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“It’s been a double-edged sword”: An online qualitative exploration of the impact of COVID-19 on individuals with spinal cord injury in the US with comparisons to previous UK findings

Running title: SCI and COVID-19 online qualitative study

Abstract

Objective: The impact of COVID-19 lockdowns and social distancing for persons with spinal cord injury (SCI) are poorly understood. This exploratory online qualitative study collected self-reported COVID-19 experiences from persons with SCI in the United States (US). To enrich understanding, these data were compared to similar previously-published data from a sample of SCI participants from the United Kingdom (UK).

Design: Explorative, online qualitative study. Participants completed an online survey of open-ended qualitative questions pertaining to their experiences during the pandemic. Thematic analysis was utilized to generate themes from the US data. These themes were compared to our previously-published thematic analysis of data from the UK.

Setting: Community-based sample of persons with SCI in the US.

Participants: Participants were recruited via SCI-focused research registries and social media outlets serving the SCI community, using convenience sampling (*n*=36). Key themes identified in the US data were compared to themes identified in a similar sample from the UK (*n*=42) collected at the same time and published previously.

Results: Analysis resulted in three themes from the US data, each containing positive and negative qualitative reflections. Themes included 1) health and access to care, 2) making sense of the pandemic, and 3) daily life during the pandemic. Each theme captured common facets of life during the pandemic, often shared by those without physical disabilities, but included accounts particularly relevant to persons with disabilities. Comparisons to thematic findings from the UK study revealed similarities (e.g. healthcare access challenges, isolation) and differences (e.g. importance of previous SCI experiences).

Conclusion: We detailed common experiences of COVID-19 pandemic lockdowns and their impact on people with SCI, while contrasting these with sense-making positive reflections and social benefits that appeared to be helpful in managing distress and coping with the pandemic.

Keywords: SCI; COVID-19; pandemic; lived experiences; thematic analysis

Introduction

In February 2020, the United States (US) declared a public health emergency due to COVID-19, an infectious disease caused by the SARS-CoV-2 respiratory virus. The high transmission rate of COVID-19 led to enforced regional lockdowns, physical distancing and masking requirements, and a reduction in nonessential services. As we approach three years of living with this disease, we are beginning to see the long-term effects of COVID-19 as well as the consequences of these emergency orders put in place to mitigate the spread. Psychological well-being has suffered as a result of the pandemic, evidenced by increased rates of depression, anxiety, and feelings of social isolation (1,2). Lockdown restrictions, overwhelmed healthcare systems, and supply chain bottlenecks disrupted access to essential medical supplies and services. While these impacts have been felt by all, they have created additional challenges for individuals with disability, including those living with spinal cord injury (SCI).

People with SCI may have a higher risk of contracting COVID-19 given more frequent interactions with medical professionals as part of routine health management (3). These individuals may also be more likely to develop severe infection due to the increased risk of respiratory complications in this population (4) and immunosuppression (5,6) making them vulnerable to infection and adding to their risk of severe COVID-19 disease. For these reasons, there is heightened concern for contracting the virus which is likely amplified by the fear of being denied lifesaving treatments as a result of triage guidelines that prioritize individuals without disability (7). Results from a recent survey revealed that concerns around medical rationing are associated with worse perceived overall and mental health among individuals with SCI (8). Additionally, these individuals were already at a higher risk of depression and anxiety pre-pandemic, so the disruption to healthcare services, including mental health services, has likely exacerbated these conditions (9). Further, disrupted access to medical supplies used for SCI-specific self-management (e.g. gloves for bowel care or wheelchair parts), likely compounded the risk of secondary health complications in this population.

While considerable work has been done to understand the impact of COVID-19 on healthcare workers and general members of the population, less work has sought to understand the impact on and perspectives of those living with SCI. The purpose of the present article is to share the experiences of a sample of people with SCI in the US during the COVID-19 pandemic, including changes to daily life, personal challenges, positive experiences, and potential future impact of the pandemic. Utilizing an explorative, online qualitative approach, we sought insights into changes to daily life, personal challenges, positive experience, and potential long-term impact of the pandemic.

In our recent article, we explored the impact of COVID-19 on individuals with SCI living in the United Kingdom (UK) (7), derived from data collected at the same time as the US sample. We gained a rich understanding of challenges and successes that people with SCI experienced while living through this ongoing pandemic. Like the US, the UK government imposed stay-at-home orders to prevent the spread of disease, which led to social distancing, self-isolation, and the common use of face masks. Mandatory social distancing policies and ‘stay at home’ orders, while protective, likewise limited access to essential services. The present work elucidates similarities and differences between the present US sample and the previously-published UK cohort, which may have important health policy and practice implications.

Materials and methods

Design

A qualitative, online survey design was employed to explore participants' experiences during the COVID-19 pandemic. Our design is based on recommendations by Braun, *et al.*(10), who advocate qualitative surveys as a way to focus on peoples' views, experiences, and meaning-making practices leading to richly detailed and nuanced data. This design has been successfully utilized in previous research in health-related contexts (e.g. endometriosis) (10,11). Further, this design allows researchers to gain rich insights into the topic of interest, while respecting participants' time and exposure risk, and was used successfully in our previous work in the UK to elicit rich, detailed data (7).

We used a convenience sampling approach. Persons with SCI were recruited from several SCI-related US community-based groups, research registries, and networks of personal contacts and social media outlets. Upon completion of the survey, participants were also asked to share recruitment materials with their networks. This convenience sampling approach allowed this survey to disseminate quickly, capturing a poorly-understood set of phenomena in a timely fashion. Preliminary understanding of these experiences allows us to build toward future work.

Participants

As this was an exploratory study, eligibility criteria were purposely broad. Eligible participants were those who self-identified as adults having an SCI and currently living in the US. Given the open recruitment approach and the broad understanding we sought, SCI subgroups (i.e. different levels or degree of injury) were not factored into sample allocation. No explicit exclusion criteria were implemented. Our approach intentionally emphasized inclusivity and self-selection to explore pandemic experiences for persons with SCI as efficiently and broadly as possible. Recruitment continued until incoming responses were not generating new insights. Participants in the UK were recruited in a similar fashion, during the same recruitment period, and met the same inclusion criteria (7).

Procedure

Three authors (one medical anthropologist; two psychologists) designed the survey. The online interface was designed using Qualtrics. We piloted the survey with colleagues with SCI to check that time to complete, clarity of questions, and depth and length of responses were appropriate and not burdensome. Individuals meeting inclusion criteria were invited to review the consent information provided via an online information sheet. If they wished to enroll in the study, participants were then able to indicate consent in the Qualtrics survey before completing the questions, after which they were provided with a link to access the survey. Data from the UK study were collected in the same fashion during the same time frame (7).

The survey was open for participation (for both US and UK) from September 30, 2020 to October 28, 2020. At this time, COVID-19 vaccines were still in trial, cases in the US began to spike in some areas again, but no national lockdown was in place. Prior to the survey being distributed, the US had a previous national lockdown (spring 2020) and another series of restrictions were being considered. Circumstances for the UK sample were similar, with a previous national lockdown ending in spring 2020 and another starting the week after data collection ended (early November 2020).

Measures

Demographic and injury-related information. Participants were asked to complete 10 questions pertaining to their demographic details, including age, gender, race, level of injury, cause of injury, year of injury, and injury completeness.

Qualitative survey. The purpose of this questionnaire was to capture the views of people living with SCI on a variety of aspects of their life during the COVID-19 pandemic. The survey used open-ended questions. Each question invited participants to share their thoughts and experiences, in as much or as little detail as they preferred. This technique has been advocated by other qualitative researchers as a practical and effective method of collecting rich qualitative data (10). The qualitative survey questions can be found in ***Table 1***.

*Insert **Table 1** near here*

Analysis

Data were analyzed using an inductive approach to thematic analysis involving three authors (ER, JH, AP) (12,13). Thematic analysis was used to identify latent themes, following a relativist social constructionist perspective, acknowledging that individuals mentally construct their world of experience through cognitive and social foci and processes (14). A social constructionist epistemological stance allowed the researcher to theorize sociocultural contexts and structural conditions which may influence experiences during the COVID-19 pandemic (12).

Analysis followed well-established qualitative methodology for the treatment of narrative data (10,11). Analysis began with a free reading of the data by study team members. Data were read to gain familiarity with the dataset. Initial thoughts and interpretations were noted. Early potential themes were also noted for further discussion. Next, the responses were open coded by hand using short descriptors that briefly characterized the content of each section of a participant's response. Following initial coding, similar codes were combined.

Groups of coded text were pile-sorted according to inductive concepts that were commonly represented in the data. The resulting categories represented themes in the data; repeated ideas and thoughts across numerous respondents. The commonality of these ideas suggested they were salient feelings, experiences, and values that captured common experiences in the sample (15,16).

All authors discussed thoughts, ideas and interpretations throughout this process in order to identify themes that best captured the data in the most appropriate and representative way. To ensure rigor, quality, and credibility, consensus was reached at each step following repeated discussions among the authors (17). This involved thorough review of themes and their corresponding quotes to ensure the findings were grounded in the data after the initial analysis. Data for the UK arm of this study were analyzed in the same way (7).

Results

The final US sample consisted of 36 people living with SCI, in line with recommendations for the online survey methodology and analytical process utilized, (10) as well as saturation of ideas expressed in the responses. All participants self-identified as over 18 years of age (no upper age limit) and had some spinal disability (see ***Table 2***). The sample was largely white (94.4%) with a mean age of 55.7 years (SD = 13.1 years). The average time since injury was 21.5 years (SD = 13.6). Sample participants largely self-identified as men (75%; in contrast to the UK sample, which was 81% women) in keeping with the normative demographic by gender of the broader SCI population.(18)

Insert ***Table 2*** *near here*

Analysis resulted in the identification of three themes, each containing positive and negative reflections relevant to the topics therein. These themes included: 1) health and access to care, 2) making sense of the pandemic, and 3) daily life during the pandemic (19). Each theme captured facets of life during the pandemic that were common for many, often shared by those without physical disabilities, but also in

cluded accounts particularly relevant to persons with physical disabilities. ***Table 3*** presents further quotes in support of each theme. Finally, we offer comparisons between these thematic findings from the US sample to previously published themes from persons with SCI from the UK (7).

Health and access to care

The concerns about health and access to care were a common theme expressed by a clear majority of US participants (articulated by 66.7%, n=24 participants); unsurprising as it is a common experience widely shared during COVID-19 lockdowns and restrictions. "Having all appointments cancelled" and "virtual health examinations are worthless" were common causes for concern. One participant commented:

> *Access to dental, medical and vision appointments delayed or even ceased. Video conferencing helps with doc appointments but impossible for dental and vision. (Participant #18*[1]*, LOI*[2]*: Thoracic)*

Many participants experienced closed clinics, canceled appointments, and delayed procedures during lockdowns. As we detailed above, persons with SCI generally rely on a greater degree of routine medical care. The lack of such care can have a more immediate and far-reaching impact on overall health and quality of life, especially considering the need for ongoing rehabilitation to maintain health and physical function (3).

Also, within this theme were reflections on the impact on physical activity. Physical activity is a major source of health and wellbeing, especially for those with SCI. Concerns

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[1] Respondent identification number

[2] Level of injury

surrounding physical deterioration were raised, with one participant highlighting the deterioration in their physical strength. In a similar vein, others echoed concerns surrounding a lack of access to activity and exercise facilities:

> *The largest single issue is inability to go to the gym, which is key to my ability to keep my motor skills functioning. The gym is back open but I have lost some strength and ability. Pool, which I did once a week to practice walking, is still not available. (Participant #6, SCD[3])*

For some, the critical lack of access to specialists combined with the lack of physical activity had a cascade effect. Diet, inactivity, and the lack of access to a wheelchair specialist resulted in increased pain for some. Over time, these challenges can lead to musculoskeletal damage, pressure sores, and other concerns (20,21). For example:

> *I have been drinking alcohol and eating more (mostly because I'm now working 10 feet from my refrigerator, and because of coping), and moving and getting out less, which has resulted in gaining at least 15 pounds. This has caused issues with alignment in my wheelchair, as well as some recent increased shoulder pain with my transfers. The options for seeing a wheelchair specialist for any wheelchair adjustments have been limited, and my wheelchair has felt very uncomfortable the last several months. (Participant #2; LOI: Thoracic)*

These issues, though perhaps familiar to those without a SCI, posed considerable long-term health risks for those in our sample.

Two major issues dominated responses specific to SCI-related care management concerns: the availability of care supplies and access to caregivers. These were critical given the risk of infection and continued degradation of physical ability. For example:

> *My personal supplies like disposable gloves have been hard to find, or suppliers are price gauging, charging 2x to 6x as much for supplies. Other supplies like hand sanitizer and sanitizing wipes have understandably been difficult to access. (Participant #2; LOI: Thoracic)*

> *There have been a few times I was not able to order medical supplies in the same quantities I had in the past because of shortages (latex gloves, specifically)… I also*

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[3] Spinal cord disease

> *worry that access to medical supplies that allow me to live healthfully and independently will be impacted. (Participant #33; LOI: Thoracic)*

Lack of access to equipment could lead to increased bladder and bowel management issues (e.g. increased UTIs, etc.). These are important secondary consequences of SCI that require careful management, and the implications of the lack of access to provisions described could feed into further complications (22). This potentially exacerbated the ways in which lack of access to healthcare hampered engagement in activities of daily living and social participation, key markers of the impact of disability on engagement in everyday life.

Further, access to competent and healthy personal care attendants (PCAs) to come into homes was increasingly challenging. PCAs had to risk their own health and assure their negative COVID status before entering others' homes – both of which were potentially impossible given the time between infection, being contagious, and the onset of symptoms (if any) for those with COVID-19.

> *PCAs impacted my cautious mind to enforce strict hand washing/gloves, hygiene and educating them as well as providing them with new masks and gloves daily, never re-use… I'm taking chances that PCA doesn't get COVID since they're at multiple patients, facilities, family/friends places. (Participant #10; LOI: Cervical)*

> *For me, having a visiting nurse has been a double-edged sword. It is nice to have a familiar face every day but I am constantly worried about their schedule of other patients and who might be asymptomatic and spreading the virus. (Participant #27; LOI: Thoracic)*

Overall, the frequency with which persons with SCI must interface with the healthcare system to maintain their health combined with the risk and impact of lockdown procedures greatly affected the health and well-being of participants in our sample. For some it became a challenge to navigate the need for social contact and support during a period of isolation and loneliness, countered by the hypervigilance surrounding the risk of contracting COVID-19.

Making sense of the pandemic

Thoughts and phrases that suggested psychological sense-making around the COVID-19 pandemic were among the most frequent thematic topics throughout the dataset (articulated by 88.3%, n=30 participants). Fear of contracting COVID-19, the dangers of misinformation, and respect for others were common ideas expressed..

Common in the data were expressions of the psychological impact of fear, risk assessment, and hypervigilance around COVID-19 exposure. For example:

> *Personally, in the beginning, I was afraid to even leave the house due to the unknown aspect of COVID and all of the random conflicting info about the virus, how it's transmitted and what having it actually does to someone. I am married with 15 Y/O boy/girl twins and they were worried as well. We pretty much locked down for 2 months. Once we learned a bit more about the virus, we relaxed our lock-down and started venturing out again but very cautiously. (Participant #7; LOI: Thoracic)*

> *Above all else, my biggest challenge is staying positive, avoiding depression for isolation and paranoia about contracting the virus. This has had a noticeable negative impact on my quality of life. (Participant #27; LOI: Thoracic)*

Expressions of worry or prevention strategies were in keeping with widespread attitudes of many around the world regarding COVID-19, disabled or otherwise (23).

In other instances, participants expressed efforts to refocus their risk assessment on what can be controlled or how to make sense of risk such that life goes on. For example:

> *Focus on the things that are in your control. Use this time to make positive changes in your life and take this time to reflect on who you are as a person. (Participant #16; LOI: Thoracic)*

> *Less irrational fear. Caution is warranted to some degree, but the social media fueled fear porn is bad for the community. Read all the data yourself. Draw rational data driven conclusions about your own vulnerability and act accordingly. (Participant #32; LOI: Thoracic)*

These sentiments suggest individuals in our sample attempted to focus away from fear and on to what was within one’s ability to control.

Of critical relevance to the study population were expressions of concern specific to the added risk of COVID-19 infection for those with spinal cord injuries.

> *Because of the level of my injury, I have always had slight respiratory issues. When I get a cold, it almost always ends up as bronchitis or pneumonia. Knowing that, I was super scared to catch COVID so as things relaxed with lockdown, I was pretty public about my not just hanging out at our office or with our friends doing socially distant get-togethers. (Participant #7; LOI: Thoracic)*

> *I am also aware that because my spinal cord injury I am probably more susceptible to having complicating difficulties if I catch the virus. So I am staying at home more. (Participant #24; LOI: Cervical)*

The added risk for those whose disability can already compromise respiratory health were obvious across numerous participants. However, at times, these reflections pointed more acutely to the differences those with SCI experience as compared to those more able-bodied.

> *Having a spinal cord injury has maybe [sic] a little more cautious than others, like being more careful about being exposed to other people. (Participant #5; LOI: Cervical)*

> *Although I have a very strong immune system, I know that I am more vulnerable than an able-bodied person because of my limited lung capacity, which keeps me more confined to staying home. (Participant #28; LOI: Cervical)*

Overall, those with SCI assessed their risk both in keeping with the rest of the community while being especially aware of their added vulnerability from severe respiratory disease.

This concern went further as some expressed a lack of respect or understanding of the unique predicament those with SCI find themselves in during the pandemic.

> *I feel like many people in the community don't respect the vulnerability of people with preexisting conditions and act selfishly, not following health guidelines. The overall stress of having a preexisting condition in the face of a pandemic has affected me in deeper ways than I think I normally allow myself to acknowledge. (Participant #2; LOI: Thoracic)*

Related comments suggest participants' experiences left them feeling particularly vulnerable. One expressed family seeing him as "less capable" and in need of protection due to COVID-19, leading to feelings of being smothered. Another cited a lack of food access to drive-through windows because their accessible vehicles aren't designed for it (and in-person eateries are closed). Finally, one person feared the medical profession will "devalue lives of people with disabilities" when faced with difficult decisions around treatment availability. Together, these cognitions leave those with SCI feeling vulnerable and anxious in their risk assessment for COVID-19 exposure.

Expressions framing vulnerability as strength also appear in the sample – in particular, self-assessments that traumatic injury has prepared a person for coping during a pandemic.

> *I believe the fact that I've lived through an incredibly traumatic experience with my SCI has enabled me to better cope with the current pandemic. I don't believe my SCI has differentiated my experiences that much from others without an SCI during the pandemic. (Participant #1; LOI: Thoracic)*

> *I don't think I have changed much. Having been paralyzed for the past 23 years, I'm no stranger to having my patience tested or adjusting to radical change. It seems like everything that I have been through since my injury has prepared me to deal with difficult situations that I know will get better in time. (Participant #28; LOI: Cervical)*

For these participants, this framing seemed to serve a form of resilience against the pressures of the pandemic. These participants framed previous SCI experiences as a source of strength, rather than vulnerability (24,25), in contrast to others who expressed greater concern for their health and wellbeing, as discussed earlier.

Finally, reflecting about COVID policies implemented to manage infections rates were one vehement frame through which some participants made sense of the pandemic. An outward refocus of anger and criticism seemed to help some cope.

> *I think that being locked up and shutting everything down has been ridiculous!!!! Yes, I know SEVERAL people who have gotten it to varying degrees and a friend's mom passed away and another friend lost someone to it as well. So I know it's real, but to lock down an entire country of healthy people sending people into suicidal depression over a bad case of the flu has been absurd!! (Participant #8; LOI: Thoracic)*

> *For me, I am not at all worried about the virus. I think the media has completely blown it out of proportion. I got COVID-19 back in July, and recovered just fine. The restrictions*

> *are what really bothers me. They are unnecessary and oppressive. I should not be forced to wear a mask everywhere I go. People are being taught to stay away from each other. The psychological and sociological effects of all of this are devastating. Everyone is suspicious of each other. People look at each other as threats. Having people treat me like an enemy simply for not wearing a mask is very hurtful and damaging. I feel like the world has gone totally mad. (Participant #20; LOI: Thoracic)*

> *Eliminate the fear mongering from the [cable news networks]. The constant bombardment of bad information weighs heavy on people for no real reason. The only people negatively affected are super old, in extremely poor health. I have zero fear of this so-called pandemic. (Participant #30; LOI: Cervical)*

Strong opinions about government response to the pandemic, minimizing the risk of the disease, and highlighting the unintended consequences of lockdowns seem to allow participants a measure of control of something that felt uncontrollable. These responses also allowed for the acknowledgement of the wider potential societal impacts of the pandemic arising from the national response, perhaps with competing priorities between social messaging and the individual response/impact.

Daily life during the pandemic

Reflections on daily life during the COVID-19 pandemic represent the most frequent thematic topics across the dataset (articulated by 86.1%, n=31 participants). These reflections included comments on the risks and benefits to social participation during the pandemic and associated lockdowns. Shifts in working life, feelings of connection with loved ones, and social support alternately caused some participants great satisfaction and others deeper feelings of isolation. The theme therefore coalesced around two main areas: gains and losses of the pandemic, with specific examples of each cited within.

Framing aspects of the pandemic as a benefit shifted discussions from the physical or psychological impact to the social connections that some developed or strengthened during lockdowns. While many people in the US experienced job loss and disconnection from work and colleagues, numerous participants in our study cited opposite experiences. While rates of unemployment are high for those with disability, some of our cohort were privileged to benefit greatly from changes in work life due to the pandemic.

For example, numerous participants cited the benefits of working from home, including less money spent on commuting or buying lunch, being able to sleep in, or having less need for hiring caregivers. Some referenced increases to disposable income because of less travel or eating at restaurants. Some referenced other kinds of work, including tackling "more projects at home," the opportunity to "read several books," or seek new "more meaningful" employment.

> *Instead of commuting 30 miles one-way to my office, I've been working from home since March 18 and will do so until July 2021 (company policy). I feel disconnected from my workplace & team but really appreciate sleeping later and only employing 2 aides instead of 3 -- that's saving me about $500 a week, not to mention buying gas monthly instead of 6 times a month. (Participant #31; LOI: Cervical)*

Similar framing helped many in the sample to see positives in their work during the pandemic along with the benefits of balancing commitments alongside losses. In the example above, while some ambivalence is clear, the financial gains of reduced commuting are presented as outweighing the potential losses (largely social disconnect from the workplace and team). The financial gains highlighted may be particularly important for people with SCI, given their complex care needs. However, while many experienced job loss during the pandemic, our sample often framed positive outcomes.

The most common topics referenced throughout this theme was the increased connection to family and friends – strengthening social networks during lockdown and finding creative ways to stay connected. For example,

> *Yes, I have been talking more regularly with my brother and sister, and have gotten out with friends to roll at the park more regularly. I feel like true friendships have become more clear. My family has established a WhatsApp stream and we chat much more frequently than we used to thanks to that. I do feel like this time has reminded me of*

> *things that really matter, but some of those things that matter are things that don't feel accessible right now. (Participant #2; LOI: Thoracic)*

The use of technology, socially-distanced gatherings, and recognition of the need for close relationships were commonly cited benefits of the pandemic across much of the sample. Despite the loss of social connection with work, participants described making concerted efforts to learning and use Zoom or FaceTime, which played an important role in maintaining or strengthening social ties.

A unifying feature of these reflections was the reframing of the pandemic into a positive opportunity, as one participant poignantly stated:

> *It really hasn't been that bad, as I'm incredibly privileged and fortunate to have the family and support that I have, while also blessed with an amazing high paying job. These privileges have kept me in a bit of a bubble of protection, enabling me to not have to stress much about the pandemic. (Participant #1; LOI: Thoracic)*

This sort of privilege was suggested throughout these comments and illuminates the contextual nature of individual experiences being influenced by access to such privilege, but was starkly lacking in the framing of the pandemic from others in the sample, as shown below.

Many others cited increased social isolation from the limits and health risks of COVID-19. While some cited the benefits of saving money, others lamented not eating out or going to social events. Exposure was the main risk cited,

> *I have about eliminated any social activities, so I just stay at home most of the time, have my groceries ordered and put in the back of my vehicle so I don't expose myself to anyone at the store. (Participant #5; LOI: Cervical)*

The result has been frustration, depression, and uncertainty about the future. Some have cited the loss of support networks – either family, friends, or formal support groups – as a major concern. Some live alone or in care facilities, further increasing feelings of isolation.

Though not a frequently cited aspect of this theme, one area in particular was of special relevance to the experiences of persons with SCI during COVID-19; feelings of being "more disabled" as a result of lockdowns and social isolation. For example,

> *Overall, this is a shitty, shitty time, and sometimes it has reminded me of the impact of my disability, and the limitations that often don't feel as present when I have more availability to live my life in the way I choose. With those options taken away, I have FELT more disabled, which has been really hard. But, keeping my chin up!!! (Participant #2; LOI: Thoracic)*

Awareness of and concerns from social contacts of the added risk of respiratory disease for persons with SCI have increased social isolation, as loved ones recognize the need for and exacerbate the risk mitigation beyond what they may for able-bodied loved ones.

We recognized a potential pattern in the cited social experiences and impact on participation for those with SCI during COVID-19. In general, these experiences seemed to exaggerate disparities between participants with stable work and rich social networks versus those with less. In other words, participants who had more pre-pandemic social and economic resources saw increased gains and benefits of working from home, close social relationships, and stable home life. Those who were already isolated, living alone or without stable incomes, appeared to worry more and suggest their lives were much worse during the lockdowns and the pandemic in general. Further research is needed to clarify potential associations between these social and economic disparities and the mitigating effect they may or may not have served during lockdowns.

*Insert **Table 3** near here*

Comparison with experiences of UK sample

Given the scope of our data collection, we took the opportunity to briefly compare data from two different social and cultural contexts: the US and the UK. In our previous article, we uncovered a range of themes that characterized the experiences of the UK sample (7). Data are from the same time period and data collection methods as the US sample. These included:

- *Impeded access to healthcare and health services*: Participants were particularly concerned with maintaining physical health and rehabilitation, and also discussed loss of access to care supplies such as gloves and wheelchair assessments.
- *Psychological risk assessment and evaluation of living with SCI as posing increased risks to health*: Anxiety surrounding health was emphasized given the context of a pandemic centering on a respiratory infection, with participants expressing concern surrounding being immunosuppressed and in need of further protection.
- *Heightened social isolation*: travel restrictions and protective behaviors (e.g. avoiding leaving the home) borne of fears surrounding contracting the virus meant that participants were not able to engage with their usual social support network in the usual way.

The broad similarities in reported experiences and concerns across the UK and US sample are clear. However, returning to the narrative data from the UK sample and comparing the broad concerns and statements to the US sample, we identified a number of key differences. For example:

- The US data contained more vocal frustrations around the purpose and utility of societal lockdowns, feeling oppressed with little ability to make one's own choices based on their personal circumstances, and stripped of autonomy. In contrast, UK respondents were largely fearful of the potential impact of the virus and appeared more resilient to the restrictions imposed by government.
- While both the UK and US respondents reflected on the impact of lockdowns and restrictions on their social engagement and support, the US respondents placed more

focus on family and engaging in meaning-making activities inside and outside of the home, and emphasized concerns surrounding lockdowns and personal autonomy influencing their ability to engage in these activities.

- Participants in the US sample eloquently reflected on their previous experiences of SCI, often being traumatic and life changing, prepared them for the high stress of a global pandemic. SCI was seen to have ‘equipped’ participants (perhaps better than those without SCI) to cope with the challenges brought about by the pandemic, such as being patient through social isolation and inability to engage in particular activities. This perhaps reflects a hopeful cognitive filter through which participants viewed the stressors that they faced.

Discussion

This paper represents a novel exploration of the experiences of people living with SCI in response to the COVID-19 pandemic and subsequent restrictions put in place to manage the outbreak across the US. The results demonstrate the impacts of the virus and infection control measures on people with SCI, such as lack of access to healthcare, while also contrasting these with sense-making positives that appeared to be helpful in managing distress and coping with the impacts of the pandemic. There was some focus in the participant narratives on a need for a sense of control in the face of a seemingly uncontrollable event. Many of the concerns reflected were also found in the UK setting, along with some differences, which will be discussed throughout this section (7,26).

SCI-related issues emerged throughout the sample; wherein the health-related, psychological, and social wellbeing were impacted in similar ways to others without disabilities, but in acutely SCI-specific ways. Daily life experiences often highlighted the benefits of COVID-19 mitigation strategies, including sense-making positives – of particular note were the instances of reflection on SCI having been an adverse event that helped to prepare individuals for future distressing events. This may be due to the psychological and physical adaptation required when one sustains a SCI, as well as engaging in ongoing rehabilitation that required patience, improved self-efficacy, cognitive (self) reappraisal, and cultivating strong social relationships. These variables have been found to be associated with less severe depressive symptoms and greater life satisfaction (27,28).

Challenges tended to be most related to two areas: access to healthcare and isolation (8). It is likely that this is due to the increased risk of depression, loneliness and barriers to mobility, transportation, and healthcare services experienced by people with SCI, issues that may be exacerbated further due to the pandemic and medical rationing (29). This may pose particular concerns to those with SCI as they require regular appointments with rehabilitation specialists and lack of access to these can have detrimental health consequences. Indeed the concerns voiced by participants in this study are reflected in recent work which indicated that concern about medical rationing, disrupted access to medical supplies, and being bothered by social isolation was linked to a tenfold perceived detrimental impact of the pandemic on overall health in people with SCI (8).

There were some notable differences in reported experiences within the current study's US sample and the previously-published UK sample. It is important to note that this work is an explorative reflection of what is important to study participants. We are presenting these differences and our interpretations for causation. The study however did not aim to explain why these differences appear.

Feelings of frustration and oppression by risk mitigation restrictions (e.g. lockdowns) were more prominent in those in the US as opposed to the overriding sense of fear within the UK sample. This may be reflective of the context of the UK rate of transmission at the time of data collection and perceptions of the UK government being ‘slow to respond’, with the restrictions imposed potentially seen as a threat to one’s worldview of autonomy to make health decisions for oneself. This is in line with previous studies that explore political polarization in response to mortality concerns in the COVID-19 pandemic and elsewhere (30–32).

However, this finding may also be reflective of the lower level of confidence in the government found in the UK compared with the US in response to the pandemic (33). Likewise, this may also reflect the gender distribution differences across the UK and US samples, with the UK sample consisting of more women than men (81% women in UK; 25% women in US). Indeed, the greater focus on fear of the virus and pandemic in the UK data may be reflective of different communication strategies/styles across genders, with women more likely to seek support in a social manner, using more descriptive and expressive language while focusing on emotional and sensory aspects of their experiences (34). This may also help to explain findings elsewhere that women report greater risk perceptions and are more compliant with protective behaviors during the COVID-19 pandemic (35), an area for further study.

US respondents placed more focus on family and engaging in meaning-making activities inside and outside of the home and emphasized concerns surrounding lockdowns and personal autonomy influencing their ability to engage in these activities. Imbuing one’s life with meaning and significance may be viewed as an attempt to manage anxiety provoked by the virus, and alludes to previous work finding that when faced with salient collective risk of mortality, there is a tendency to search for meaning and to connect with others to build solidarity, through enacting behaviors that encourage a sense of purpose, such as engaging in prosocial behaviors and fostering positive mindsets (36,37). Likewise, close relationships become an important source of meaning and support that helps to maximize a sense of security in the face of health threats such as COVID-19, which may be more pronounced in people with SCI, given the further potential vulnerabilities associated with injury (38).

We recommend that health professionals identify and address the concerns raised in the current study to minimize health anxiety and to encourage the use of alternative methods of accessing rehabilitation support. Online and telehealth support and interventions have the potential to reach a wider geographical net and are convenient, safe options for people with SCI to engage in at least some rehabilitation. These alternative methods also allow for maintained connection to others in the SCI community, which is especially important during periods of isolation. In addition to the sense of connection with others, online and telehealth support and interventions may also be used to support mental and physical health, as demonstrated in a recent online mindfulness course that reduced depression, anxiety, and chronic pain among individuals with SCI (39). Such connection and quality in therapeutic relationships is often central to the shaping of rehabilitation experiences and should be considered in SCI care, particularly during especially isolating circumstances (40). Drawing from this research would likely be useful in the context of a global pandemic.

Limitations and Future Research

The findings of this study represent the opinions, attitudes and experiences of the relatively small sample studied, which may reduce ability to draw causal links between concerns. Further work is required to empirically validate the interpretations made in this study and examine the relationships between the issues highlighted so as to identify which, if any, are stronger/more important predictors of wellbeing, health outcomes, and social connections/engagement. This would allow for targeted intervention to ensure the SCI community feel appropriately supported to cope with the consequences of the COVID-19 pandemic.

Similarly, there is potential for selection bias, in that people who had experienced more distress, concerns, or barriers to healthcare may have been more likely to respond to the survey so as to make their voices heard. A sampling strategy targeting a diverse sample with a range of experiences would be helpful in mapping the impact of the COVID-19 pandemic on people with SCI. For example, clinical screening of wellbeing through SCI rehabilitation units with referral to the research team might be a useful approach to considering a more diverse group.

Further, the findings presented need to be considered reflective of a single time-point and that causality cannot be inferred. This could be countered with longer-term follow-up work in a mixed-methods approach, such as via survey-based qualitative and quantitative data collection. Responses could be followed-up through individual interviews to facilitate in-depth exploration of the participants' constructed meanings and exploration of perceptions of causality and interrelationships between issues highlighted in this paper.

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Statement of Ethics

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

Declaration of Interest Statement

The authors declare no conflicts of interest.

Author Contributions

ER, JH, and KM were responsible for study design, oversight of data collection, and extracting the data. All authors were involved in analyzing data, interpreting results, and writing the manuscript.

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Table 1. Survey questions.

1. The world has changed so much in the last few months. Many people are worried about their health, their jobs, their families, and even just day-to-day living. What kinds of changes have you experienced personally? How do you feel about these changes and their impact on you, your family, and your job?

2. What have been your key personal challenges during the pandemic? How do you feel about these challenges? (e.g. health, safety, access to healthcare, condition self-management, future prospects, family/relationships etc.)

3. What positive experiences have you had since the pandemic started? How do you feel about these experiences? (e.g. more time with family)

4. We imagine that having a spinal cord injury may lead to different experiences during this pandemic than for someone without an injury. Can you provide 2 or 3 examples of how your pandemic experiences have or have not been different for you, as compared to friends and family without a spinal cord injury?

5. If you could change any part of your community's response to the pandemic, in a way that would help you, what would you change and why?

6. If you could give advice to a friend who also has a spinal cord injury, who may be struggling during the pandemic, what would you tell them?

7. Thinking about the future, how do you think your experiences during this pandemic will factor into whatever comes next for you?

8. Is there anything we haven't asked about that will help us understand your experiences during COVID-19?

Table 2. Participant demographics

	N	%
Gender		
Man	27	75.0%
Woman	9	25.0%
Race		
White	34	94.4%
Black	2	5.6%
Level of injury		
Cervical	18	50.0%
Thoracic	15	41.7%
Lumbar or Sacral	1	2.8%
N/A (spinal cord disease)	2	5.6%
Cause of injury		
Fall	6	16.7%
Road traffic accident	12	33.3%
Sporting injury	4	11.1%
Non-traumatic	4	11.1%
Gunshot wound	1	2.8%
Other	9	25.0%
Completeness of injury		
Complete	34	94.4%
Incomplete	2	5.6%
	Mean	SD
Age	55.7	13.1
Time since injury	21.5	13.6

Table 3. Themes and examples of further affirming quotes

Health and access to care	That I cannot see a Dr. is the absolute worst!!! All my adaptive sports were canceled. Being grounded like a child has been taxing on my emotional wellbeing!!!! I want out… (Participant #8, LOI: Thoracic) My physical therapy can no longer treat out patients. I have not been able to find another who does. As a result, I have increased weight, spasticity, pain and weakness, depression, frustration, and unsure of future… For me, exercise is huge. I thrive with intense physical exercise 4 or 5 days a week. To accomplish this I need help from PT and friends. They are now not available due to COVID. (Participant #11; LOI: Cervical) Since the pandemic, I have noticed that the availability of home health caregivers has decreased. This has a direct impact on choosing a good aide, and I have lowered my criteria in hiring them - often settling on lower quality aides. (Participant #15; LOI: Cervical) Loss of caregivers, loss of experience in caregivers, caregiver apathy about Covid, loss of function due to lack of care and problems with access to help with necessary rehab exercise support on VA provided equipment...falls on equipment due to maintenance delays... (Participant #26; LOI: Cervical)
Making sense of the pandemic	Also, the fear of getting Covid because I'm not sure how well I would recover from it so there was/is a slight hesitation to go out in public more due to others' lack of being considerate/safe than our own. (Participant #7; LOI: Thoracic) For me the biggest challenge has been how to navigate all the restrictions and regulations being put in place. Having my freedoms taken away is extremely difficult to deal with. There has been strain on relationships because people think I'm careless for things like not wearing a mask or even giving someone a hug. It's insanity. (Participant #20; LOI: Thoracic) It had been hard to realize how alone we are in this world. I don't feel comfortable going anywhere outside my property, even to a clinic. (Participant #21; LOI: Thoracic) It's my belief that it affects us pretty much all the same. Sure there are some things I'm on able to do like social gatherings and lunches/diners out but everyone is Experiencing the same things as I am. It may affect me a little bit more because of the fewer things

	available to me but this type of life is challenging anyways so I'm used to it. (Participant #29; LOI: Cervical)
Daily life during the pandemic	I currently work from home, for my company decided to close our offices until further notice. My work has laid people off, but my role isn't at a high risk for being let go. I've enjoyed being home more, and having time to do things that I typically didn't have time for pre-COVID. (Participant #1; LOI: Thoracic) I suppose the most positive things are that family and friends are tending to reach out and check with one another as to how everybody is getting along and if anybody needs anything. It brings out a lot of good in people, not always but you see the good come out and people in most cases. (Participant #29; LOI: Cervical) Our social interaction with family and friends has been severely impacted since COVID. We were having get togethers a few times a month and that has almost come to a stop. Both my wife (my primary caregiver) and myself need that social interaction and really miss it. (Participant #18; LOI: Thoracic) There has been strain on relationships because people think I'm careless for things like not wearing a mask or even giving someone a hug. It's insanity. (Participant #20; LOI: Thoracic)