‘One Step at a Time, One Day at a Time’: Life Profiles of Individuals with Disabilities across the First Year of the COVID-19 Pandemic

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Abstract: Individuals with disabilities underwent substantial changes in life due to the COVID-19 pandemic. However, little is known about the experiences of this population during the first year of the pandemic. Hence, drawing on data from a longitudinal mixed-methods study, this study aimed to identify different COVID-19 life profiles among people with disabilities. Sixty-one participants were interviewed at four timepoints, which paralleled restriction changes in British Columbia, Canada. These data were analyzed to identify different life profiles over the course of the first year of the pandemic. The analysis identified three interlinked profiles: (1) ‘being in a straitjacket’ examines the increasing restriction-related frustrations experienced by participants; (2) ‘seizing the reins’ explores the positive routines that participants established by filling the gaps with meaningful activities; and (3) ‘staying content during COVID’ describes a ‘keep calm, carry on’ attitude, where minimal impact of the pandemic was observed by participants. The three COVID-19 life profiles provide insight to the challenges encountered, resources used, and the varying experiences of individuals with disabilities as they adjusted to a different way of living. These findings can facilitate future research that could develop interventions and services for individuals with disabilities in subsequent pandemics or disasters.

Keywords: COVID-19; stroke; spinal cord injury; disabilities; disaster; lived experience

1. Introduction

In March 2020, a pandemic was declared by the World Health Organization due to an outbreak of the coronavirus disease-2019 (COVID-19). To reduce the spread of COVID-19, protective measures were implemented worldwide, with countries enforcing lockdowns, travel restrictions, and social distancing guidelines [1]. In British Columbia, Canada, public health services introduced a series of restrictions and recommendations that constantly changed depending on the rise and fall of COVID-19 cases. While these restrictions impacted the general population, there were substantial changes in the daily lives of those with disabilities.

The implementation of the COVID-19 restrictions exacerbated challenges with mobility, social isolation, and finances. When using transportation, individuals with disabilities (e.g., physical, visual, cognitive) already faced difficulties such as reliability or safety...
concerns [2]. During the COVID-19 pandemic, there were more problems in accessing transport, such as being denied assistance due to physical distancing guidelines [3]. People with physical and mental health conditions experienced social isolation pre-pandemic [4]. As such, a further increase in social isolation was experienced due to the virtual shift or reduction in activities, impacting the mental health of these individuals [5]. Financially, individuals with disabilities experienced challenges prior to the pandemic. The majority of studies in a systematic review that focused on middle and low-income countries identified positive associations between economic poverty and having a disability [6]. Additionally, in Australia, households consisting of individuals with disabilities faced lower standards of living when compared to those without disabilities, despite having the same amount of income [7]. During the COVID-19 pandemic, a greater financial strain may have been experienced. Underlying health issues, such as immune or respiratory conditions, placed these individuals at an increased risk of complications if exposed to the virus, prompting reduced employment [8]. This had implications on income as well as the loss of employer-sponsored healthcare benefits, which caused financial hardships and a negative impact on life [9].

Individuals with disabilities faced new difficulties caused by the COVID-19 pandemic, such as health and safety concerns. For people who depended on daily caregiver assistance, such as those with stroke, there was an increased risk of infection given these regular in-person interactions [10]. Those with physical, mental, or emotional disabilities were inclined to postpone or avoid their routine in-person medical appointments. This was either due to the stay-at-home orders or associating health-care facilities as locations of increased exposure to COVID-19 [11].

People with disabilities have also reported experiencing some positive benefits from the COVID-19 pandemic. For example, the increased use of remote work produced more opportunities for people with various disabilities in the employment sector, given the more flexible and accommodating schedule [12]. People with disabilities reported their preference for the use of telehealth as an alternative to in-person appointments, with individuals with mobility issues more likely to use it than individuals with other disabilities (e.g., hearing impairment) [13]. The use of telehealth, which was adopted broadly during the pandemic, resulted in increased accessibility and savings in transport costs [14]. Additionally, there was a reduction in the preparation time for medical appointments, such as the need to arrange personal assistance or organize accommodation [14].

The life course approach by Elder explores how experiences throughout a person’s life can impact and influence them and is used in this study to explain how individuals with disabilities respond to the COVID-19 pandemic by examining the principles of ‘human agency’, ‘linked lives’, and ‘time and place’ [15]. Additionally, this approach supports the notion that an individual’s health status is the product of a combination of health conditions that develop overtime [16]. The first principle of ‘human agency’ indicates that people are active agents. However, a person’s choices are influenced by their circumstances (e.g., deciding to follow physical distancing guidelines to reduce exposure to COVID-19). The second principle of ‘linked lives’ refer to the social dynamics surrounding an individual, and how these social relationships shape their interpretation of life events (e.g., feeling more equipped with a strong social network to face adverse outcomes of the pandemic). Finally, the principle of ‘time and place’ describes the present culture and context that an individual is situated in. Since there is a strong technological influence in today’s world (e.g., virtual platforms, mobile devices), people may rely on virtual means to adjust to the way of living during the COVID-19 pandemic.

There is growing literature on the impact of the COVID-19 pandemic on individuals with disabilities. However, even though many studies explored the effects of COVID-19 on individuals with disabilities using quantitative data [17,18], there is little known about the types of experiences across the first year of the pandemic. Additionally, other previous qualitative data studies investigating the impact of the COVID-19 pandemic were focused on specific disability populations [19,20]. This present study included different types of
disabilities (i.e., stroke, spinal cord injury, sensory, and mental health disabilities) when exploring the experiences during the COVID-19 pandemic. Therefore, the aim of this study is to explore the experiences of individuals with disabilities and identify a typology of COVID-19 life profiles over the first year of the pandemic.

2. Materials and Methods

2.1. Study Design

The data from this study were collected as part of a larger longitudinal, mixed-methods study, which took place over four timepoints from May 2020 to March 2021 [21]. The current study was based on a constructivist paradigm [22]. Ethics approval was obtained by the Research Ethics Board of the University of British Columbia. The data are reported using the consolidated criteria for reporting qualitative research [23].

2.2. Participant Recruitment

Convenience sampling was used to recruit participants for this study with advertisements posted on social media sites (e.g., Facebook) and circulated via online postings within community networks (e.g., Vancouver Coastal Health, International Collaboration on Repair Discoveries). Additionally, participants from previous research studies who consented to be contacted for future projects were recruited. To be included in this study, participants had to: (1) be 19 years or older; (2) reside in British Columbia; (3) have a spinal cord injury, stroke, or other disability; (4) speak and understand English; and (5) have access to the internet. Individuals who had a moderate to severe cognitive impairment or aphasia were excluded as their ability to provide consent and communicate in interviews may be impacted. Written consent was obtained from all individuals prior to data collection.

2.3. Data Collection

Participants took part in four semi-structured interviews, each approximately 60 min in length. These interviews occurred over a duration of 10 months and were conducted using an online platform (Zoom). No participants withdrew from the study, and only the participant and interviewer were present during the interviews. Each of the four interview timepoints corresponded with the change in restrictions mandated by the public health services in British Columbia, Canada. The first round of interviews (T1) was conducted from May to July 2020, when participants had lived with the COVID-19 restrictions for 2 months, allowing interviewers to witness their initial reactions to the pandemic. The next interviews (T2) were from June to August 2020 in which restrictions were eased, and July to October 2020 (T3) when restrictions were tightened again due to the rise in cases. The final round of interviews was conducted in January to March 2021 (T4) during the start of the immunization plan. The interview guide was developed in collaboration with a person with lived experience of a disability and was changed for each round of interviews in accordance with the restrictions in that timepoint.

The study team consisted of nine interviewers (six females and three males), and each participant had the same interviewer for all four interviews. The interviewers consisted of master’s and PhD students in research and clinical programs at the University of British Columbia. The interviewers received extensive training on how to conduct interviews from authors WCM and WBM. The participants did not have any previous relationships with the interviewers or the authors of this study. Additionally, all participants were aware of the interviewers’ background and research goals for this study. All interviewers were trained by authors WCM and WMB. Authors SM, WCM, WBM, and JS are researchers while authors RM, EE, and IR are master’s and PhD students enrolled in research programs at the University of British Columbia.

2.4. Data Analysis

All interviews were audio recorded and transcribed verbatim by a separate team of transcribers; identifying information was replaced with pseudonyms. To create a typology
of different COVID-19 life profiles, a novel three-step process was applied. First, the interviewers developed written vignettes for the participants they interviewed, which were their interpretation of the participants’ life experiences over the four interviews. To create the vignette, the four interview transcripts for each participant were examined and used to answer the following topics: demographic information, changes experienced, and participants’ life trajectories. Second, author RM imported the vignettes into the software NVivo (QSR International, Release 1.0, Burlington, MA, USA), and created detailed storylines for each participant based on the vignettes, additional contextual information, and quotes from the original transcripts. Finally, author RM grouped these storylines into life profiles and sub-life profiles (termed facets) that depicted different experiences of the participants across the first year of the pandemic. Facets were generated within each COVID-19 life profile and helped illustrate a clearer picture of the participants’ experiences. The other authors on this paper provided input and reviewed the life profiles and facets that were identified.

The research team employed two main trustworthiness strategies: researcher reflexivity and the involvement of multiple researchers [22]. Interview notes reflecting the interviewers’ role and experiences with the participant were maintained after each interview to examine the influence of the interviewers’ positionality during the research process. The inclusion of multiple researchers throughout data collection and analysis added to the richness of our understanding of the data.

3. Results

In total, 22 participants with a spinal cord injury, 26 participants with a stroke, and 13 participants with other disabilities were included in this study (Table 1). Participants’ demographic information, such as time post-injury, employment status, and living environment, were collected.

Table 1. Socio-demographic characteristics.

<table>
<thead>
<tr>
<th></th>
<th>Spinal Cord Injury (n = 22)</th>
<th>Stroke (n = 26)</th>
<th>Other Disabilities (n = 13)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>m ± SD/n (%)</td>
<td>m ± SD/n (%)</td>
<td>m ± SD/n (%)</td>
</tr>
<tr>
<td>Age</td>
<td>53.77 ± 11.06</td>
<td>65.54 ± 12.68</td>
<td>55.76 ± 16.72</td>
</tr>
<tr>
<td>Sex: Female</td>
<td>9 (40.9)</td>
<td>7 (26.9)</td>
<td>8 (61.5)</td>
</tr>
<tr>
<td>Disability Duration:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since birth</td>
<td>2 (9.1)</td>
<td>0</td>
<td>8 (61.5)</td>
</tr>
<tr>
<td>Since childhood</td>
<td>1 (4.5)</td>
<td>0</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Since adolescence</td>
<td>4 (18.1)</td>
<td>0</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Since adulthood</td>
<td>6 (27.3)</td>
<td>2 (7.7)</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Later in life</td>
<td>9 (40.9)</td>
<td>12 (46.2)</td>
<td>2 (15.4)</td>
</tr>
<tr>
<td>Employment:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full-time</td>
<td>3 (13.6)</td>
<td>1 (3.8)</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Part-time</td>
<td>3 (13.6)</td>
<td>2 (7.7)</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Unemployed</td>
<td>1 (4.5)</td>
<td>2 (7.7)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Student</td>
<td>0 (0)</td>
<td>1 (3.8)</td>
<td>1 (7.7)</td>
</tr>
<tr>
<td>Retired</td>
<td>5 (22.7)</td>
<td>15 (57.7)</td>
<td>4 (30.8)</td>
</tr>
<tr>
<td>Disability assistance</td>
<td>7 (31.8)</td>
<td>2 (7.7)</td>
<td>4 (30.8)</td>
</tr>
<tr>
<td>Homemaker</td>
<td>0 (0)</td>
<td>1 (3.8)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (13.6)</td>
<td>2 (7.7)</td>
<td>2 (15.4)</td>
</tr>
<tr>
<td>Living environment:</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Alone/Independent</td>
<td>7 (31.8)</td>
<td>7 (26.9)</td>
<td>9 (69.2)</td>
</tr>
<tr>
<td>Assisted living</td>
<td>1 (4.5)</td>
<td>1 (3.8)</td>
<td>0 (0)</td>
</tr>
</tbody>
</table>

Notes. Other disabilities = physical disability (i.e., cerebral palsy, Ehlers–Danlos syndrome, arthritis, amputation, arthrogryposis multiplex congenita) = 10; sensory disability (i.e., vision impairment) = 1; cognitive disability (i.e., brain injury) = 1; mental health disability = 2. One participant reported having both a physical and mental health disability.
Three COVID-19 life profiles were identified, ‘being in a straitjacket’, ‘seizing the reins’, and ‘staying content during COVID’, with facets being developed within each COVID-19 life profile as described below.

3.1. Being in a Straitjacket

The participants with this profile (N = 20) spoke about how they felt their lives deteriorated throughout the pandemic. Growing frustrations were experienced as well as a feeling of confinement and inability to adjust to this new way of life. Two facets were generated: ‘increasing sources of stress’ and ‘the COVID clock’.

3.1.1. Increasing Sources of Stress

Various sources of stress were reported by participants including changes in social interactions and concerns over health issues. Some participants who lived with family members described strain as a result of being constantly surrounded by others. For example, participant 45 (female, age 40, spinal cord injury), 3 months into the pandemic stated, ‘everyone’s probably a little bit, just a little bit more on edge, being home all the time’. Additionally, this individual was already working remotely pre-pandemic and valued her ‘alone time’:

“I kind of already work from home, so I do spend all my week at home anyways and now that the kids are home, I mean, that’s the only thing that’s really changed. So, when I was working at home, that was like my escape. Everybody left the house. I was home alone. And now nobody leaves. So, I’m kind of stuck and I don’t have an escape anymore. Kind of the biggest thing for me.”

This contrasted with participants who lived alone and talked about the negative impact of having to rely on social media platforms (e.g., Facebook) or phone calls as their only form of interaction with friends and family. Participant 53 (female, age 53, spinal cord injury) said, ‘It’s kind of a double-edged sword. I mean, do I stay home and not let anybody near me? But that’s going to really increase my anxiety and stress and not do well for my mental health.’

Health issues were another concern for participants, with many indicating they perceived a need to be in ‘survival mode’ throughout the pandemic (i.e., being vigilant in their day-to-day lives). Participant 49 (male, 62, spinal cord injury), 4 months into the pandemic, expressed the additional COVID-19 risks encountered by people with disabilities:

“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... I can imagine for those that have caregivers, that would be very challenging to make sure the caregiver is masked up and doing proper sanitation and things like that. There’s a lot of worry, I think as a disabled person.”

Participant 17 (male, age 72, previous stroke), 4 months into the pandemic, talked about complying with COVID-19 precautions even if others are not, ‘I just see the rest of the world acting like nothing’s going on ... we’re protecting ourselves as best we can ... there’s still an inherent risk of COVID-19, and I’d rather be cautious than sick’.

As participants adapted to schedules that revolved around virtual platforms, some participants reported a transition to sedentary-based routines. This alteration seemed to impact their well-being, as noted by participant 42 (male, age 54, spinal cord injury), 10 months into the pandemic, ‘I’m spending a lot of time sitting down ... it’s hours a day, before [it was] 1 h a day a week or something ... because I’m not active, I have a lot more pain ... twice as much as I used to have before’. Furthermore, this participant expressed additional impacts of not being able to exercise, ‘I really miss the exercise part, because for me, it’s a really big stress reliever. I use sports for that’.
3.1.2. The COVID Clock

Throughout the first year of the COVID-19 pandemic, a few participants reported a sense of monotony with daily routines, which contrasted with their lives prior to the pandemic. A loss of interest and motivation to maintain their seemingly tedious and repetitive daily routine may have contributed to this. For example, participant 28 (male, age 31, physical disability), 4 months into the pandemic, said:

"... I'm at home everyday, I wake up, I see the [inaudible chatter] Do I want to go today? No. [Laughs]. Yeah, if I were just in school right now, I'd be like, I don't even want to do school. That's pretty much it. It's hard to work from home."

This was echoed by participant 42, with a spinal cord injury, who expressed that he felt the days blend into one another, 'The inactivity and not so much the inactivity, but during this period of COVID-19, the days have all gone one into the other. It's really hard to differentiate whether we're on Monday or Tuesday'.

Another factor acknowledged by some participants was the restlessness that stemmed from the uncertainty of the future due to the evolving COVID-19 restrictions. Participant 27 (female, age 60, physical disability), 3 months into the pandemic, conveyed how the ambiguity of the situation had impacted her, 'I find that in some ways I'm still stuck at the beginning part, thinking too far ahead is just too scary. And I get more anxious, so I just stop. I mean nobody knows what it's going to be'.

3.2. Seizing the Reins

Participants with this life profile (N = 24) described being proactive in taking the steps they needed to navigate the COVID-19 pandemic. Even though these participants were concerned about the challenges posed by the pandemic and spoke of the problems they encountered, they appeared to display resiliency in the face of the COVID-19 restrictions. Two facets were identified: ‘a saving grace’ and ‘cultivating connections’.

3.2.1. A Saving Grace

Participants described taking an active effort to improve their lives as the pandemic unfolded. Most participants redirected their extra time and energy into meaningful routines, hence deflecting their attention from the adverse consequences of the pandemic. Participant 32 (female, age 69, lower limb amputation), 11 months into the pandemic, spoke of how she rediscovered her love for music:

"It represents sort of immersion, you know, being able to be out of the world as it is ... if I let myself get involved in the music and do the work I'm supposed to be doing ... all of a sudden it's time to make supper. You lose track of time ... it's a way of being absorbed in doing something and not just sitting back on the sidelines going, yeah, it's another day."

The idea of experiencing a sense of freedom was associated with engaging in meaningful activities as emphasized by participant 9 (male, age 76, previous stroke). He stated the benefits of his boating activities throughout the pandemic, 'I guess that's the blessing of the boat and the availability of it. Because without that we'd be stuck at home'.

3.2.2. Cultivating Connections

The importance of being connected was a prominent idea for many participants with this profile, as they talked about investing in relationships with their community and close ones. Some participants reflected on the initiatives taken to improve their relationships such as participant 20 (female, age 36, previous stroke), 3 months into the pandemic, who decided to take the first step to reach out to others:

"Maybe it's my own fault that I don't have the community that I'd like to have because we've all been in lock down. Maybe we're all feeling this way. Maybe I need to get out there and just ask and instigate, rather than sitting here and not doing anything. Yeah, be the instigator instead of the follower."
Additionally, other participants talked about how connections within their community were improved through occupying new roles. For example, a participant described how she was finally able to become a board member 10 months into the pandemic as her traveling obstacles were removed, ‘I’ve been wanting to do it, so I’m going to do it now because I don’t have to drive all the way… it also means I could make some decisions for our particular group … I want to have a voice’.

3.3. Staying Content during COVID

With this COVID-19 life profile, participants (N = 29) talked about how they developed a sense of acceptance as they lived through the pandemic. Three facets were identified ‘appreciating life as we know it’, ‘technological transitions’, and ‘already prepared for a world not built for us’.

3.3.1. Appreciating Life as We Know It

Many participants appreciated their life circumstances during the COVID-19 pandemic, such as experiencing minimal impact from the pandemic and having a strong social network. For example, participant 12 (male, age 53, previous stroke), said 2 months into the pandemic, ‘I haven’t had a huge change, I can’t really quantify it … it’s just close enough to the same that it’s just not that really noticeable for me’. Furthermore, participants felt their lives were not as afflicted when compared to others, such as participant 61 (male, age 71, spinal cord injury) who expressed, ‘We’re fortunate because of our situation, both where we are and financially and so on. But I think for some people, it would be like if you’ve lost your job and you got financial strains and, it would be terrible’.

Some participants viewed their family and close ones as a constant source of strength during the pandemic. Participant 26 (female, age 79, previous stroke), 4 months into the pandemic, described her gratitude towards her close-knit neighborhood, ‘They’re always coming over to see how we’re doing and if they can help us in any way … I’m very fortunate with the fact that, as I said, I have friends and neighbors who are there to help’. These participants discovered that they were able to spend more time with their loved ones as a result of the pandemic. For example, participant 11 (male, age 82, previous stroke), said 3 months into the pandemic:

“... even exhausted as I was, and I was by the end of term, it wasn’t as exhausted by it as I would be if I had been in the past just even TA-ing courses. So, it’s been a really good experience, actually working remotely. And I hope that it continues to be an option.”

This participant expressed how the transition to online medical appointments enabled her to have an increased capacity to do other essential activities such as household chores, ‘That’s
always a huge outlay of energy for me, having to go to any number of appointments in a week. And because I haven’t had to do that, I have a lot more energy’. This sentiment was echoed by participant 52 (female, age 69, spinal cord injury), 4 months into the pandemic, who stated the benefits of telehealth care, ‘My insurance company now has sent me, I get a free pass to telenet doctors. And for me, like for someone that’s disabled, it would be a real bonus to have a teledoctor’.

Many participants reported how they increasingly relied on technology as an alternative for in-person social activities, such as taking part in online theater shows or celebrations with family. For example, participant 4 (male, age 72, previous stroke) described the ‘brand new’ way he celebrated Christmas, 10 months into the pandemic, ‘it’s the first time we’ve used Facebook for a face-to-face meeting for the family. We’ll probably do it again’. Another individual, participant 10 (male, age 75, previous stroke), 4 months into the pandemic, said while digital interactions were not equivalent to in-person socializing, he still found it to be beneficial, ‘I have two stroke groups, three stroke groups frankly speaking, we’ve been doing that online weekly. That’s been good. Not quite a replacement for the traditional way . . . but still good and entertains’.

3.3.3. Already Prepared for a World Not Built for Us

Some participants expressed how their disability had already prepared them for some aspects of the pandemic. These participants signified being accustomed to living a life where they had to overcome challenges. They described adaptability as a key concept embedded throughout their lives, which now helped them through the pandemic. This view was echoed by participant 52, stating that people usually adapt to ‘whatever life is throwing at them . . . it’s just adapting to different circumstances. And anybody that’s been disabled all their life, we’ve been doing that all along anyway’. Participant 35 (male, age 68, multiple sclerosis), stated 5 months into the pandemic, that his adaptability made him a role model to those around him:

“I think that overall, with my family, my immediate family, people have taken how I’ve adapted to things and maintained a more or less positive attitude as a good example of how to adapt to this COVID-19 thing, it is what it is, when there’s nothing you can do, you’ve got to just take it in stride.”

This sentiment of adjusting better to the effects of the pandemic was further expressed by participant 10:

“[I have been] rehearsing for such a change in my environment through dealing with my stroke . . . And I’ve been practicing doing that, so when COVID-19 came along, it’s just using skills that I’ve been learning in the last few years since my strokes. I actually have an advantage over many people who have not had my experience with recovering from a stroke.”

Another individual, participant 49 (male, age 62, spinal cord injury), echoed a similar outlook 2 months into the pandemic, ‘It’s like becoming disabled… And I think a lot of people, they get a hardship in life. They just can’t get over it. But anybody who’s got a spinal cord injury, they’ve learned something’.

Most participants with this profile indicated that COVID-19 highlighted many social inequities such as racism and ageism, as well the multiple issues they faced. Participant 31 (female, age 31, visual impairment), talked about how those in the disability community were familiar with isolation, an issue that the rest of the population have just started to become aware of, ‘And now that the world for a period of time has been forced into engaging in that way, they are now meeting us there in this place where we have already lived’. This participant introduced the concept of ‘temporal entitlement’, where some people without disabilities were unsettled when their plans became unpredictable, ‘It’s a disruption, but disruptions are part of the expectation. So, it’s not an unexpected disruption. And so yeah, perhaps we in some ways don’t have that same temporal entitlement that a lot of people have’. She expressed that the disability community learnt to navigate
such occurrences to their timelines and have accepted that ‘sometimes you don’t get what you want’.

However, while these issues have been outlined, participant 30 (female, age 40, mobility impairment), spoke to the misconception that everyone were in identical situations both before and during the pandemic. They likened the situation to the Titanic:

“Some people are at the bottom of the ship and have no access to the lifeboats and some people have a huge cabin and all the luxuries and so, we may be in the same year together but we’re certainly not experiencing it at the [same level], even myself, like I’m on disability but I’ve got family support and I have a lifestyle where I can make it work on the money that I have.”

This participant believed that each person experienced a different reality as each individual navigated the pandemic depending on a multitude of factors contributing to their circumstance.

3.4. Interlinking Life Profiles

These COVID-19 life profiles were interlinked for some individuals as this study captures a whole year of a person’s life. Not all participants experienced the same life profile throughout the study, so some individuals were represented by more than one profile (Figure 1). Hence, while there were 61 participants in this study, Figure 1 consists of a larger number of total participants, as 12 participants identified with more than one profile. For instance, participant 36 (female, age 62) with a kidney disease, had a challenging time coping during the pandemic but then took control in improving an area in her life. As a public service worker, she faced numerous occasions where customers did not adhere to COVID-19 protocols and as a result, was in a continuous state of tension and stress. In addition to the precautionary measures taken to combat this problem, such as self-isolating herself from friends and family, she had an ongoing fear of retribution from her customers when requesting them to follow COVID-19 guidelines. This participant communicated her exasperation and helplessness with these challenges throughout all four timepoints. However, during the latter interviews, she visited a psychologist and created an outlet where she could address these emotions. As such, this individual could be described with both ‘being in a straitjacket’ and ‘seizing the reins’ life profiles, combining her experiences of frustration, as well as her conscious efforts to improve her situation during the pandemic.

Figure 1. Three COVID-19 life profiles and corresponding facets.
4. Discussion

Our study identifies three COVID-19 life profiles that describe the experiences of people with disabilities during the first year of the pandemic: ‘being in a straitjacket’, ‘seizing the reins’, and ‘staying content during COVID’. The study was initiated early in the course of the pandemic, only 2 months after the declaration of the state of emergency in British Columbia. As such, the findings account for both the initial experiences as well as longer term adjustments, obtaining an overall view of a participant’s journey amidst the changes in restrictions. The following discussion has been organized based on the participants within the different COVID-19 life profiles identified in this study.

4.1. Being in a Straitjacket

Participants in our study experienced various problems with changes in social interaction due to the COVID-19 restrictions. Reduced social interaction may expose individuals with disabilities to negative health outcomes, such as a decline in mental health [5], and hence, this outlines the necessity for the provision of social support. A contrasting perspective was outlined with this profile in which participants felt overwhelmed as families were suddenly confined together at home. A qualitative data study showed that having personal space being constantly imposed on by others, contributed to strained family relationships [24]. Particularly for individuals who provide care for their family members with disabilities such as stroke, it can potentially increase caregiver burden, as they may be involved in longer hours of care [10].

During the pandemic, individuals with this profile were increasingly apprehensive about their health and safety. This is consistent with the findings of a clinician survey study in which prominent concerns of clients with spinal cord injuries were reported, such as exposure to COVID-19 and worries about caretaker supply [25]. Another finding from our study indicated participant concerns about other people not adhering to the COVID-19 safety regulations and hence increasing risk of transmission. Those with higher psychological entitlement may display non-compliance with COVID-19 guidelines due to beliefs that the consequences of the virus are exaggerated [26]. This can highlight how individuals with disabilities were constantly impacted during the pandemic through the actions of others despite other people’s knowledge of the existing safety guidelines.

Our study identified a decline in motivation and interest in the everyday lives of some participants with this profile. Due to the constant repetitiveness of their activities and an increase of inactivity, there was a perception of the pandemic creating its own timeline, consisting of slower-paced unstructured hours. An observational descriptive study echoed similar findings where individuals reported experiencing a stagnant passage of time during the COVID-19 lockdown [27]. This was attributed to an increase in levels of boredom and sadness, as even though some individuals perceived themselves as having more time, they were unable to use this extra time in the way they desired [27]. Hence, a person’s sense of time could be associated with their sense of self and existence [28]. Another outcome from this profile was the anxiety that revolved around the inability to anticipate or strategize for the future. As COVID-19 is a new virus, it was difficult to predict if or when it would be eradicated. Hence, contrary to previous viruses the world is accustomed to, a lot of ambiguity was associated with the timeframe of the pandemic [29].

4.2. Seizing the Reins

This COVID-19 life profile portrayed individuals with disabilities taking the initiative to explore activities and grow relationships. Participating in activities and receiving social support may be important for individuals with disabilities, as illustrated by a survey study in which individuals with physical disabilities viewed these factors as a contributor to their happiness [30].

An attribute of resilience can be perceived from this profile through the participants’ efforts to adapt to the adverse consequences of the COVID-19 pandemic. According to the traumatic brain injury resiliency model, positive outcomes of resilience include re-engaging
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in meaningful activities as well as adjusting usual participation patterns [31]. Additionally, the traumatic brain injury resiliency model regards social support as a protective factor [31]. Hence, as participants develop connections in their social networks, the support they gain may sustain them through the problems of the pandemic. However, while resiliency is often viewed as an individual trait, it must be noted that it is a socially developed response to an adverse environment [32]. This notion can be expanded upon by the social model of disability [33]. This model states that the way society is constructed (e.g., inaccessible buildings for wheelchairs, attitudes towards individuals with disabilities) is the cause for the challenges a person experiences, not an individual’s impairment or condition. Hence, resiliency may have been demonstrated by the participants in this study because they have been continuously placed in these situations of hardships or societal constraints.

4.3. Staying Content during COVID

Some participants with this profile stated they were in a more privileged position compared to others and as such, they felt the pandemic did not have the same effect on them. An individual’s socioeconomic status, which consists of a person’s economic and social resources, can determine their psychological well-being [34]. Hence, some participants indicated that they had a higher socioeconomic status, describing their financial stability and supportive communities. Maintaining a strong social network has been found to be essential, especially during uncertain and stressful times [35]. As such, during the COVID-19 pandemic, those surrounded by caring communities and families have found this to be an imperative factor of support [36].

Prior to COVID-19, people with disabilities applied technology in their workplaces and used virtual platforms to promote community participation [37]. Participants in our study continued to rely on technology during the pandemic, reporting it as a main contributor to maintaining a relaxed attitude during the abrupt and rapid changes in restrictions. Our findings emphasize the outcomes of the pandemic occurring during the 21st century, the digital age where technology is at the most advanced, hence facilitating the engagement of activities not possible a few decades ago. However, this highlights the potential for a digital divide for individuals with disabilities who have reduced accessibility, training, and support to use technological platforms [38]. A survey study showed that during the COVID-19 pandemic, individuals with disabilities were aware of online healthcare information services but were less likely to use them, compared to those without disabilities [39]. Additionally, digital services such as delivery, subscription, and social networking services were underutilized [39]. Hence, our findings advocate for the need to provide digital assistance as being unfamiliar with technology impacted a person’s ability to establish remote relationships and purchase necessities virtually.

Individuals have developed adaptation and coping strategies to help them navigate changes after their disability [40]. For example, after a spinal cord injury, individuals experience changes in motor and sensory function that may limit engagement in activities, hence adaptations and adjustments are required to gain function and ability in meaningful occupations [41]. The findings in our study align to the above, indicating that individuals with disabilities may have adjusted to the COVID-19 restrictions with more ease due to the use of their previously established adapting strategies. However, participants with this profile spoke to the disparities of the realities faced during the pandemic by those with disabilities and those without. Misconceptions were noted with phrases such as ‘the new normal’ and ‘we’re all in this together’ commonly used during the pandemic. While every individual has been impacted by this pandemic, the circumstance of each person varies. The collective concept of ‘we’ advertises a false impression that all individuals are in identical circumstances. It must be noted that while everyone has been impacted by the pandemic, the resources accessible to each person varies, particularly regarding individuals with disabilities [42].
4.4. Limitations

This study has three main limitations. First, only participants who had access to the internet and online platforms were included, and therefore, the study might not have captured the experiences of people with disability without access to technology. There is still little information on how the pandemic affects those with no online access, particularly as adopting a more virtual-based lifestyle was an important factor in navigating the pandemic. Second, this study explored the COVID-19 life profiles during the pandemic restrictions but not prior to the start of the pandemic in British Columbia. As such, this study does not gain insight into the experiences of individuals with disabilities during their pre-pandemic lives without restrictions. A future area of research could involve the continuation of data collection throughout the duration of the restart plan to explore how individuals with disabilities respond in adjusting to the return to their previous routines. Additionally, targeted interventions could be developed to aid individuals who exhibit the more adverse COVID-19 life profiles. Finally, translators were not included in the study due to funding constraints; therefore, this study recruited participants only if they were able to speak English. This may have excluded individuals who may not converse in English or use alternate communication methods. Hence, this study precluded the challenges faced by these individuals. Additionally, while our study aimed to include diverse experiences of disability, we recruited mostly people with physical disabilities. Future studies could explore the populations with disabilities that are often excluded in research (e.g., individuals with alternate communication methods or with intellectual, sensory, or psychosocial disabilities). It is important to know the experiences of these populations to further our understanding and effectively translate it into policies and development of public services.

5. Conclusions

Our findings provided perspective on experiences among individuals with disabilities with the identification of three COVID-19 life profiles. Additionally, our study raises concerns as well as possible solutions that can be evaluated and addressed in future studies. By recognizing the experiences and needs of this population, our study can help facilitate future guidance for those with disabilities in subsequent pandemics or disasters.


Funding: This research received no external funding.

Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Research Ethics Board of the University of British Columbia (protocol code H20-01109 and date of approval: 17 April 2020).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study.

Data Availability Statement: Not applicable.

Acknowledgments: The authors would like to thank all the team members of the COVID project as well as the participants in this study.

Conflicts of Interest: The authors declare no conflict of interest.

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