

Article

Experiences of Individuals Living with Spinal Cord Injuries (SCI) and Acquired Brain Injuries (ABI) during the COVID-19 Pandemic

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Abstract: The COVID-19 pandemic presents unique challenges for people living with acquired neurological conditions. Due to pandemic-related societal restrictions, changes in accessibility to medical care, equipment, and activities of daily living may affect the mental health of individuals with a SCI or ABI. This study aimed to understand the impact of the pandemic on psychological wellbeing, physical health, quality of life, and delivery of care in persons living with SCI and ABI. A secondary objective included exploring the use of virtual services designed to meet these challenges. In a companion study, participants were surveyed using validated scales of psychosocial health, physical health and healthcare access. In this study, 11 individuals gathered from the survey participated in virtual individual semi-structured interviews to provide accounts of lived experiences regarding critical health challenges and eHealth. Two researchers independently coded interviews for themes using a hermeneutic phenomenological approach. Through analysis of interviews, 5 themes were identified regarding COVID-19 and recovery, access to care, virtual healthcare, systemic barriers, and coping. Overall, limited opportunities due to the pandemic led to a need for adaptation and multifaceted outcomes on one's wellbeing, which provides guidance for future clinical practice.

Keywords: COVID-19; pandemic; experience; perspective; disability; spinal cord injury; brain injury; telerehabilitation; qualitative; interviews



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1. Introduction

The coronavirus disease 2019 (COVID-19) outbreak has rapidly evolved into a global public health emergency, with widespread impacts on individuals worldwide. Measures, including nationwide confinement, physical distancing, and personal protective equipment regulations have been societal responses to the pandemic. In Ontario, COVID-19 restrictions fluctuated from 2020–2021, ranging from emergency “stay-at-home” orders, indoor capacity limits, proof of vaccination requirements, and economic reopening of businesses. These drastic changes may have affected accessibility to medical care, equipment, resource allocation, delivery of care, and activities of daily living.

There is a pressing need to address challenges of people living with chronic conditions during these times of crisis. Common changes to practice during the pandemic include an increased use of telemedicine, limited access to therapies, and reduced outpatient services [1]. People living with a spinal cord injury (SCI) or acquired brain injury (ABI) are vulnerable to psychological outcomes, including anxiety and depression [2,3]. Along with decreased motor or cognitive function resulting from existing injury, pandemic-related societal restrictions may further impact the mental health of these individuals [4–6]. Healthcare providers also relayed concerns from their patients with SCI, including vulnerability to infection, fragility of caretaker supply, inability to obtain routine supplies, transportation

to appointments, and inability to self-quarantine [1]. Rehabilitation physicians further reported that the COVID-19 pandemic caused worsening medical complications, and limited access to clinician and support services [7]. People with SCI expressed concerns including a negative impact on mental health, poor impact on home care, reduced access to medical supplies, medical discrimination, and possibility of being denied access to medical care due to their disability [8]. In surveys distributed to ABI survivors, mental health, social health, and physical health were the most reported factors impacted by social distancing measures [9]. Some people living with ABI reported increased reliance on caregivers or family members to provide healthcare support, and some reported the inability to access regular healthcare services [9]. In a survey distributed to those with disabilities including neurological disorders, majority of respondents expressed unmet needs during the pandemic including emotional counselling, income support, specialized health care, peer support, accessible housing, attendant care, and transportation [10]. An overview of many existing challenges caused by the pandemic postulates a need for further investigating these effects on individuals with neurotrauma.

Objectives

Although scientific and grey literature regarding COVID-19 and neurological conditions is emerging, there remains a lack of insight on the firsthand experiences of these individuals during the pandemic to date [1,7–10]. Thus, the primary aim of this study was to explore the lived experience of persons living with SCI and ABI, with a focus on their psychological wellbeing, physical health, and quality of life related to the pandemic. A secondary objective included exploring the use of virtual services designed to meet these challenges. As the COVID-19 pandemic continues to evolve, a better understanding of impacts on these individuals can provide recommendations to improve current healthcare practices and prepare for future public health crises.

2. Methods

2.1. Procedure

As part of a companion study, an online longitudinal survey was administered at enrollment, 3 months, and 6 months to 142 persons living in the community with an SCI (traumatic and non-traumatic), ABI (all severities, including concussion), or stroke [11]. Participants needed to be 18 years of age or older at the time of the survey. The number of participants was based on an a priori sample size of 117 individuals, calculated from an alpha level of 0.05, 3% level of acceptable error, and accounting for up to 20% loss of follow-up rate. Participants were recruited among those who attended virtual medical appointments at Parkwood Institute, as well as liaising with the following community agencies: SCI-Ontario, Ontario Brain Injury Association, Dale Brain Injury Clinic, and March of Dimes. The qualitative study gathered interview participants from a subset of the population involved in the original online survey.

Of those completing the survey, 11 participants engaged in virtual semi-structured individual interviews. Potential participants were recruited if their responses from the initial survey indicated they have (1) Experienced care delivered through eHealth, and (2) Demonstrated little or great confidence in the ability to manage their health condition. For the latter criteria, participants needed to have scored either low (≤ 3) or high (≥ 8) on Question #5 of the Self-Efficacy measure, “How confident do you feel that you can complete the different tasks and activities needed to manage your health condition so as to reduce your need to see a doctor?”. This criterion was selected to explore potential differences between those who were on the high or low end of the spectrum of the self-efficacy measure. To avoid recruitment order bias, two participants were randomly selected from each consecutive cohort of 10 survey respondents, until 11 individuals agreed to take part in the interview (as determined by saturation of themes).

Participants ranged from age 36–75, with a mean age of 54.4 (Table 1). Of the 11 individuals, 6 participants had an acquired brain injury, 4 had a spinal cord injury, and

1 presented with a spinal cord injury and concomitant brain injury. 7 participants identified as female, and 4 identified as male. All respondents participated in the interview without the assistance of their caregivers. All names are pseudonyms for participant confidentiality. Upon analyzing the transcripts, 5 main themes were discerned, along with 11 subthemes.

Table 1. Demographics of interview participants.

ID/Pseudonym	Age	Sex	Injury	Months Since Injury	Self-Efficacy (1–10)	Location	Interview Platform	Date of Interview
1 (John)	75	M	SCI (T4 Complete)	240 months	8 (High)	Town or Village	Telephone	10 November 2020
2 (Ben)	65	M	Concussion (TBI)	50 months	2 (Low)	Large City	Telephone	2 and 3 December 2020
3 (Jade)	39	F	Concussion (TBI)	26 months	9 (High)	Farm	Telephone	26 January 2021
4 (Adam)	36	M	SCI, TBI	30 months	1 (Low)	Small to Medium City	Video (Cisco WebEx)	2 February 2021
5 (Lucy)	54	F	Adhesive Arachnoiditis	240 months	8 (High)	Large City	Telephone	8 February 2021
6 (Charles)	44	M	Post-concussion syndrome (TBI)	34 months	3 (Low)	Large City	Telephone	9 February 2021
7 (Amy)	56	F	ABI	57 months	2 (Low)	Town or Village	Telephone	16 February 2021
8 (Julia)	40	F	SCI (C3 Incomplete Quadriplegic)	219 months	9 (High)	Farm	Telephone	3 March 2021
9 (Vera)	67	F	ABI	35 months	1 (Low)	Town or Village	Video (Cisco WebEx)	4 March 2021
10 (Sandra)	57	F	Post-Concussion Syndrome (TBI)	81 months	8 (High)	Large City	Telephone	8 March 2021
11 (Monica)	65	F	SCI	23 months	10 (High)	Large City	Telephone	21 May 2021

2.2. Data Collection

The interviews involved a semi-structured approach focusing on psychological wellbeing, physical health, and telehealth. Interviews began with open-ended questions, followed with probes to deeper explore different aspects of participant experiences, based on each interviewee's response. Interviews were split in up to two sessions if needed to avoid respondent fatigue and ranged from 30 to 120 min in total. In some cases, the second interview was not necessary. At the participant's discretion, interviews were conducted through telephone call, or video conferencing using Cisco WebEx (Cisco, Version 41.2.3.17, San Jose, CA, USA). Audio was recorded and transcribed for thematic analysis. The interviewer encoded any identifying information into pseudonyms.

2.3. Data Analysis

A hermeneutic phenomenological analysis was conducted, following Van Manen's approach [12]. Two individual researchers, one of whom was the interviewer, independently coded the transcripts. Analysis was first conducted by both researchers individually, then jointly in order to maintain rigor. Thematic analysis began with a macro-thematic reflection (reading to get a sense of the whole) and then a micro-thematic reflection (highlighting line-by-line phrases that stood out to the researchers). Researchers reflected continuously on the 'whole' and the 'parts' in each interview, then between all the interviews. Themes were finalized between the researchers after on-going reflection and discussion between the two researchers, then with the rest of the team. NVivo qualitative data analysis software (QSR International, Release 1.0, Burlington, VT, USA) was used to organize data.

2.4. Risk Management

During initial baseline survey collection, if a participant endorsed items suggesting suicidal ideation (based on PHQ-9 item #9), the research team ensured further follow-up with medical contact to manage any risk. A similar process was planned during the individual interviews if issues related to suicidal ideation or other significant psychosocial effects emerged. No intervention was needed for any participants during the individual interviews.

3. Results

From a phenomenological analysis, 5 overarching themes and several related subthemes were identified by the researchers (Table 2).

Table 2. Themes.

Category	Theme	Subthemes
Wellbeing and Quality of Life	Adaptation to Current Physical Condition and Disruption in Recovery	Life During COVID is “Not the same”: COVID Disrupted Life Previously Known
		Personal Relationships
		Pain
Access to Care	Receiving Limited Care and Dependence on Homecare	
	Virtual Healthcare Services vs. In Person	Positive Aspects of Telehealth
		Limitations Within Telehealth: Craving Human Interactions
Systemic Barriers	People with Disabilities are ‘Forgotten’	Barriers to Virtual Care
		Limitations in Built Environment
		Perception of Disability in Society
Coping	Coping during the COVID-19 Pandemic	Financial Barriers
		Coping Strategies
		Positive Outlook and Gratitude

3.1. Adaptation to Current Physical Condition and Disruption in Recovery

Adaptation is not a novel life experience to people with SCI or ABI, who have been presented with life changes due to their condition. However, the added COVID-19 related restrictions heightened those challenges and presented new complexities for these individuals. The COVID-19 pandemic presented as an obstacle in the progression of their recovery. Participants often felt a need to “take more breaks”, and “find motivation to push oneself”. Adjustment to COVID appeared to depend on how similar life was pre-pandemic and during COVID. The individual’s response to adjustment was also highly dependent on their stage of recovery. There are a myriad of life stressors that contributed to this disruption in recovery, as illustrated in the following subthemes.

“So it’s almost like a glitch, where you’re kind of stagnant for the time of the pandemic, in the hopes that you’re going to be able to be recharged when it starts again.” Sandra

3.1.1. Life during COVID Is “Not the Same”: COVID Disrupted Life Previously Known

A unique interaction exists between living in a pandemic and having a neurological condition. As participants are living with comorbidities, there is additional stress of unpredictability regarding their existing SCI and/or ABI. Seven participants reflected on activities that brought them joy before COVID that were taken for granted, such as seeing family, friends, getting groceries without worrying about being exposed to a virus. The

pandemic also shed light on the importance of certain aspects of the human condition (e.g., mortality, physical touch such as hugging loved ones).

Overall, COVID-19 has disrupted everyone's lives, and participants emphasized how "it is not the same". The added demands and regulations posed by COVID-19, including mask wearing and social distancing regulations, can be taxing to remember for those with impaired cognitive function from brain injury. Small life stressors (e.g., kids being home all the time) aggravated one person's brain injury symptoms because of the noise level, which added to the multitude of other inconveniences. One participant mentioned that although she was not physically unable to go anywhere, she felt psychologically confined in a 'bubble' because it felt safe. An aggregate feeling of mental and physical fatigue was experienced by many interviewees.

"... I think it's particularly hard on people like me who had a head injury—so we're already wrestling with or trying to come to terms with our diminished capacity, our diminished ability to be as we were before. When you add something like COVID on top of it, it's quite anxiety producing, it's quite stressful." Vera

COVID also resulted in an abundance of life stressors, and additional triggers for stress. Five participants noted simply watching the news, considering the mental well-being of family and friends, anxiety of catching COVID-19 and requiring readaptation to an injury as additional stressors related to the pandemic. The pandemic has taken away simple things that brought joy, which created a sense of loss in participants. The thought of change was unsettling for people, intensifying the feeling of chaos and abnormality in life.

3.1.2. Personal Relationships

Social relationships were undeniably influenced by COVID-19, causing individuals to feel a sense of confinement, loss, and restriction. One participant felt their "world was shrunk down" with the inability to interact with loved ones and added concerns of being immunocompromised due to their health condition. Social support is a vital component to the recovery and rehabilitation of someone with a neurological injury; reduced social networks have thus limited these patients' recovery and adaptation to injury.

"I've had to live such a quiet, isolated life, which was already a huge change for me to cope with my pacing and managing a different life, [...] but it was just another loss I think, not seeing my daughters who bring me great joy, and friends like the encounters that I do have because my energy is so limited, so just made my world even smaller, I guess than it previously had been." Amy

3.1.3. Pain

Pain is another complex experience that has been affected by the pandemic. Participants, specifically those with a brain injury, noted how their chronic pain has been complicated by various stressors brought upon during the pandemic. To cope with the experience of pain, one participant reminded themselves of what gives their life meaning, whether it be family, relationships, projects, hobbies, physical activity. As pain includes physical and psychological components, it has been a significant struggle added onto the difficulties of the COVID-19 pandemic.

3.2. Receiving Limited Care and Dependence on Homecare

A distinctive pandemic-related restriction included the inability to access care and services that are regularly needed by these individuals. Although participants were satisfied with previous in-person care, non-urgent physical assessments were postponed under COVID-19 circumstances. Healthcare personnel understaffing and untrained/inexperienced workers were common concerns mentioned by participants. For example, one interviewee could not contact her mom who resided in a retirement home, due to the absence of staff. Other aspects of wellbeing were ultimately impacted due to the reduction in services.

“I haven’t seen my doctor, I have 6 of them and I haven’t gone to see them. And so, I feel as if my level of care has significantly dropped off, and my ability to access care has significantly reduced. [. . .] and to be able to have a doctor feel, touch and press, that helps them diagnose some of the things that are going on. And to not be able to access that part of my care is really detrimental to the trajectory of my well-being.” Adam

For participants with significant physical impairments, the need for attendant services and therapies introduced the concern of exposure to COVID-19 from interacting with caregivers. In-person appointments that require close physical contact with providers added stress for many participants who have pre-existing health conditions. A sense of trust was needed, as patients had to rely on the conscientiousness of their healthcare workers to minimize transmission of the virus. Conversely, the therapeutic effect of being able to interact with healthcare providers during the pandemic was a huge positive contributor to individuals’ wellbeing.

“Once I was able to get back to therapies, it certainly helped me physically. My body feels better with the various therapies. And even psychologically, I mean I see so very few people right now, as I mentioned, a lot of people in the COVID world. It’s nice to actually get out there and out of the house, and see somebody, talk to somebody, real face to face conversations.” Charles

The implications of reduced access to care have considerably affected many participant’s roles and everyday lives. As those with neurological impairments may require assistance from healthcare workers to participate in what brings meaning to them (e.g., everyday social roles, activities, occupations), the diminished access to care has significantly influenced their lives and caused frustration.

“So in fact, I have had a good portion of my daily care support stripped from me. And that has meant that the things I would normally do, for example, last week I couldn’t go to a Zoom meeting. [. . .] I had had no one come to change me or get me ready for that entire day [. . .] and I had to bow out. And these are things that are not typically something that would occur, and didn’t occur before COVID, but is now occurring to me. So even like my professional things that I would like to do, because my support is limited, has therefore limited me and what I can do.” Lucy

3.3. Virtual Healthcare Services vs. in Person

The COVID-19 pandemic has shifted many aspects of care towards delivery through online means. All interview participants have been involved in virtual care to some extent, and they have described many multifaced implications of telehealth services.

3.3.1. Positive Aspects of Telehealth

Participants appreciated the efficiency and convenience compared to in-person appointments, which saved time for patients and healthcare providers. Video calls were generally accepted as more satisfactory, as they allow healthcare practitioners and patients to view facial expressions and provide a sense of human connection. Eliminating the need for transportation to appointments was another advantage, especially for those living in rural areas. A participant noted how online appointments required less energy to prepare for.

“This is funny, but when I don’t have a lot of energy, like I don’t—it takes a lot to just get up and get showered and get dressed and everything. So now, if I have a phone call, I can just sit there my pajamas, [. . .]—and then I’m not driving and then that’s pretty much all my main activity of the day would be. So that’s kind of an advantage of less physical energy to get myself to the appointment.” Amy

3.3.2. Limitations within Telehealth: Craving Human Interactions

Along with significant advantages, telehealth services had a number of important drawbacks; they were reported to be less satisfying overall. The effectiveness of virtual

services ultimately depended on the purpose of the appointment. For consultations that required physical diagnoses, patients felt reluctant to receive virtual care as substitutes, as patients felt the need to be “seen” and “touched”. Patients further expressed concerns regarding privacy within online care. Instances were also reported where there was a lack in continuity of care, specifically when scheduling follow-up appointments. Furthermore, limitations existed within the opportunities for learning and the care that can be provided, for instance, a participant’s speech-language pathologist was unable to use her usual teaching aids virtually, which hindered therapy.

A huge shortcoming included the inability to maintain human aspects of patient care, specifically human touch. The efficiency of telehealth coincided with the impression of appointments lacking personal attributes of being individualized and tailored. Occasionally, the inability to visualize healthcare providers face-to-face contributed to feelings of social disconnection and severed connections.

“I mean, the lack of being able to—not so much consult—but even share your experiences with another professional, except via Zoom or some other similar method, or by email, is kind of depressing in and of itself. So I think I can say legitimately that the pandemic has made me more depressed, but I was already pretty depressed to begin with.” Vera

The effectiveness of telehealth initiatives ultimately depended on one’s recovery state regarding their condition, including the type and severity of injury. The relationship with one’s healthcare provider also had a notable influence on the impact of virtual appointments. Interacting with clinicians and peers is a prominent source of support during recovery, and this was identified as lacking in virtual appointments.

“I feel, because I knew my people really well, that made a difference. I think if it was a new experience with someone, I’m not sure I could have created the effective healing relationship [through telehealth] that I’ve had with particular couple of my people.” Amy

Overall, a preference for in-person care was widely noted, because of its ability to embody the essence of human interaction. The following sentences describe that ‘essence’, which includes feeling seen, supported, and connected with one another. Participants craved in-person interactions with peers and healthcare professionals, as they have provided an immense amount of support during their recovery. In particular, four people reflected on their experiences in the BrainEx90 Rehabilitation program at Parkwood, and valued the support given by rehabilitation professionals, connections with peers, and felt that they were ‘seen’ during therapy. The program’s absence during COVID-19 has led patients to reflect on what they valued most from therapy. The multidimensional nature of rehabilitation emphasizes how in-person therapy results in better healing, learning, and outcomes.

3.3.3. Barriers to Virtual Care

Barriers to virtual care include factors that prevent a person from being able to access healthcare services virtually, rather than the limitations/benefits of virtual healthcare. Virtual healthcare presented an overload on the nervous system. People with brain injuries reported that symptoms of cognitive, sensory, and physical limitations manifested in difficulties concentrating, feelings of fatigue, and exhaustion during lengthy video calls. Additionally, expenses associated with equipment, issues with internet connection in remote areas, and increased cost of living associated with the pandemic, were other contributing factors identified that may impede access to telehealth.

“I think honestly the biggest limitation that I would find is the money to get the right, best equipment for the handicapped. I know what I need to do to adapt so I can handle it more. I know it wouldn’t be the same for someone else, but I know someone else might need the head gear or something of that nature. I just think it’s the infrastructure that stops us more than the actual software.” Lucy

3.4. People with Disabilities Are ‘Forgotten’

Pre-existing inequalities experienced by people with disability were exacerbated by the COVID-19 pandemic. Participants stated how the society we live in (e.g., environmental, absence of resources) ‘disabled’ them more than the injury itself.

3.4.1. Limitations in Built Environment

COVID-19 has heightened existing restrictions in our society’s physical environment which does not allow people with disabilities to participate, stay active, etc. A common barrier identified in maintaining physical activity regimens was the reduced access to public facilities, which participants felt contributed to increased weight gain, lower motivation in carrying out exercises, and overall dissatisfaction with one’s physical health. Two individuals acquired more physical complications (e.g., more pressure sores in SCI), which may have been associated with decreased physical activity.

3.4.2. Perception of Disability in Society

Normative assumptions of people living with disabilities became especially apparent to individuals during the COVID-19 pandemic. Individuals living with SCI and ABI expressed feeling overlooked in many of the government-mandated policies and resources designed in response to the pandemic, including lack of financial support and access to healthcare. Participants also noted how the government has not exempted people with healthcare conditions who may need extra caregivers, to increase their ‘social bubble’. Along with feelings of being discounted, participants felt stigma through many regulations and restrictions (e.g., access to services).

“But the assumption is. That that’s all I’m gonna do. That I’m just not going to have any appointments, I’m not going to have any responsibilities, I’m not going to have business. I can, you know, ‘she doesn’t get fed, doesn’t get changed for a few hours, what difference does that make? she’s just going to be in bed all day anyway’—that’s kind of just thinking that goes on, I feel.” Lucy

3.4.3. Financial Barriers

Increased costs of living were prominent, including inflated prices for medical supplies, and individuals raised concerns regarding the lack of extra financial support. By living on fixed incomes and being ineligible for financial supports (e.g., CERB), individuals felt challenged in the ability to sustain themselves with the complicity of the pandemic and reduced access to resources.

*“And so, the systematic punishment of disabled people at the will of the people who say, well **** them, we couldn’t give them any more money because of the fact that they’re not contributing to society from a completely ableist viewpoint, is one of the most detrimental things I’ve experienced in the past year.” Adam*

3.5. Coping during the COVID-19 Pandemic

3.5.1. Coping Strategies

The pandemic has led people towards identifying their own strategies for coping with adversity. Many participants experienced life with COVID as a challenge that led them to reflect on their lives and pay attention to themselves. Participants contemplated on what they valued the most in their lives precisely because it was absent during the pandemic, specifically things that previously brought joy, such as seeing family members in person or receiving care in a therapeutic group setting in person at Parkwood. Individuals found that enjoying hobbies, maintaining social contact with their close networks, and virtual support groups has helped manage the culminating effects of living during COVID-19.

Five participants mentioned that their physical and mental health was maintained during the pandemic, and even improved because of walking. Physical activity was found to be a significant coping strategy, which participants further reported to be interrelated

with emotional wellbeing. Two individuals noted that walking was ‘the highlight’ of their day, and that walking helped them ‘get through’ the pandemic.

Although people have developed and demonstrated immense strength and resiliency during the pandemic, some have felt these coping strategies simply acted as a distraction, and “a mental escape from reality”. It remained challenging to undergo these changes that the pandemic brought forth. Although the pandemic has forced people to recognize their own coping strategies, participants felt unmotivated to participate in daily activities due to elevations in mental and physical exhaustion. Consequently, people felt less energized to participate in coping activities (e.g., social support) that are common protective factors in dealing with challenges.

Talking to healthcare professionals was mentioned as a source of support for many participants during the pandemic. This highlights the importance of the therapeutic relationship between healthcare providers and individuals with neurological disabilities and its effect on their recovery journey.

3.5.2. Positive Outlook and Gratitude

Having gratitude and maintaining a positive viewpoint in situations despite difficult circumstances, was found as another way to help manage stressors. Two participants described strategies such as recalling past accomplishments, and “finding joy in small wins” which helped face the elevated difficulties encountered during the pandemic. One participant with a brain injury found new ways to engage in hobbies such as switching to audiobooks instead of reading paper books.

“I feel pretty fortunate, I guess in comparison to a lot of people if they’re living alone or in cities and apartments and don’t have supports and access. And I think COVID could be really, really, very hard for a lot of people.” Amy

4. Discussion

From the accounts of those living with neurological conditions, it is strikingly complex to navigate life during the pandemic. Persons living with SCI or ABI are presented with significant additional challenges to meeting their needs. It remains important to gather first-person accounts to better understand the multidimensional factors influencing the daily experience of living with a disability.

4.1. Psychological Well-Being

The COVID-19 pandemic has unequivocally affected the wellbeing of those with neurological conditions. Yet, the challenges brought upon by COVID-19 may not be as drastic compared to many of the changes experienced while learning to live with their conditions. Notably, the unique life experiences, resilience, and strength that those with ABI and SCI have accumulated is important to acknowledge. However, COVID-19 has emphasized many existing limitations that our society has built into the environment which prevent people with disabilities from participating in activities.

Limited contact with loved ones was identified as a profound outcome of restrictions imposed by COVID-19. For those living with chronic conditions, it is a further obstacle in recovery and adaptation as social connections have proven to be an immense support in rehabilitation [13]. Social isolation, a commonly reported feeling caused by pandemic-related restrictions, is a consistent finding within the literature. Adults with disabilities reported a greater level of social isolation than the general population [10]. It remains valuable to create initiatives in rehabilitation that address negative consequences of social isolation, including loneliness and depression, regardless of the pandemic [14].

Society’s perception of disability perpetuates challenges to the wellbeing of those living with a neurological condition. A negative gaze of others on bodies that deviate from ‘normal’ can substantially affect one’s psychological wellbeing, as viewed from an embodiment perspective [15]. Participants felt that the public’s perception on those with disabilities evidently became heightened in the distribution of resources during the

pandemic. Fewer government funding and supports during the pandemic was thought to be fueled by ableist ideas, that those with disabilities do not contribute to society in the same capacity as able-bodied people. Systemic barriers and policies have historically excluded people with disabilities from receiving equal resources as the public [16]. As a person's wellbeing can be defined as a dynamic balance between resources and challenges, the inadequate support given to these individuals had a consequential effect on many dimensions of daily living [17].

Humans employ coping strategies as a response to stressors that occur in everyday life. Participants mentioned a variety of ways in which they coped with COVID-19 related challenges, which continuously change and exist on a continuum. Consistent with other studies, social support of family and friends, online support groups, physical activities, and mindfulness have been helpful for brain injury survivors during COVID-19 [9]. However, factors including distance from family and friends, and personal preferences in receiving support may have constrained these strategies or led others towards using different methods. Gratitude and optimism that some participants expressed during this time has historically been proven to generate positive mental health effects, which may have contributed to building resilience in these individuals [18].

4.2. Physical Health

It is difficult to distinguish how one's physical and mental health have been altered, as the mind and body are interdependent. Often, individuals described positive psychological and physical benefits when receiving patient care (e.g., occupational, physical therapy). The non-dualistic nature between the mind and body may further explain why participants placed value on in-person physical healthcare appointments. Additionally, many participants reported psychological benefits when they engaged in physical activity, such as walking. Similarly, studies have shown that many psychological benefits, such as reducing depressive symptoms, exist for those who engage in physical activity [19].

A remarkable decrease in overall physical health, possibly due to lower physical activity level and poorer diets, were reported during COVID-19 [20]. Findings were consistent in a survey distributed to people with disabilities, as they described worsening diet, lower physical activity, and increased substance use including alcohol, cannabis, and smoking during the pandemic [10]. During the interviews, participants with chronic pain associated with brain injuries, noted increases with their pain experiences (e.g., headaches) that substantially affected their physical and psychological wellbeing. The pandemic may potentially exacerbate chronic pain due to multiple psychological stressors [21,22]. Considerations regarding the multidimensional factors of pain present many implications for future care, recovery, and impact on health systems.

4.3. Telehealth

Consistent with previously reported findings, telemedicine has numerous advantages including eliminated travel time, environmental benefits, and limiting spread of infection for vulnerable populations [1]. Although participants valued these benefits of virtual care, there were also considerable limitations in the effectiveness and quality of care delivered through telehealth.

As a historic belief, humans value the physical aspect of touch in the process of recovery [23]. Patients often look towards healthcare providers as 'healers', through hands-on contact [24]. Similar limitations of remote care were reported from another survey, which raised how complex care needs of individuals with SCI may necessitate more dependence on physical examination for diagnoses, rather than non-injured individuals [7].

The value of healthcare providers in aiding several facets of wellbeing is also apparent. Patients substantially noted the psychological benefits of interacting with healthcare professionals to cope with stressors, which are worsened during these times. It is critical to bring attention to how healthcare providers offer much more psychological and social support than they may perceive.

Furthermore, rehabilitation is characterized by an abundance of skill-learning to aid in recovery and self-management [25]. However, this learning process may be hindered through virtual platforms as a means of providing care. Participants noted difficulties in visualizing what occurs through a two-dimensional screen (e.g., exercises in physical therapy). The importance of observation and mirroring that typically occurs during rehabilitation and its virtual limitations is further emphasized.

As neurological impairment manifests in unique ways in everyone, there are distinctive challenges that vary with each person. However, people who have sustained their injury for a longer period of time, or who view themselves to be considerably healthy, seemed to be more satisfied with virtual care. Additionally, a study found that among healthcare providers who transitioned some practices to telehealth, technology did not fully meet their patients' needs [7]. An interesting avenue of future research includes investigating the drawbacks of virtual care from the perspectives of providers, to provide a more comprehensive outlook.

4.4. Delivery of Care

The inequities and care gaps highlighted and exposed during the pandemic are extremely concerning for those with chronic conditions. Paralleled with findings from another survey, people with disabilities reported greater unmet needs and services during the pandemic, which support health, wellbeing, and social participation [10]. An unfortunate reality exists where marginalized populations may be more likely to suffer from negative effects, and experience inadequate access to services during the COVID-19 pandemic. The broadened disparate influences on the distribution of resources are ultimately detrimental to these individuals' wellbeing. As previously mentioned, people with disabilities may be denied care when decision makers determine how limited services are distributed [1]. These disruptions in care may be particularly problematic for vulnerable individuals in the early stages of injury, or those who have not developed reliable self-management techniques.

Furthermore, the unequal distribution of care and assistance by authorities have led to individuals becoming more reliant on others, while juggling the need to be independent. A balance between independence and dependence is a need that humans constantly strive towards [26]. Although a person's disability can arguably affect what one is able to do, the effects of COVID-19 have worsened one's ability to participate in what brings meaning to them. As a result, many everyday opportunities for these individuals, such as activities and community involvement, were taken away because of pandemic-related consequences.

A call for more equitable approaches in adapting to public health emergencies is crucial to ameliorate these negative effects. Healthcare systems may be criticized for a reactive method of responding to arising problems, instead of a more preventative and proactive approach. As a result, the pandemic has brought to light many areas of improvement that can be made within healthcare, through addressing stakeholders and policymakers that fundamentally influence decisions of action. Findings may also inform efforts to support inclusive policy change within multiple levels of government (e.g., provincial, federal) or with other healthcare decision makers. By investigating these questions, improvements will hopefully be made towards delivering patient care and outcomes.

4.5. Implications

A multitude of factors exist that contribute to effects experienced by these participants. For example, geographical barriers may present limited supports and services for those with neurological conditions. Additionally, a participant's occupation (e.g., nurse, veteran) may affect their experiences and perceptions of stressors during the pandemic. An overall hindrance in the timeline of recovery for many patients has clearly been exhibited throughout the study, involving several dimensions of wellbeing. Thus, it is important to consider the consequential impact on patients, healthcare providers, and systems.

There are many potential benefits of providing more accessible, evidence-based resources for people living with chronic conditions. Targeted outreach through social support

networks, and educational resources on topics such as COVID-19 preventative measures may be advantageous [27]. Similarly, healthcare providers have reported an increased need for education on how COVID-19 impacts those with disabilities, patients' rehabilitation, practice adaptations, advocating for patients, and telehealth [7]. Existing recommendations, such as frequent hand-washing and personal protective equipment, presented as a response to the pandemic, may not have considered those with limited physical or cognitive abilities. Many participants further noted a gap in initiatives, such as group support, that they would have liked to participate in. Increasing the accessibility to these resources is needed.

4.6. Limitations

The virtual method of conducting these interviews, due to circumstances of the pandemic itself, may have affected how participants reported information. Although there were little to no technical difficulties when administering the interviews, the ability to build rapport may have been affected through an online platform. Demographics including age, location, ethnicity, and culture may further contribute to each individual's experiences. The attributes of these participants are instrumental factors towards their lived experiences. These stressors related to COVID-19 may not be unique to people with disabilities. Additionally, the variability in each participant's interview time, along with coinciding local and global COVID-19 restrictions that were constantly varying over time is another factor that may have affected participant responses.

4.7. Future Directions

This current study suggests various avenues and areas of future research. By further investigating and contrasting findings within injury subgroups (SCI, ABI), tailored recommendations to optimize interprofessional care can be made for specific conditions. Discussions with healthcare practitioners about their experiences during the pandemic regarding reflections on their patients, delivery of care, as well as strategies to effectively implement better practices, may provide another outlook.

5. Conclusions

The pandemic has posed multidimensional challenges on the wellbeing of those with neurological conditions. Potential increases in psychological and physical consequences during the COVID-19 pandemic raise critical concerns that require further investigation. As voices of those with chronic conditions continue to be underrepresented in the literature, this study aims to express the significance of incorporating lived experiences in forming policies and services for these individuals. It is critical to consider the unique health needs and issues faced by these vulnerable groups of people in the current pandemic.

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