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Experiences of Social Participation for Canadian Wheelchair Users with Spinal Cord Injury during the First Wave of the COVID-19 Pandemic

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Abstract: The COVID-19 pandemic caused drastic life changes for people with spinal cord injury (SCI). The objective of the study is to explore the social participation of Canadian wheelchair users with SCI during the first wave of COVID-19. **Methods:** Fourteen participants from Quebec and British Columbia participated in a multi methods cross-sectional study. Three themes were identified, including (1) perceived participation restrictions for people with SCI and their loved ones, which revealed interruptions and changes in service provision during COVID-19, barriers and inconveniences to maintaining life habits and strategies developed during the pandemic to continue participating in meaningful activities; (2) There was no change in life habits (but some subjects found new ways to perform some activities), which highlights that life simply continued as usual and the participants developed new pastimes and interests; and (3) future hopes and concerns, which explained participants’ concerns about changes in interpersonal relationships after the pandemic. This study highlights daily participation challenges for people with SCI during the pandemic. Even though the use of technologies, delivery services and social support seemed to facilitate engagement in meaningful activities, mental health challenges and concerns for future relationships persisted for some.

Keywords: COVID-19; manual wheelchair; social participation; spinal cord injury; rehabilitation; social support



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1. Introduction

In March 2020, the World Health Organization declared a global pandemic caused by the coronavirus, COVID-19 [1], which resulted in a public health response of social distancing, isolation and protective health measures to limit transmission [2]. Whilst addressing the immediate physical health of the population, the resulting public health measures had various negative impacts on the daily life of many individuals, such as increased financial worries [3], sleep disturbances [4], elevated anxiety [5], psychological distress [6], and decreased walking and exercising [7], which has contributed to reduced well-being [8].

Disruptions in life habits and social participation associated with COVID-19 are anticipated for the foreseeable future, especially among vulnerable populations, such as people with disabilities. The Human Development Model—Disability Creation Process (HDM-DCP) conceptual model defines social participation as the “total accomplishment of life habits, resulting from the interaction between personal factors (impairments, disabilities and other personal characteristics) and environmental factors (facilitators and obstacles)” [9]. In the same model, life habits are defined as “daily activity or social role valued by the person or their social-cultural context according to their characteristics (e.g., age, sex, socio-cultural identity)” [9]. Given that social participation represents a continuum ranging from total accomplishment of life habits to a total disabling situation, these two concepts are interrelated. Although social participation has been identified as an important contributor to quality of life, well-being, and life satisfaction for people with spinal cord injury (SCI) [10–12], people with physical disabilities such as SCI are particularly vulnerable to social isolation [13], which is associated with reduced well-being [14].

A rapid review conducted in August 2020 summarized the impact of the COVID-19 pandemic and the associated isolation and protective health measures for people with physical disabilities [15]. Results revealed increased daily challenges among people with physical disabilities, such as increased barriers to community mobility and social participation. Reported barriers among people with physical disabilities included limited access to transportation, decreased access to healthcare [16–18], frequent behavioral and sleep disturbances [19–21], changes in social and lifestyle habits and reduction of physical activity [22–24]. Nonetheless, results of this rapid review revealed a lack of research about the impacts of COVID-19 experienced by people with physical disabilities, with only 11 studies reporting on people with disabilities (and non-specific to people with SCI).

Given the unique healthcare and social participation needs of people with SCI, and potentially higher consequences of COVID-19 (e.g., proneness to reduced respiratory function [25], participation restrictions [26], depression, and anxiety [27]), there is a need for further research on participation experiences of people with SCI during the pandemic. Therefore, the main objective was to explore participation experiences of Canadians with SCI in an ongoing study during the COVID-19 pandemic between May and July 2020.

2. Materials and Methods

2.1. Design

A multi methods design was used to conduct qualitative interviews and quantitative surveys. A qualitative descriptive approach [28] was used to explore participation experiences of people with SCI through interviews, complemented by standardized participation questionnaires. This project was approved by local Research Ethics Boards.

2.2. Participants and Recruitment

Participants represented a convenience sample recruited from an ongoing Canadian multi-site trial (Quebec City, Montreal and Vancouver) called ALLWheel (ClinicalTrials.gov Identifier: NCT02826707) [29], which aims to increase physical activity among people with SCI who use manual wheelchairs through peer coaching. Participants in the ALLWheel intervention who had given their consent to be contacted for further studies were solicited by telephone to take part in the present study, which is independent from the larger trial.

As described by Best et al. [29], the inclusion and exclusion criteria were to: be 18 years or older, live in the community, have a SCI for ≥ 1 year, use a manual wheelchair for mobility and physical activity, be able to self-propel their wheelchair ≥ 100 m, not meet the SCI physical activity guidelines (90 min/week) [30], be able to communicate in English or French, and be cognitively able to engage in the ALLWheel intervention. Participants were excluded if they had a degenerative condition expected to progress quickly (e.g., amyotrophic lateral sclerosis) or if they had contraindication to physical activity.

2.3. Procedures

Data were collected remotely by telephone or videoconference (Webex, Zoom) over one or more instances within a week depending on participant preferences. Questionnaires were sent by e-mail and participants could complete them with the assistance of a research assistant (by telephone or videoconference) or independently. The duration of the interview and the completion of the questionnaire was 90 to 120 min in total. Non-participants were not present during the interviews. All procedures were conducted by the same researcher in English or French according to participant preference.

2.4. Data Collection

Sociodemographic data (i.e., age, sex, province of residence, employment status, time using wheelchair) were collected at the baseline of the larger intervention (ALLWheel) [29]. Between May and July 2020, each participant participated in a semi-structured interview. Figure 1 presents the timeline of the implementation of public health mandates in British Columbia and Quebec during the interview period [31,32]. Interviews were conducted by the study coordinator (C.R.), who is a research professional and a physiotherapist, to explore the impact of the COVID-19 public health recommendations on social participation experiences. A semi-structured interview guide based on two validated questionnaires [33,34] including 25 open-ended questions and prompts was developed by the ALLWheel research team. Given the small purposeful sample, the interview guide was not pilot tested. The complete interview guide is available in the Supplementary Material. More specifically, to explore social participation the interview questions were related to the satisfaction and realization of life habits, which is consistent with the HDM-DCP conceptual model. The interviewer (C.R.), identifying herself as a woman with no physical disability and having had previous contact with the participants in the larger study, was trained before the interview. All interviews were audio recorded and transcribed verbatim (by a study investigator or using TranscribeMe services). Transcripts were not returned to the participants for validation.

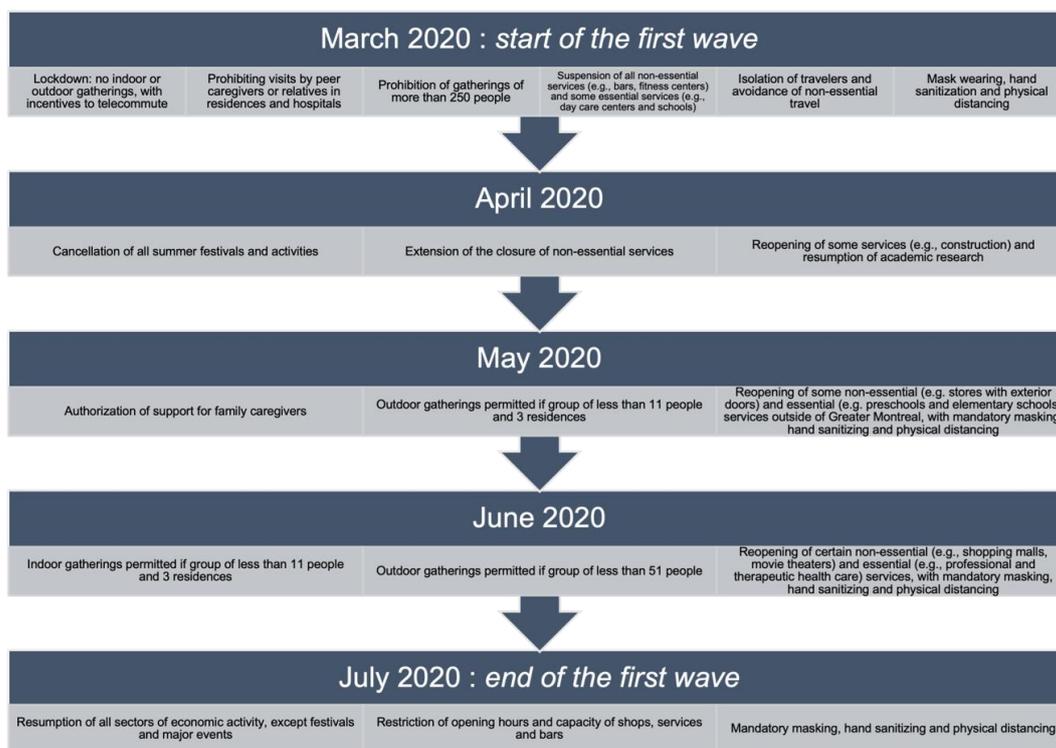


Figure 1. Timeline of the implementation of public health mandates in British Columbia and Quebec during the first wave of the pandemic.

To triangulate the qualitative information, participants completed two validated questionnaires that were modified in the context of the pandemic. A group of expert researchers determined which items from Assessment of Life Habits (LIFE-H 4.0) and from Measure of Quality of the Environment (MQE) were the most relevant in the context of the pandemic.

2.5. Assessment of Life Habits (LIFE-H 4.0)

Assessment of Life Habits (LIFE-H 4.0) measures the perception of the level of achievement of participants' life habits as well as their satisfaction. Twelve life habits divided into two categories (i.e., day-to-day habits, and social roles) were evaluated. The two categories include respectively six life habits (i.e., communication; mobility; nutrition; physical fitness and psychological well-being; personal care and health; employment; housing; responsibility; interpersonal relationships; community and spiritual life; education; employment and, recreation) for a total of twelve life habits evaluated. [33]. Thirty-two items from the LIFE-H 4.0 were used to assess social participation according to the conceptual Model for Human Development (HDM-DCP) [33] to capture the twelve life habits, including: the realization of the life habits, if applicable (binary scale, 0 (no) 1 (yes)); the assistive device and adaptation needed (binary scale, 0 (no) 1 (yes)); human assistance needed (4-point scale ranging from 0 (no assistance) to 4 (complete help)); the level of difficulty (3-point scale ranging from 1 (little difficulty) to 3 (a lot of difficulty)); and the level of satisfaction (4-point scale ranging from 0 (very satisfied) to 4 (very unsatisfied)). Each participant responded to the 32 items and an individual score of level of social participation was calculated. All individual scores were then rescaled over 10 points for comparison purposes.

2.6. Measure of Quality of the Environment (MQE)

The MQE was used to assess the role of the environment on the performance of daily activities [34]. Participants responded to 45 items that were pre-selected by expert researchers to be indicative of a situation or factor that could influence daily life. Participants rated whether items were a facilitator or an obstacle during COVID-19 based on a 7-point Likert scale ranging from -3 (major obstacle) to 3 (major facilitator). Responses options, "I don't know" or "Does not apply" were also possible.

2.7. Data Analysis

Line-by-line coding and thematic analysis [35] was conducted using a dualistic inductive and deductive technique [36] by two authors (A.d.S.-L. and N.F.-B.) in the original language. Trustworthiness strategies were used at each phase of the analysis [37]. First, two study investigators (A.d.S.-L. and N.F.-B.) became familiar with the data and, prior to the analysis, they created an early codebook template using the main questions covered by the interview. The themes and sub-themes in this first template included changes in services, autonomy, and strategies developed by people with SCI. Once the analysis began, they used an iterative process to add, modify, and delete themes and sub-themes according to the emerging data from the interviews. The interpretation of code was based on the objective of the study, which is to present the impacts of the pandemic on the achievement and satisfaction of life habits as well as social participation. Themes and subthemes were developed in English and French and kept in the original language until completion of the thematic analysis to limit interpretations of translations. Validation of themes and subthemes was conducted bimonthly between two study investigators and the bilingual investigator who conducted the interviews validated codes midway (C.R.) to maintain a common understanding among coders, contributing to a greater inter-rater reliability. NVivo 12 (QSR International, Melbourne, VIC, Australia), a qualitative data analysis software was used to organize and analyze the data. To triangulate the qualitative data, descriptive statistics (mean, standard deviation, percentage) were calculated for the MQE and LIFE-H questionnaires and were used to describe the sociodemographic profile of the participants. No participant checking was conducted.

3. Results

3.1. Demographics

Among the 19 participants contacted, 14 agreed to participate and five refused to participate. Six were still active in the ALLWheel study, and eight had finished. Participants were predominantly male $n = 9$ (64%), 47.1 ± 15.7 years of age, and had 14.2 ± 13.8 years of wheelchair experience (Table 1).

Table 1. Characteristics of participants.

| Participant Number | Sex | Age, Years | Province of Origin ¹ | Employment Status | Highest Education Level | Annual Household Income, \$ | Diagnosis | Time Using any WC ² , Years |
|--------------------|-----|------------|---------------------------------|-------------------|------------------------------|-----------------------------|---------------------|--|
| 1 | M | 30–39 | BC | Employed | College/University | <30,000 | Transverse myelitis | 6–10 |
| 2 | F | 30–39 | BC | Unemployed | Post Graduate studies | <30,000 | Paraplegia | 21–25 |
| 3 | M | 70–79 | BC | Retired | Post Graduate studies | ≥60,000 | Paraplegia | 41–45 |
| 4 | M | 30–39 | BC | Employed | College/University | <30,000 | Paraplegia | 6–10 |
| 5 | M | 20–29 | QC | Unemployed | High school or no diploma | 30,000–59,999 | Paraplegia | 0–5 |
| 6 | F | 50–59 | QC | Unemployed | College/University | 30,000–59,999 | Paraplegia | 11–15 |
| 7 | M | 30–39 | QC | Unemployed | Other | 30,000–59,999 | Paraplegia | 0–5 |
| 8 | F | 60–69 | QC | Retired | College/University | ≥60,000 | Paraplegia | 41–45 |
| 9 | F | 20–29 | QC | Unemployed | College/University | <30,000 | Paraplegia | 0–5 |
| 10 | M | 60–69 | QC | Retired | High school or no diploma | <30,000 | Paraplegia | 11–15 |
| 11 | M | 40–49 | QC | Unemployed | High school or no diploma | <30,000 | Tetraplegia | 6–10 |
| 12 | M | 50–59 | QC | Retired | College/University | 30,000–59,999 | Paraplegia | 0–5 |
| 13 | M | 40–49 | QC | Retired | High school or no diploma | 30,000–59,999 | Paraplegia | 16–20 |
| 14 | F | 50–59 | QC | Unemployed | College/University (started) | Missing | Paraplegia | 0–5 |

¹ BC, British Columbia; QC, Quebec. ² WC, Wheelchair.

3.2. Qualitative Findings

Three interrelated themes were identified: (1) “Perceived participation restrictions for people with SCI and their loved ones during COVID-19”, which revealed interruptions and changes in service provision during COVID-19, barriers and inconveniences to maintaining life habits compared to before the pandemic and strategies developed during the pandemic to continue participating in meaningful activities; (2) “There was no change in life habits (but found new ways to do some things)”, which highlights that life simply continued as usual and the participant’s developed new pastimes and interests; and (3) “Future concerns and hopes”, which explains participants’ perceptions about the pandemic during lockdown and for the months to come. Tables S1–S3 in the supplementary material illustrate citations from the qualitative themes 1–3, respectively.

3.2.1. Theme 1: “Perceived Participation Restrictions for People with SCI and Their Loved Ones during COVID-19”

We identified three subthemes in theme 1, including: interruptions and changes in service provision during COVID-19, barriers and inconveniences, and “it’s better than nothing”.

Interruptions and changes in service provision during COVID-19. Some services that were scheduled prior to the pandemic were cancelled or postponed, which was an obstacle to the accomplishment of personal care and health habits. In fact, a few participants reported temporarily experiencing interruptions in the provision of home-based services:

“Regarding my services, the only thing that I lost is the house cleaning, so my son does some (housecleaning) as well as my wife.” (Participant 10)

Regular check-ups with doctors and health care related to SCI were also paused. For example, a participant reported:

“It’s only for the rehab, for the wheelchair, it’s harder. You can’t take appointments. And some appointments of the doctors, for example, the radiology and something like that, it’s all cancelled.” (Participant 3)

A few participants postponed non-essential appointments because they did not feel they were a priority during the pandemic. However, most participants did not experience delivery delays.

Since some participants continued to use home delivery services for grocery and pharmacy during the pandemic, others began using home delivery services to maintain their social participation. As reported by a participant:

“Grocery shopping was as usual, I used to do all my shopping online before, it didn’t change much in this regard either.” (Participant 10)

Alternatively, another coping strategy was getting groceries less frequently or avoiding places with long lineups or asking relatives for help. Most participants continued to receive services during the pandemic (e.g., home services, medical appointment, supplies, home deliveries) while integrating public health recommendations (e.g., wearing a mask, washing hands). Although one participant had difficulty getting essential medical equipment, few participants mentioned they had backup supplies at home (e.g., catheters, incontinence pads). Almost all participants reported receiving significant help from loved ones during the COVID-19 pandemic by doing chores, shopping for groceries or pharmacy needs, which was an important facilitator to maintain the realization of life habits. In this regard, a participant reported:

“Well, when you need a hand, that’s for sure . . . it just blows up all over the place. I mean, they’re all ready to help us. (. . .) the three of us were able to organize. So, everyone was helping . . . ” (Participant 7)

Among these, some participants also reported that their loved ones were helping them before COVID-19. Furthermore, a few participants from Quebec also reported having financial support because of COVID-19 from the government. Participants reported positive changes and opportunities due to the COVID-19 pandemic. For example, some participants reported that they appreciated not having to travel for certain medical appointments that could be done remotely using technology. A participant reported:

“I think that phone consultations are useful, I think it is great that we do not have to go on-site.” (Participant 6)

Barriers and inconveniences. Participants reported various physical and social obstacles hindering the accomplishment of life habits. Difficulties related to SCI and wheelchair use, public health measures and interpersonal relations, physical activity, and psychosocial factors were expressed. Most participants expressed difficulties regarding outdoor transportation and increased risk of contamination (e.g., inaccessible infrastructures, avoiding people on sidewalks, constantly touching their wheels). In addition, the need to cancel social events (e.g., birthday parties, work events and family vacations) due to public health measures were difficult for some participants.

Imposed social distancing also increased perceived loneliness, which was particularly difficult for those who expressed that activities with loved ones represented the only meaningful activity that they looked forward to on a regular basis. Although half of the participants were more solitary or managed to see friends from a distance or by using technology, physical contact and emotional bonds with others (i.e., loved ones, colleagues and even strangers) were missed and impacted the life habits (i.e., interpersonal relationships). In contrast, few participants conveyed that living with others during the

lockdown was exhausting, because they did not have enough personal space or needed to entertain children who were home with minimum engaging activities (e.g., homework, activities with friends). One participant also mentioned the unpredictable and precarious nature of the constantly changing directives as an additional stressor. Given the lack of clarity and implementation of public health measures by essential service providers, a few participants were anxious about compliance with the measures to avoid contracting COVID-19. Nevertheless, one participant said that her life experiences with SCI had taught her to reinterpret situations during the lockdown in a positive light.

The isolation measures decreased the frequency of outdoor activities and transfers for one participant, who perceived a decrease in endurance, balance, and muscular strength in the upper limbs. It also led to a sedentary lifestyle for half of the participants (e.g., watching television all day, not getting dressed or taking a shower, scrolling on cellphones, reduced motivation to be productive, not going outside at all). While few participants reported starting to go out again and exercising more often as the first-wave pandemic restrictions eased, others did not because they continued to feel unmotivated, lonely, or anxious. In addition, some activities (e.g., swimming, yoga classes, music therapy) were still not available. Moreover, one participant talked about exercises (e.g., yoga kickboxing) available online offered during the pandemic by a community SCI organization, but they did not participate due to a lack of interest and motivation. Few participants said that nothing changed, because they did not exercise before the pandemic.

More than half of the participants expressed that the lockdown was mentally challenging, which had an impact on their life habits. Among those, some reported an impact on their autonomy (i.e., they felt more dependent on others), a few reported an impact on their sense of self-worth and one on their freedom. In this regard, a participant mentioned:

“The pandemic and the lockdown is like putting myself on the ground, in a state of inertia. (. . .) During the whole period, I do nothing. (. . .) The (activity) must be physical, sensory, all of that. But right now, I’m really not into it, it worried me and still worries me. (. . .) It affects my self-esteem because I really don’t feel capable.” (Participant 8)

In fact, given that people or services were not always available during the pandemic, few participants explained feeling the need to take additional caution. More precisely, a participant added:

“Not that we are more independent, but people are less willing to help you with contamination. (. . .) So, every day, I still pay more attention to what I’m doing so that I don’t need help.” (Participant 8)

Moreover, one participant elaborated on the emphasis put on older and vulnerable adults during the pandemic and felt stigmatized because they perceived that people were staring and appeared concerned or thought they were sick based solely on their visible disability:

“The association between sick people and disabled people is quite strong.” (Participant 10)

Consequently, a participant mentioned:

“I think it puts us, the people who have dependencies on services or technical assistance, it puts us in the position of a person where we are asked to not make things worse. (. . .) through the pandemic, we were unintentionally labelled as people who had a good potential to do damage, to get sick, (. . .) so our situation wasn’t very good.” (Participant 8)

It’s better than nothing. All participants reported following public health recommendations. Although participants were employed before the pandemic, three people reported changes or disruptions in their work situation (e.g., leaving a job, change in roles, reduced workload). One participant also expressed how the rewards experienced from volunteering were halted during the pandemic. To maintain their participation in vocational activities, participants expressed being diligent about wearing masks, washing their hands and wheels, maintaining social distance, avoiding touching their face, using gloves, cleaning

their car often, and mapping out an itinerary before leaving the house (i.e., reduce unnecessary movement and minimize contacts). Finally, risk of contamination was minimized by not sending children to school and changing living situations (e.g., a loved one who was working in high-risk areas temporarily left the home).

Creative strategies to continue participating in meaningful activities were commonly achieved using digital technology, which increased participants' feeling of comfort during the pandemic. All participants reported participating in various digital hobbies (e.g., online games, newspapers and exercises, meditation, as well as sharing pictures, poems or songs with loved ones around the world), which enhanced relaxation and positive thoughts about staying isolated at home. Since digital technologies were supportive to social participation, almost half of the participants reported a considerable increase in cellphone usage with multiple purposes (e.g., online shopping, virtual meetings with videoconference platforms such as Zoom). Of note, one participant reported:

"Technology helped (kept) independence during COVID-19." (Participant 5)

Additionally, most of the participants were happy that they could contact health professionals by phone or videoconference for various needs (e.g., exercise recommendations, prescriptions), as they felt considered and this reduced the need to travel for in-person consultations. For instance, a participant mentioned:

"It (facetime with health professionals) was good. Yeah. You just phoned in, and then they set up a time, and then the doctor would phone you back and do everything over the phone." (Participant 4)

All participants had access to digital technology during the pandemic, which facilitated participation in life habits. However, they did not all have the same interest nor satisfaction in using technology for this purpose. A few mentioned that virtual conversations are not the same as face-to-face. For example, they expressed that non-verbal communication is more difficult in virtual conversation, since the whole body of the person talking is not visible. Consequently, multiple people often talk at the same time. One participant anecdotally mentioned not taking part in videoconference activities due to the lack of face-to-face interactions.

3.2.2. Theme 2: There Was No Change in Life Habits (But Found New Ways to Do Some Things)

We identified two subthemes in theme 2, including life simply continued as usual, and new pastimes and interests.

Life simply continued as usual. Lockdown did not greatly influence the life habits of participants during the pandemic. In fact, a few participants mentioned that even before the pandemic they experienced social and physical factors influencing their social participation. Even before the pandemic some participants were isolated, living away from family members, or they already experienced restrictions in visiting others due to architectural barriers in their homes. For instance, a participant expressed:

"(Lockdown) did not have much influence, because I am in a wheelchair, sometimes I am a little bit restricted in advance. And it gets worse in winter." (Participant 12)

While the winter season compelled them to stay at home for various reasons (e.g., cold temperatures, sidewalks not plowed, crowded spaces) as reported by a few participants:

"Well, I didn't have a problem with that (lockdown). It didn't bother me, it was winter. And then in the winter I am not going out, I am less out in the winter than in the summer. It didn't affect me too much." (Participant 13)

Some participants explained that they still had a backyard where they could move around, enjoy nature, and exercise their dogs, allowing them to maintain their social participation in certain life habits during the pandemic. Few participants reported that the public health measures did not influence their autonomy.

More than half of the participants perceived no major barriers to continuing usual physical activities (e.g., morning stretches, stationary or regular bike, weights, elastic bands, taking walks outside) during the pandemic. Despite the isolation measures and the closing of gyms, participants were able to stay active because most exercises could be done at home and participants had the necessary equipment. Various motivators to staying physically active during lockdown were reported, such as calling a friend during activities, listening to music, having a peer-trainer (for some active ALLWheel participants), exercising with their service dog, and exercising with family members they live with.

New pastimes and interests. All participants were not working or were working less at the time of the interview, and reported finding new hobbies (e.g., cooking, writing, exercising), and, for some of them, spending more time with loved ones. Similarly, participants expressed social connectedness with others during lockdown, as almost half of participants perceived having increased telephone or text contact with their entourage:

“I’ve been using my phone and internet a lot more than I used to.” (Participant 2)

Few participants even reported that being missed by others during lockdown reduced feelings of loneliness, as they realized they were more important to others than they had perceived. In addition, one participant mentioned that the social distancing measures helped to reinforce personal space and reduced stress experienced in public when people sometimes get too close to them or their wheelchair. An atmosphere of mutual aid and solidarity in the community during the pandemic was also highlighted by a few participants, whether by respecting protective measures to avoid contamination, congratulating essential workers (e.g., firefighters, nurses) and displaying the globally recognized symbolic rainbow. The attitudes of people in the community were thus comforting for these participants. A few participants expressed that the pandemic and resulting public health recommendations enhanced appreciation of their lives and facilitated enjoyment in what they currently have:

“Well, I think I’ll be a lot more appreciative of my friend, the community, and just more appreciative about the fact that I’m able to get out and enjoy my life. So just an increase in appreciation of the enjoyment that’s available.” (Participant 3)

Participants who were experiencing pain said they benefitted from the time to rest during the lockdown, and the opportunity to try new exercises to relieve pain. While the majority did not change their physical activity routine, a few participants developed new ways of doing things, such as buying active Wii video games, beginning home renovations, playing Pokemon Car by driving to a place with plenty of space, and going for a stroll outside.

3.2.3. Theme 3: “Future Hopes and Concerns”

We identified two subthemes in theme 3, including concerns and hopes.

Concerns. Participants expressed concerns regarding obstacles inhibiting their engagement and satisfaction in their future life habits. In general, a few participants said they feared the future because of the uncertainty regarding the current situation and the implications of the pandemic due to economic instability and protests. Other participants mentioned that they were concerned about the recklessness of people who do not respect public health recommendations, as they put their own life and those of others in danger. In this respect, a few participants said they felt more at risk of catching COVID-19 because of their SCI. For example, one participant reported that it felt risky to touch their wheelchair rims and that they felt vulnerable because they were at the same height as children. In addition, during the pandemic some sanitary measures were not adapted, thus exposing them to additional difficulties in integrating protective measures in their daily habits, which made them feel vulnerable:

(. . .) Like the water pumps with the feet, it is a little difficult when you are in a wheelchair, or the openers with the feet because they have deactivated the automatic opening. (participant 5)

Additionally, one participant who had experienced acute health problems (e.g., pressure wounds, urinary tract infections, cellulitis, infections) feared not having access to health services if needed during the pandemic. Another participant reported that it would be particularly challenging for people with SCI to maintain their physical functional because of the lack of physical activity opportunities due to lockdown restrictions:

“It will get worse. The thing that they are . . . for example a lot of them was doing their workout and their moving, and now they lost all what they had from the strain and injury because (. . .) the spinal cord injury people stop work out, they will lose what they have.” (Participant 9)

Almost half of the participants believed the protective measures were going to be maintained for a long time, especially the physical distancing of two meters. Some participants expressed concern about the changes in interpersonal relationships after the pandemic, especially regarding physical contact to show affection. They feared that people will be more reluctant to be close to each other:

“I think people will be more cautious about maybe handshakes and hugging people. Yeah, I think people will just be a little bit more paranoid about the possibility of another infection.” (Participant 3)

Hopes. Some participants suggested recommendations to facilitate the accomplishment and satisfaction of their life habits in the future. One participant reported that a government initiative to reserve the first opening hour in grocery stores and pharmacies for older adults and people with disabilities was a good idea and would be relevant to maintain. On the other hand, another participant felt that this measure was unnecessary because his disability is not that big of a problem even if he is in a wheelchair.

One participant reported that it was motivating and helpful to have someone with a physical disability supporting their physical exercises (i.e., remotely through online technology) because they understand their situation and they have tips, and that this would be appreciated if maintained in the future. A few participants also mentioned that it would be relevant to be in contact with someone in a wheelchair experiencing the same things during the pandemic. This could help them by sharing advice to better manage the crisis:

“People who have that (SCI), they understand our situation and they have tips, that’s what helps.” (Participant 12)

While doing their exercise and medical appointments remotely using technology was suggested as something to keep in the future. However, another participant suggested:

“(About) the virtual long-distance way of offering services. I don’t think you can replace a human experience itself, so maybe have that as an option, or as an add-on, (. . .) I think the idea of having a choice, rather than having to do things one way.” (Participant 1)

This highlighted the importance of making buildings more accessible in the future (e.g., ramps) to reduce the architectural obstacles faced. Given that some participants felt that hand-washing, and physical distancing should be maintained in the future, a participant reported that adaptations are needed to ensure accessibility for wheelchair users.

A few participants suggested that there should be better communications with people with chronic problems during the pandemic to allow them to maintain their current activities and their social roles, for example, services to call in case of problems such as adapted transportation or urgent need of attendants.

3.3. Quantitative Findings

3.3.1. Social Participation

Assessment of Life Habits (LIFE-H 4.0) measures the perception of the level of achievement of participants’ life habits as well as their satisfaction. The mean scores of the LIFE-H were the highest for the life habits related to communication, interpersonal relations and

responsibilities (9.8, 9.22 and 8.8, respectively; Figure 2). On the contrary, the mean scores were the lowest for moving, associative and spiritual life, and leisure (4.5, 4.4 and 4.3, respectively; Figure 1). Details about how individual participants carry out their life habits (Figure S1), the assistive device (Figure S2), adaptation (Figure S3), and human help needed (Figure S4), and the level of difficulty (Figure S5) and satisfaction (Figure S6) are presented in Supplementary Materials. Regarding transportation, although all participants were able to mobilize over short distances (e.g., move inside their residence) with their assistive device, four participants were not able (and three were not satisfied) to move outside (e.g., on the street, sidewalk). When the public health guidelines allowed access to these places, nine participants were not able to enter and move around businesses public, and community services (e.g., restaurant, grocery store, recreation/medical clinic) during the pandemic (Figure S1), seven of whom were left unsatisfied/very unsatisfied about it (Figure S6).

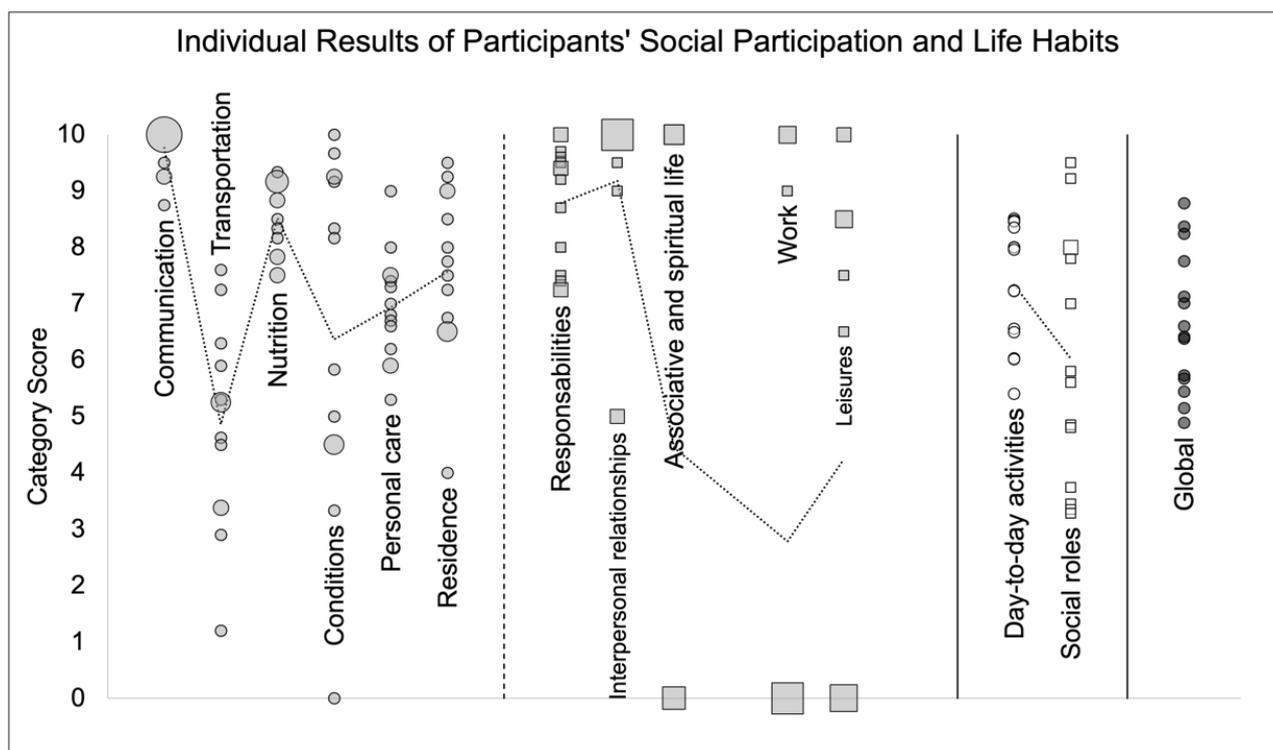


Figure 2. Individual scores of the Assessment of Life Habits (LIFE-H). Presentation of the participants' social participation according to twelve life habits separated in two categories (day-to-day habits and social roles) in the LIFE-H 4.0. The life habits are presented along the horizontal axis and the scores are presented on the vertical axis. Score can range from 0 to 10 for each item of the questionnaire. Squares were used to illustrate items related to social roles, and circles for items related to day-to-day habits. The size of the shapes is proportional to the quantity of participants having obtained the corresponding score. The lines on the graph indicate the average value of each item. The dark circles represent the overall score for all lifestyle habits of all participants.

Firstly, regarding the accomplishment of day-to-day habits during COVID-19, nine participants maintained good physical and mental condition. Eight participants engaged in physical activities to maintain or improve their physical condition (e.g., walking, exercises), or to enhance psychological well-being (e.g., yoga, meditation, music) as reported in Figure S1. All participants maintain the accomplishment of their personal care (hygiene, appearance, health care) during COVID-19, but three experienced difficulties (Figure S5).

Second, regarding the accomplishment of life habits related to their social roles, six participants used health services (e.g., medical/dental clinic, hospitals, rehabilitation center) and five said they were unsatisfied/very unsatisfied (Figure S6). All participants reported

assuming financial, civil and family responsibilities, and the upkeep of their residence (e.g., cleaning, washing, minor repairs), while three said they were independent in completing indoor chores (Figure S3). Ten participants mentioned purchasing and using community services (Figure S1). All 14 participants indicated advocating for their rights, but four perceived difficulties and were unsatisfied (Figures S5 and S6).

All fourteen participants indicated having social, emotional or intimate relationships with their spouse or family members, and twelve participants maintained social connections with acquaintances (e.g., neighbors, co-workers' colleagues or leisure activities partner) as reported Figure S1. Finally, seven participants engaged in leisure activities (e.g., art, sports, hobbies, travel). Amongst them, two (29%) needed human assistance (Figure S4), and one (14%) expressed difficulties (Figure S5). Six (42%) participants mentioned being unsatisfied or very unsatisfied concerning their leisure activities (Figure S6).

3.3.2. Quality of the Social and Physical Environment

The Measure of Quality of the Environment (MQE) was used to assess the role of the environment on the performance of daily activities. Participants identified facilitators and obstacles to the accomplishment of their life habits in their environment during the pandemic. Facilitators of the social environment during COVID-19 included living situation and support of the family for ten participants, while nine said their friends were supports (Figure 3). Additional facilitators included attitudes of service providers, and personal revenues for seven participants. Three participants perceived attitudes of family or friends as obstacles.

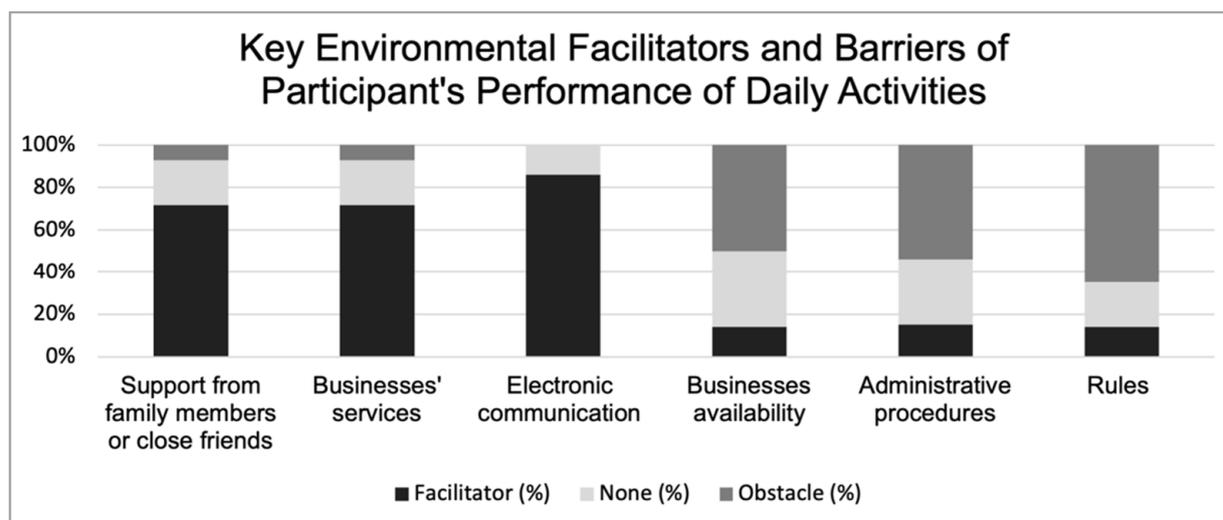


Figure 3. Key Facilitators and Barriers Identified in the Measure of Quality of the Environment (MQE). Presentation of the main environmental factors that facilitated or inhibited participants' accomplishment of the day-to-day habits and their social roles, and consequently their social participant during the pandemic. The percentage is the proportion of participants with the corresponding score.

Seven participants indicated that the availability of businesses in their community (e.g., grocery store, restaurants, retail stores) was an obstacle to their day-to-day habits. In this regard, services offered by businesses in their community were a facilitator for ten participants. Health services in their environment (e.g., hospital, medical clinic, dentist, etc.) were considered a facilitator for four participants, while three indicated health services posed obstacles. A personal vehicle was reported as a facilitator for 13 participants, while three people reported public transportation (e.g., train, bus, plane) as an obstacle.

Nine participants indicated that radio and television (e.g., access, quality of information, subtitling, Quebec sign language) was a facilitator to the realization of their life habits, while electronic communication services (e.g., telephone, fax, e-mail, Internet) was

a facilitator for twelve participants. The availability of technical aids (e.g., wheelchair, orthotics, writing aid, service dog) and the use of technical aids were facilitators for nine and ten participants, respectively. However, maintenance service provision was an obstacle for four people. Government policies and programs were a facilitator for eight participants, while administrative procedures (e.g., bureaucracy) were obstacles to the social participant for seven participants. Finally, rules (e.g., at school, in public places) were obstacles for eight participants.

4. Discussion

The results of this study reported novel findings about the participation experiences of Canadian with SCI who used a manual wheelchair during the first wave of COVID-19. On one hand, our results highlighted the pandemic had little impact on the lives of some people with SCI, as they already expressed facing similar daily social and physical obstacles to social participation before the pandemic. On the other hand, most of the participants expressed that lockdown was challenging and had a negative impact on psychological well-being (e.g., autonomy, sense of self-worth, and freedom). Consequently, the changes in the socio-cultural context due to the pandemic had various impacts on the accomplishment and the satisfaction of the life habits of people with SCI. The results highlight the critical importance of social support and assistance from family and friends during the pandemic and the positive influence of technology to maintain social participation.

Despite the heterogeneity in the public health measures and associated restrictions across the provinces, our findings revealed that restrictions did not have a large influence on participation because “life simply continued as usual”. According to the HDM-DCP, the social participation of people with SCI are already influenced by the interaction between personal factors, such as disability, and environmental factors causing obstacles to the achievement of life habits [9]. In this regard, considering the mutual influence of the person and the environment, some participants reported that the COVID-19 pandemic had little influence on how they interacted with their environment or on their social participation. This finding is consistent with the notion that people with SCI already face daily challenges and obstacles, such as developing and maintaining social relationships and community participation [13]. In addition, several pre-pandemic studies revealed that people with SCI perceived lack of companionship, felt socially disconnected, and experienced isolation from others either some of the time or often [13,38]. In addition, people with SCI face daily barriers to accessing the environment [39]. Of note, climate can significantly impact mobility for people with SCI, with weather sometimes making wheelchair use energy consuming or impossible. Given that data were collected during spring and the beginning of summer, the perceived impacts of the pandemic on the social participation may have been reduced because wheelchair users often experience reduced barriers during these seasons. As evidenced by Monden et al., people with a SCI developed resilience and coping abilities through the ordeal of having a SCI [40]. This previous experience of adversity may have influenced the adaptation and the perceived social participation of this population during the pandemic.

The importance of social support and assistance received by loved ones for people with SCI as a facilitator to maintain social participation during the COVID-19 pandemic was also highlighted. The qualitative and quantitative results support the importance of receiving significant help from loved ones during COVID-19. Some participants also reported that their loved ones were helping them before COVID-19, which is consistent with the notion that people with SCI faced obstacles even before the pandemic. In this study, the help received from loved ones helped to overcome obstacles faced such as the interruptions in home care services. Moreover, nine participants needed significant or complete assistance to perform interior maintenance to their place of residence according to the LIFE-H. A systematic review similarly revealed that greater social support was associated with greater mobility, independence, productivity and interest in leisure activity [41]. Indeed, social support was associated with better health and functioning in people

with SCI [41]. As highlighted in our results, it would be relevant to offer peer support to help keep motivation for physical activity and receive tips. Future studies may consider variations in participation restrictions and coping during the pandemic between those with and without social support network.

Participants in this study developed strategies such as the use of technology to maintain participation in meaningful activities during the pandemic. For example, technological devices were used to facilitate some life habits such as physical activity, to connect with peer trainers, to stay informed, to maintain pre-existing social contacts and for medical appointments. Autonomy is an important determinant of participation for people with SCI [42]. Nevertheless, there are limits to be considered in the use of technology that may reduce satisfaction of carrying out certain life habits (e.g., lack of face-to-face contact). There were additional issues associated with digital technologies, such as accessibility, cost and ease of use that should be addressed. Indeed, some participants reported a considerable increase in cellphone use during the pandemic. However, Hearn et al., reported that the use of the technologies would be useful to ensure that people with SCI continued to receive support during the pandemic, such as access to rehabilitation service. Future research is needed to explore how these services may be better adapted for people with SCI to support autonomy and independence.

Although some participants reported that public health measures (i.e., social distancing and isolation) did not have a large influence on participation, this study highlighted new considerations for individual with SCI. Participants expressed a greater fear of having COVID-19 due to the lack of adaptation of the environment, leaving them feeling vulnerable. For example, some sanitary measures (e.g., disinfecting product dispensing machines with a foot pump) were not adapted, thus exposed them to additional difficulties in integrating protective measures in their daily habits. In fact, a previous study reported that almost 77% people with SCI reported feeling vulnerable to COVID-19 infection [43]. Participants also had to ask for more support from loved ones to compensate for the lack of services and to use home delivery services for essential goods, while others began using home delivery services. This finding is consistent with the notion that even before the pandemic, people with SCI developed several strategies to maintain autonomy [44]. In this context, these strategies allowed participants to maintain the accomplishment of their life habits and their social participation while respecting the new health directives.

Some participants expressed feeling mentally and emotionally challenged during the pandemic. Indeed, according to our results, five participants were not able to maintain a good physical and mental condition and among them, four were dissatisfied or very dissatisfied about their condition. Considering that even before the pandemic, people with SCI had a greater probability of emotional disorders compared with the general population [45] and that they faced challenges regarding the maintenance of a good physical condition [46], this observation further suggest that an additional focus may be relevant for this population. Finally, the long-term effects of the pandemic brought new concerns for some participants regarding the changes in interpersonal relationships after the pandemic, especially regarding physical contact to show affection.

For example, during the first wave (just before data collection), the COVID-19 epidemiological situation in Montreal was critical due to the number of confirmed cases, hospitalization, and deaths, compared with British Columbia. Given there were few cases in Vancouver at the time of the interview, the participants seemed happy with the public health measures.

Limitations must be acknowledged. First, the small heterogenous sample with higher socioeconomic status limits generalizability to other SCI populations. In addition, some participants were actively involved in the larger intervention trial, which may have influenced their social participant. Our study included participants from British Columbia and two cities in the province of Quebec. The location of participants was not explicitly considered in the analysis. Therefore, the climates, public health measures and the varying intensity of the pandemic in each area may have also affected perceived social participation

in participants from different areas. However, the multi methods design allowed for an in-depth exploration of social participation experiences beyond quantitative assessment [47]. Second, while the two quantitative questionnaires (MQE, LIFE-H) were modified to be applicable in the context of COVID-19, the most relevant items were selected by expert researchers. Third, this study used a cross-sectional design with data collection during the first wave; therefore, the results may not accurately reflect social participation during subsequent COVID-19 waves as the situation changed quickly and constantly across the country. Therefore, future studies should examine how subsequent COVID-19 waves influenced social participation, and how to improve social participation in the future.

5. Conclusions

This study provides first evidence about the social participation of people with SCI during the pandemic in Canada, highlighting additional difficulties in achieving their life habits such as the lack of physical adaptation of the protection measure for their disability. Our results underlined facilitators in maintaining social participation such as the support and assistance received from loved ones as well as the use of digital technology. This study provides an opportunity to suggest changes to promote optimal facilitators such as technologies and social support for a better social participation of people with SCI beyond the pandemic. Governmental decisions and future crisis strategies must consider the risks and consequences for people with disabilities, including the unique needs specific to SCI. Future studies may consider variations in participation restrictions and coping between people with SCI with access to these facilitators to accomplish their life habits during the pandemic.

Supplementary Materials: The following supporting information can be downloaded at: <https://www.mdpi.com/article/10.3390/disabilities2030028/s1>, Table S1: Selected quotes of the 14 people with spinal cord injury from Canada related to perceived participation restrictions during COVID-19 pandemic; Table S2: Selected quotes of the 14 people with spinal cord injury from Canada related to change in life habits and new ways to do some things during the COVID-19 pandemic; Table S3: Selected quotes of the 14 people with spinal cord injury from Canada related to future concerns and hopes during the COVID-19 pandemic; Figure S1: Participants' realization of their lifestyle habits according to the Assessment of life-habits questionnaire; Figure S2: Participants' assistive device needed to the realization of their lifestyle habits according to the Assessment of life-habits questionnaire; Figure S3: Participants' adaptation needed to the realization of their lifestyle habits according to the Assessment of life-habits questionnaire; Figure S4: Participants' human assistance needed to the realization of their lifestyle habits according to the Assessment of life-habits questionnaire; Figure S5: Participants' level of difficulty to the realization of their lifestyle habits according to the Assessment of life-habits questionnaire; Figure S6: Participants' level of satisfaction to the realization of their lifestyle habits according to the Assessment of life-habits questionnaire.

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Informed Consent Statement: Written consents were obtained from participants.

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