 (0)

We identified three themes that spanned the four time points. The themes were: (1) dealing with the emotional impact of pandemic-related restrictions, (2) changing daily routines, and (3) revisiting social engagement. Each theme consisted of 2 sub-themes with 3-7 codes in each. Table 2-4 illustrates the changes in these codes across time points. When reporting each theme below, the focus was primarily placed on the codes that changed at one or more time points, as indicated by the symbols in Table 2-4. Themes, subthemes, and codes were labelled using first level (i.e., 1, 2, 3), second level (i.e., 1.1, 1.2, etc.), third level (i.e., 1.1.1, 1.1.2, etc.) headings, respectively (Tables 2-4). Participants were identified using a numbering system (e.g., P1, P2, etc.) in addition to the time point they were interviewed (i.e., T1, T2, T3, or T4).

#### DEALING WITH THE EMOTIONAL IMPACT OF PANDEMIC-RELATED RESTRICTIONS

In the first theme, participants described frustration with the behavior of others and the consequences of the restrictions, along with sources of anxiety stemming from the virus and/or evolving situations around them. They also discussed the importance of adopting a positive mindset in order to promote personal wellbeing and to help others around them (Table 2). Within the first sub-theme (1.1), 'feeling frustrated and anxious', we identified two codes that changed over time (1.1.1 and 1.1.2). Code 1.1.1 was not present at T1, but emerged at T2 and T3, when participants described feeling the

impact of the COVID-19 pandemic on their lives. A participant explained how life had become tedious:

And now it's almost more like a chore you know, oh man I have to do this, I'm losing a lot of [...] that character if you want, a lot of life, interest in doing stuff. Now it's more like what day is it, do I have anything to do today. I don't like it, but that's the way it is. (P03-T2)

By T4, participants expressed criticism and exasperation with the authorities in charge of public health, as noted by a participant's frustrations with the government not being proactive enough:

I'm just fed up with it. I'm really mad with the government because they didn't put stronger restrictions on people traveling into our country and spreading it. In fact, I heard Quebec and Ontario, they have some restrictions. They cannot go out at night or whatever, so [...], I hope, [...] BC will not be like Ontario and Quebec. (P05-T4)

Participants highlighted their increasing frustrations that more restrictions should have been enforced earlier in the pandemic. Participants expressed that the consequential fear of more severe restrictions being implemented contributed to the COVID-19 fatigue that was experienced throughout the first year of the pandemic.

**Table 2.** Illustration of codes over time for the first theme

Theme	Sub-theme	Code	T1	T2	T3	T4
1 Dealing with the emotional impact of pandemic-related restrictions	1.1 Feeling frustrated and anxious	1.1.1 Experiencing COVID-19 fatigue	NP	I	X	Δ
		1.1.2 Feeling anxious about the foreboding situation around them	I	Δ	Δ	X
		1.1.3 Feeling anxious about themselves	I	X	X	Δ
		1.1.4 Having frustrations inside the home	I	X	X	X
		1.1.5 Having frustrations outside of the home	I	X	X	X
	1.2 Adopting a positive mindset	1.2.1 Empathising with others and being mindful	I	X	X	X
		1.2.2 Expressing enhanced gratitude and appreciation	I	Δ	Δ	Δ
		1.2.3 Thinking about life post-pandemic	NP	NP	NP	I
		1.2.4 Trying to stay mentally healthy and active	I	X	X	X
		1.2.5 Trying to stay positive	I	X	X	X

(NP = code not present; I = initial presentation of code; Δ = change in code; X = no change in code).

The second evolving code, 1.1.2, described aspects of the pandemic that were potentially outside their control and caused anxiety. As COVID-19 was still relatively new at T1, many sources of anxiety related to factors of uncertainty, such as the constantly changing information, the actual magnitude of the pandemic, and the vast overlap between COVID-19 symptoms and symptoms of other illnesses like the common cold. By T2, initial causes of anxiety had been replaced by concerns about the longevity of the pandemic and the importance of minimizing the spread of the virus. A participant expressed their concerns about border travel:

Crazy, keep the borders closed for the rest of the year, they're contemplating whether to open the Canada US border again this month. Crazy, just it would be suicide. That's my opinion, unless it's essential travel, don't need to travel. If they're serious keep the borders closed (P17-T2)

At T3, some participants described experiencing continued unease with conflicting feelings about lockdowns, for example, while participants were reluctant to stay indoors, they understood its necessity. A participant conveyed their fear of losing outdoor activities as the weather changed from summer to winter:

In the end of summer, summer activities are becoming less frequent and less possible because of rain, so I'm hoping that we won't have another situation where they close down all the stuff indoors and the outdoors is not available. And then you're basically left with staying at home, I hope that doesn't happen. I hope the city finds a way to find ongoing activities after the end of summer. I really don't look forward to winter sitting at home. (P03-T3)

Comments at T4 followed the same trend as T3, including statements that the media was not helping to reduce anxiety.

As shown in Table 2, there were three codes in the first sub-theme (1.1.3 – 1.1.5) that did not show substantive change. Code 1.1.3 mainly consisted of feelings of anxiety and concerns in both contracting and spreading the virus. Code 1.1.4 entailed the challenges of cohabitation, with people staying at home more and hence experiencing the challenges of varying views

within a household. Code 1.1.5 was broader and mainly covered frustrations with others not adequately following guidelines.

In the second sub-theme, 1.2, 'adopting a positive mindset', we noted one changing code. At T1 and T2 of code 1.2.1, participants expressed gratitude and reported appreciation for organizational structures, such as the government, health authorities, and health protocols, as described by P23:

I think we can pat ourselves on the back and our governments has done fantastic and our health system. [...] we're in Canada, we have that overall umbrella federal health as well. And I think we're very, very, very lucky again considering, not to be trite but, [...] just 100 kilometers south of us, they're having huge problems like crazy problems and even though we have less population, the numbers don't match. I mean they're different societies, and I'm very thankful that we're living in ours, so thankful. (P23-T2)

At T3, many participants reported a shift in gratitude, focusing more on their personal lives. For example, a participant reflected on the importance of being grateful:

The other thing I've been practicing is gratitude. [...] even though I'm a quad and I have all kinds of things wrong and pain and I mean, I could focus on a lot of the negative things, but, [...] there are still people who are worse off. So, I try to focus on the thing I'm grateful for, which really helps... I've got a roof over my head. I'm pretty sure that I'm gonna have food and a roof and clothing, and more than I need actually through the winter. When you look at the way other people are suffering, I wouldn't even just say around the world, even in our own backyard. (P14-T3)

By T4, participants voiced that they were appreciative for the way they had been able to adapt to their new pandemic life:

Despite my spinal cord injury, you know, we've managed to carve out a lifestyle that works for

us at this stage. I wouldn't have welcomed it when I was 32 but, you know, I was well into my sixties when this thing happened. So, you kind of deal the hand that's dealt to you, and you make the best of it, and your attitude reflects your altitude. (P24-T4)

Although the foci of gratefulness have shifted during the pandemic, participants described a consistent increase of gratitude since the start of the COVID-19 pandemic.

In this second sub-theme, four codes had little change (1.2.2 – 1.2.5). Code 1.2.2 demonstrated participants being empathetic towards people in different situations to them and concerned for their welfare. Code 1.2.3, which was only present at T4 described participants who started to think about life post-pandemic. Code 1.2.4 explored how people tried to stay mentally healthy and active by using brain stimulating games, reading, online courses, and meditation. Lastly, code 1.2.5 expressed the importance of staying positive and how to do so.

**CHANGING DAILY ROUTINES**

The second theme identified aspects of participants' normal routines that had altered, such as work, chores, travel, perception of time, and medical adjustments. It also identified ways of adapting to those alternations, which included planning, adjusting, using prior experiences, and following guidelines (Table 3). Within the first sub-theme (2.1), 'recognizing the changes to normal routine', we identified four codes that changed over time. Between T1-T3 of code 2.1.1, participants largely focused on the changes in interactions with caregivers and the transition to online healthcare appointments. By T4, participants had mostly adjusted to these changes, however, having already experienced the

first wave of the COVID-19 pandemic, participants were now more concerned at how potential restrictions would impact their medical treatments, as described by P09:

A little bit nervous come Friday because people are speculating there's gonna be some possible changes in terms of restrictions. So, I'm hoping that that doesn't impact my medical treatment, because I had about three months where we're in lock down and I had no medical treatment whatsoever. (P09-T4)

Code 2.1.5 showed more change across time points. At T1 and T2, participants discussed having to cancel trips and being unable to enjoy holidays they had been looking forward to. A participant reflected:

My family just made plans to go to the island like even before Covid-19, before usually we would try to get further away than that. Um but it's always when you can't go that you miss it the most. (P03-T2)

At T3, the disappointment of canceling trips had shifted to not wanting to travel in the midst of the pandemic, even if it was allowed, as described by P14:

I was the first one in the group to say we're not, I'm not going. First of all, [...] look at how many people are getting sick flying on the plane and then Florida is not the best place to be right now. And neither [are] the cruise ships. (P14-T3)

By T4, participants still missed traveling but were generally unsure when or if they would be able to travel in the future.

**Table 3.** Illustration of codes over time for the second theme

Theme	Sub-theme	Code	T1	T2	T3	T4
2 Changing daily routines	2.1 Recognizing changes to normal routine	2.1.1 Adjusting to medical system changes and changes in caregiving	I	X	X	Δ
		2.1.2 Experiencing changes in work-life and education	I	X	X	X
		2.1.3 Experiencing some lifestyle changes to normal routine	I	X	X	X
		2.1.4 Experiencing some lifestyle changes with daily chores	I	X	X	X
		2.1.5 Experiencing some lifestyle changes with travel and transportation	I	X	Δ	Δ
		2.1.6 Experiencing time differently during the pandemic	I	X	Δ	Δ
		2.1.7 Having disability related struggles	NP	I	Δ	Δ
	2.2 Adapting to changes in daily life	2.2.1 Considering planning and preparing essential	I	X	X	X
		2.2.2 Experiences changes to traditions	NP	NP	NP	I
		2.2.3 Relying on previous experiences	I	X	X	X
		2.2.4 Starting to do old activities again	NP	I	X	Δ
		2.2.5 Staying up to date with potentially stressful information	I	X	X	X
		2.2.6 Trying to follow COVID-19 precautions and guidelines	I	X	X	X
		2.2.7 Trying to stay physically healthy and active	I	X	X	X

(NP = code not present; I = initial presentation of code; Δ = change in code; X = no change in code).

For code 2.1.6, T1 and T2 had participants describing how time felt different during the pandemic, with individuals feeling less busy. There were conflicts, however, with some participants feeling like they had extra time to do things whereas others felt that time was

dragging on. A participant described how they tried to spend their time:

Try to kill a couple hours and I'll either read or go on Twitter or whatever. Watch TV. And read. And that's pretty much it. Just kill time. (P02-T2)

By T3, participants were being more focused with their time on activities such as work and family. A participant, for example, used their extra time to make some home improvements:

With all this extra time, I've [...] ended up getting a new standing chair, so I've taken delivery of that. [...] This computer I'm on now is a new laptop, I actually finally got on that. My desktop finally died. You know, took the opportunity to turn my computer room into more of a library. [...] And just ordering a bunch of other pieces of equipment: bath, bench, and all this stuff that... little projects that I [...] hadn't dealt with, that now I've got the time where I'm around, and I've got time to book the appointments. (P01-T3)

Similarly, at T4, participants had settled into and understood their new realities, finding ways to stay occupied.

Code 2.1.7 was not present at T1 but across T2-T4 it highlighted crucial examples of SCI-specific challenges faced during the pandemic. A participant listed some of the problems they faced as a wheelchair user:

Not only do we touch our wheels, which have touched the ground, but we're at a lower stature so that somebody who talks to us or sneezes above us, all those droplets will fall on us. [...] So we do have to be a little more careful because of that. [...] There's a lot of worry, I think as a disabled person. Not to mention the fact that spinal cord injury people, when they're high spinal cord injuries, often will have poor ability to cough. Which means that if we were to get the virus [...], then we might have more difficult time recuperating. (P10-T2)

Regarding accessibility, a participant explained how travelling on busses or other transit options can be stressful:

And I know [with the segregated, accessible transportation system], one of my friends, it's really stressful because the drivers are supposed to wear masks and you know not like touch you more than necessary, like just do the minimal but a lot of people aren't wearing their masks and she just finds it really stressful. Yea. So, she always reports the people but it's like just annoying right. (P08-T3)

One of the most notable issues was that participants with minimal hand function often relied on their mouth as an extra tool, and this increased their risk for COVID-19 susceptibility:

One of the biggest things I've found is struggling to not use my mouth for everything, which is kind of what with limited hand function, I just you know, the first thing I do is grab my keys with my mouth to separate the key, you know, and it may not be the best thing to do at the best of times, but, you know, it's just a necessity. And so, I've really struggled. (P01-T4)

Across this code, participants highlight societal reactions to their disability have increased their risk of exposure, susceptibility, and accessibility limitations.

There were three codes in this sub-theme with minimal change (2.1.2 – 2.1.4). Code 2.1.2 explored the impact of the pandemic on work and education, such as the shift to remote working. Code 2.1.3 looked at changes to normal routines, such as spending more time at home. Lastly, code 2.1.4 explored changes to daily chores, such as going shopping at different times to avoid busy periods.

The second sub-theme (2.2), 'adapting to changes in daily life', had one code with a distinct change related to reengaging with pre-pandemic activities. Code 2.2.4 was not present at T1, but at T2 and T3, individuals started doing old activities again, specifically with an increase in sporting options. A participant recited some of their plans:

They reopened [adapted] kayaking. And I think the sailing also the beginning of July. I know I've got [adapted] sailing booked for the end of July and one for the end of August. (P20-T2)

As summer had turned to winter by T4, participants returned to indoor activities. Participants talked about how they felt they had fewer options due to the cold, started losing interest in activities, and potentially felt unsafe doing the indoor activities that were still available. A participant voiced this latter concern by saying:

I'm seeing lots of people in [the gym], especially the guys, [...] because some of them have got good arm use, right? So, they're on the machines and they're like, huffing and puffing and yeah, everyone has a mask on I guess, but [...] it wouldn't be enjoyable. (P05-T4)

This code showed the substantial impact that weather can have on the availability of activities for participants. There were six codes with negligible change (2.2.1 – 2.2.3, 2.2.5- 2.2.7). Code 2.2.1 covered the need to prepare and stock on essentials during the pandemic. Code 2.2.2 was only present at T4, following winter seasonal celebrations. Code 2.2.3 explored how participants used experiences prior to the pandemic to help them cope. Code 2.2.5 described how participants engaged with the media and stressful news related to COVID-19, and how they were generally disappointed with the coverage. Code 2.2.6 listed general COVID-19-related precautions participants followed, such as mask wearing, hand washing, and physical distancing. Code 2.2.7 illustrated ways in which participants managed to follow a healthy diet and be physically active.

#### REVISITING SOCIAL ENGAGEMENT

The third theme highlighted various changes in participants' abilities to socially engage with others and limited recreational options, and coping strategies that participants implemented to maintain social support (Table 4). All three codes within sub-theme 3.1, 'struggling with a lack of social engagement', changed over time. At T1 for code 3.1.1, participants experienced some changes with socializing as a result of the need to

adopt social bubbles and the shift towards technology-based communication. At T2, while participants highlighted similar thoughts about missing in-person social interactions, the idea of using online communication platforms, such as Instagram and Facebook, was introduced. For example, one participant stated:

We talk online on a children’s messenger; it’s monitored by the parents and we talk on there. And I talk with my grandson on Instagram as well. My granddaughter is not on Instagram but they are both on messenger. [I: Okay] I actually Facetime with them as well. It’s hilarious. (P05-T2)

At T3, participants described the increasing opportunities to visit family and friends, as the pandemic restrictions

began to loosen for the first time since the start of the pandemic. A participant described one such experience by stating:

But actually, being over there at their place and just hanging out with them and being with my niece and nephew, first time this year. So, um, yeah. So it’s kind of, it’s kind of sad, to be honest. I mean, you know, seeing how much my niece and nephew have grown at five and seven years old, they’re growing like weeds at this point...I really feel like I missed a good chunk. (P01-T3)

However, as a result of restrictions beginning to increase during the winter season (T4) participants highlighted a shift back towards primarily engaging with others online.

**Table 4.** Illustration of codes over time for the third theme

Theme	Sub-theme	Code	T1	T2	T3	T4
3. Revisiting social engagement	3.1 Struggling with a lack of social engagement	3.1.1 Experiencing some lifestyle changes with socialising	I	X	Δ	Δ
		3.1.2 Missing social interaction	I	X	Δ	Δ
		3.1.3 Feeling there are limited activities	I	Δ	Δ	X
	3.2 Employing social engagement coping strategies	3.2.1 Intentionally connecting with others	I	X	Δ	Δ
		3.2.2 Offering and providing support and help to others	I	Δ	Δ	X
		3.2.3 Receiving and being offered support and help by others	I	X	X	X

(NP = code not present; I = initial presentation of code; Δ = change in code; X = no change in code).

Another code demonstrating change, code 3.1.2, initially described similar concerns about feeling cooped up and not being able to see friends at T1. This longing for social interaction appeared to persist among many participants at T2 with one stating: “Without TV, I feel...I feel more lonely nights. So I feel alone now in the house, you see. Yes, I live by myself” (P21-T2). Despite many restriction-appropriate activities being described in T3, many participants felt tired of engaging in these activities because of the lack of a social component. For example, one participant stated:

I could learn a new topic, but it’s of limited interest because of the [lack of a] social aspect. To me, it’s one of the most important things about learning. It’s what you learn from other people, not just from the prof, but from the other students. (P03-T3)

This sentiment of losing interest in available activities due to a lack of social engagement was shared by most participants at T4.

For the third code, 3.1.3, participants at both T1 and T2 shared similar views about the limited activities available as a result of the pandemic lockdown. In particular, participants highlighted concerns about their disability being an additional barrier in finding recreational activities during the pandemic. For example, one participant stated:

I am really missing the sports and the activities that I did and even more so now, because they’re restarting. The group that I used to play pickleball with plays every second day and unfortunately, the only way for me to bring my sports stuff there would be with the van that I had to leave in [Place 1]. So right now most of my friends are going out to the courts and I can’t participate, so I really miss that. (P03-T2)

At T3, when pandemic restrictions were eased, participants shared feelings about being cautious and hesitant to re-engage in recreational activities. For example, one participant stated:

If that doesn’t work out, then I will, I will definitely start to look... and it depends [on] how everything else goes. If the gym starts to open up more, then I’m there, I could be there every day. [...] I’m gonna give it a bit more time, let the summer pass through, and then in September when the organization opens for business again, we’ll see where they’re at. (P01-T3)

By T4, participants began engaging in some recreational activities, particularly ones that were accommodating and accessible to individuals with disabilities and followed pandemic restrictions including personalized fitness classes and wheelchair curling.

Within the second sub-theme, 3.2, 'employing social engagement coping strategies', two of the three identified codes (3.2.1 and 3.2.2) changed over time. At both T1 and T2 for code 3.2.1, participants described the importance of intentionally connecting with others as a major coping strategy to promote social engagement. For example, one participant stated:

Met them outside just out of respect for the other people here, so I'd meet them outside. Their family and their kids. They're safe and not sick so I'm not sick so... And I'm not going to go that long without seeing my grandkids. Not going to do it. (P05-T2)

At T3, however, participants highlighted that they slowly transitioned towards intentionally finding means to meet people online rather than in person: "Oh, I've had lots of connections. I mean, I'm connecting with Facebook, with email, with phone and with Facetime, and meeting in person" (P10-T4). By T4, many participants described how they became used to virtually engaging with people for activities such as meetings, Zumba classes, and Facebook chats.

Participants, likewise, demonstrated significant changes across all four time points in code 3.2.2. For example, whereas at T1 participants highlighted the importance of supporting friends and family early on in the pandemic, at T2, many participants described the importance of supporting local community causes, including businesses and charities. For example, one individual stated:

So I'm doing the best I can to try and support the local businesses. But only so much one person can do. But if we all work together, it goes to show how much we really are interconnected. (P14-T2)

At T3, some participants shifted focus by expressing the importance of offering and providing support from a disability perspective to members of the SCI community in order to give back for help they received. For example, one individual (participant number omitted) stated:

I am now on the [Board 1] and which is a grouping of five [in which] volunteers who come together to assist people who have disabilities in order to devise innovative one-off solutions to their particular problem.

This experience of giving back to the SCI community became even more prevalent at T4.

The final code, 3.2.3, did not demonstrate any change across time points with participants describing how receiving help and encouragement from others was a consistent social engagement coping strategy. Participants described examples of support, which included receiving help with exercising, food delivery programs, helping with walking their pets, and financial aid programs.

## Discussion

This was the first longitudinal qualitative study to explore experiences and changes in daily and social activities among individuals living with SCI during the COVID-19

pandemic. It identified three themes: 1) dealing with the emotional impact of pandemic-related restrictions, (2) changing daily routines, and (3) revisiting social engagement. The discussion below has been organized based on the themes generated.

### DEALING WITH THE EMOTIONAL IMPACT OF PANDEMIC-RELATED RESTRICTIONS

Participants described a sense of frustration throughout the first year of the COVID-19 pandemic. They expressed being impacted by the effects of COVID-19 related fatigue from the first timepoint onwards as sources of stress, anxiety, and fear may have become a recurring factor in their new way of living. This aligns with the findings of a prospective observational study, which indicated that participants with SCI had a greater level of anxiety and depression during the first couple of months of the pandemic compared to pre-pandemic levels<sup>18</sup>. This could be due to the negative outcomes experienced, such as increased social isolation and sedentary routines, from the implemented COVID-19 restrictions<sup>19</sup>. Participants reported constant concerns regarding potential COVID-19 health issues throughout the first year of the pandemic, as this population is already susceptible to other health risks such as respiratory infections<sup>11,20</sup>. The problems encountered when employing protective measures, such as disinfection practices, against the COVID-19 virus, may also have contributed to these concerns<sup>21</sup>.

Despite the frustrations participants experienced, feelings of increased gratitude were reported during the COVID-19 pandemic. The appreciation voiced for the government is consistent with other studies where individuals with disabilities indicated that the Canadian government had prioritized factors such as retaining jobs and providing emergency support during the first lockdown period<sup>22</sup>. Towards the end of this study, some participants shifted the focus to positive factors in their personal lives. Finding meaning and reflecting on positive aspects of life have been shown to provide comfort for individuals during the pandemic<sup>23</sup>. Additionally, experiencing gratitude has been linked to numerous benefits such as reducing depression, lowering stress, and fostering positive emotions<sup>24,25</sup>.

### CHANGING DAILY ROUTINES

A key change during the pandemic was a shift from in-person appointments to telemedicine, and the deference of several elective procedures. Although an increased adoption of telemedicine appeared largely beneficial for individuals with SCI, certain practices that required an in-person format were not available. A study among individuals with SCI in the UK found that services such as physiotherapy and massage were cancelled for large portions of the pandemic resulting in significant implications for health management, including physical strength deterioration and increased pain<sup>11</sup>. This often resulted in individuals feeling sad, angry, and fearful for their health. Contrarily, fear triggered many individuals to voluntarily avoid medical appointments due to concerns of contracting COVID-19 from healthcare settings<sup>26</sup>. A study by Splinter et al<sup>27</sup> found that 1 in 5 community dwelling adults over the age of 65 reported avoiding healthcare, even for urgent symptoms. Those avoiding healthcare were often the ones who needed it

most, such as those with poorer health or chronic conditions. For spinal cord injury, neglect or improper management of secondary conditions, such as urinary tract infections and pressure sores, can lead to serious health complications and may prove fatal<sup>28</sup>. Beyond the fear factor, individuals with SCI have to contend with an array of considerations and challenges, including wheelchairs, transit, and limited hand function. The continued issues are partially indicative of a societal failure to help alleviate such challenges. Concerns about health inequities and ableism among countries such as China have been raised due to their adoption of a one-size-fits-all model to healthcare during COVID-19 and a failure to consider disability needs<sup>29</sup>.

Participant's typical routines were also disrupted by fears of traveling, altered perceptions of time, and the impact of weather and closures on available activities. While the initial timepoints reported disappointment of cancelling trips, the shift into a fear of traveling is also reported in broader society. Varying levels of threat severity and susceptibility can lead to 'travel fear', which can trigger protection motivation, coping strategies, and protective travel behavior<sup>30</sup>. Along with regulations, this altered attitude to traveling may indicate why participants were unsure when they would resume traveling. The feeling of time passing differently during the pandemic is also reported in broader society. On the one hand, a sense of time slowing and the need to "kill time" is associated with increased stress, increased age, reduced task load, and reduced satisfaction with social interaction levels<sup>31</sup>. On the other hand, the mundane monotony of life under restrictions can lead to days feeling longer but larger epochs of time seeming to fly by<sup>32</sup>. A factor that can inadvertently influence this, and particularly impact activity options, is that of seasonality and weather. A systematic review indicated that, even pre-COVID-19, community dwelling individuals were generally more physically active in the summer, partially due to longer days and preferable weather conditions allowing outdoor activities<sup>33</sup>. With the closure of many indoor facilities and requirements to physically distance, it is understandable that this seasonal disparity is further accentuated during COVID-19, as discussed by participants in code 2.2.4.

#### REVISITING SOCIAL ENGAGEMENT

Various aspects of a participant's social engagement experienced significant negative changes throughout the pandemic, including how individuals engaged with their friends, family, and their communities. Similar to sentiments expressed by participants in our study, a study on pandemic-related experiences among individuals with mobility disabilities found that access to family and friends was among the most prevalent challenges experienced<sup>10</sup>. Similarly, for individuals living with disabilities, recreational settings such as community recreation facilities and cultural centers play a significant role in promoting social inclusion and interaction<sup>34,35</sup>. To overcome these challenges, the COVID-19 pandemic has resulted in increased engagement with internet-based technologies for social communication<sup>10,36,37</sup>. One quantitative, cross-sectional study found that individuals with disabilities demonstrated more pronounced engagement with social media for sharing information, accessing health-related content, and supporting others

compared to people without disabilities<sup>37</sup>. Furthermore, a survey conducted in Italy during the initial months of the pandemic found that to overcome lock-down restrictions, digital technologies were primarily used to facilitate use of online emotions and online social support, which in turn, were positively associated with greater engagement in prosocial behaviors and positive mental health<sup>38</sup>. This positive feedback loop may explain why participants in our study readily transitioned to using technology-based communication as a social engagement coping strategy during times of heightened social restrictions throughout the pandemic.

#### STRENGTHS & LIMITATIONS

This study had various strengths and limitations. A strength of this study was its longitudinal approach, capturing the experiences of participants with SCI across multiple time points in the COVID-19 pandemic. Due to the dynamic nature of this pandemic, it is important to capture the changes in experiences as participants may have had a difference in their perspectives about the pandemic at different timepoints. A limitation was the use of convenience sampling which may have reduced the representativeness of the sample to the population of interest. This was accompanied by the fact that the majority of participants resided in British Columbia which limits the breadth of pandemic experiences. Additionally, only participants who had access to online videoconferencing platforms were included in this study. This likely excluded those who had limited access to technology or digital literacy.

#### Conclusion

Our findings describe the experiences of the SCI population across four timepoints during the COVID-19 pandemic. Participants discussed feelings of frustration, anxiety, and gratitude, adapting to changes in their usual routines, and described the challenges and strategies used when navigating life during the pandemic. The increased shift to telehealth has been largely beneficial for individuals with SCI but it is still imperative to provide access to in-person services that support management of secondary conditions. Furthermore, it is apparent the transition towards technology-based communication played a major role in promoting and maintaining social engagement between families, communities, and globally. There were a range of both positive and negative experiences described. The challenges and silver linings identified by this population may provide insights on how to improve the way of living in future pandemics. Future research could address adverse encounters experienced by this population and develop guidelines that might improve the way of living in future pandemics.

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