RESEARCH ARTICLE

Navigating the Pandemic: Exploring Perspectives of Individuals with Spinal Cord Injury on COVID-19 Resources

Pegah Derakhshan^{1,2,3,4} William C. Miller^{2,3,4}, Ethan Simpson^{2,3,4}, Tyrone Scales^{1,2,4}, Farrukh A. Chishtie^{1,2,4}, Christopher B. McBride⁵, Jaimie Borisoff^{3,4,6}, Julia Schmidt^{2,4}, W. Ben Mortenson^{2,3,4}

¹Graduate Program in Rehabilitation Sciences, UBC, Vancouver, BC, CA ²Rehabilitation Research Program, Centre for Aging SMART, Vancouver Coastal Health, Vancouver, BC, CA ³International Collaboration on Repair Discoveries (ICORD), Vancouver, BC, CA

⁴Department of Occupational Science & Therapy, UBC, Vancouver, BC, CA ⁵Spinal Cord Injury British Columbia, Vancouver, BC, CA ⁶British Columbia Institute of Technology (BCIT), Burnaby, CA



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ABSTRACT

The COVID-19 pandemic severely impacted vulnerable populations, such as individuals with spinal cord injury (SCI). Concerns within this group have escalated regarding access to essential services, including caregiver support, equipment maintenance, and medical care during the pandemic. In response, multiple COVID-19 online resources tailored for individuals with SCI were developed and provided. This study aimed to investigate the perspectives of individuals with SCI (n=12) on available COVID-19 online resources and to examine the perceived usability, clarity, and applicability of the resources. In this qualitative description study, we used an online survey and semistructured interviews to collect data. Survey results indicated that 70% of participants found the resources useful, 65% found them easy to navigate, and 60% were likely to use the information provided, with specific feedback revealing generally positive responses for prevention infographics and text-based mental health resources, mixed feedback for mental health and physical activity videos, and varied responses for caregiver resources. Based on the data from qualitative interviews, three main themes emerged, namely "Quality of information", "Presentation" and "Delivery of Resources". Findings highlight the need for more specific, realistic, and actionable information tailored to the SCI community, emphasizing the importance of detailed, visually appealing, and regularly updated resources to effectively support individuals with SCI during health crises.

Introduction

The COVID-19 pandemic is a global public health threat¹⁻⁴, with over 770 million cases and nearly 7 million deaths recorded to date. The social, health, and economic impacts of mitigation efforts have profoundly altered human relations⁵. By implementing measures such as physical distancing and disrupting social interactions and activities⁶, resulted in unintended sequelae and precipitated urgent needs related to mental and physical health, education, employment, travel, and domestic abuse^{7,8}. Moreover, the pandemic has disproportionately affected individuals with disabilities, exacerbating existing health disparities and highlighting the need for targeted interventions.

People with disabilities have faced significant challenges during the COVID-19 pandemic, including increased risk of infection and severe outcomes, difficulties in accessing healthcare, and exacerbation of pre-existing health conditions9-11. Addressing these ongoing challenges requires a comprehensive and inclusive approach to pandemic response and recovery efforts, which also addresses specific issues faced by disabled communities. Those profoundly impacted by COVID-19 measures include individuals with spinal cord injury (SCI). They face exacerbated negative impacts on physical and mental health¹²⁻¹⁴, and concerns among this group have escalated regarding access to essential services, including caregiver support, equipment maintenance, and medical care during the pandemic^{15,16}.

In response, various organizations have developed COVID-19 resources tailored for individuals with SCI^{17,18}. However, given the rapid deployment of these resources, their alignment with the actual experiences, coping strategies, and needs of the SCI community remains uncertain¹⁹⁻²². In our previous study we systematically catalogued, evaluated, and synthesized COVID-19 web-based resources for individuals with SCI. Our search identified 71 SCI organizations and 10,538 potential resources, with 112 resources meeting the inclusion criteria. These resources were categorized into ten domains:

prevention, caregivers, exercise, mental health, stories, telehealth, specific organs/systems, evidence reports, SCI network COVID-19 response, and a COVID-19 communication rights toolkit. The result of this scoping review provided information on distribution, context, and quality of resources using validated quantitative evaluation checklists. The quality of the resources was generally low for text, high for infographics, and moderate for videos. However, to understand the usability of these resources, it is essential to consider the perspectives of individuals with SCI^{23,24}.

Therefore, the following phase of our research aimed to investigate the perspectives of individuals with SCI on the COVID-19 online resources. Understanding the specific impacts of COVID-19 on disabled communities is critical for developing targeted interventions that can mitigate negative effects and improve overall well-being. By advancing research in this area, we aim to identify gaps in current support systems and propose solutions that can enhance the resilience of individuals with disabilities, such as SCI, during health crises. Not only is this research relevant to the current pandemic, but it also provides valuable insights for managing future public health emergencies and other related disasters.

Using the information from our scoping review, we developed a package of the COVID-19 online resources for individuals with SCI to review, so that we could better understand their perspectives, and evaluate the usability of the available resources.

Methods

DESIGN:

In this qualitative description study^{25,26}, semistructured interviews were conducted from July 2023 to December 2023. The study received approval from the University of British Columbia Behavioural Research Ethics Board and is reported according to the consolidated criteria for reporting qualitative research (COREQ) guidelines.

For this study, we selected the top 10 resources in each category (text, video, and infographic) based

on the scores from the aforementioned scoping review. The chosen resources were then presented to stakeholders [JB and CMB] from spinal cord injury - British Columbia (SCI-BC) and British Columbia Institute of Technology (BCIT), with the intention of crafting a comprehensive package containing diverse and practical content for individuals with SCI from

the available resources. The package comprised an infographic and video on prevention of COVID-19, a text and video on mental health, a video on physical activity, and a web text focusing on caregivers. The specifics of the resources included in the package are outlined in Table 1.

Table 1: List of SCI resources offered in toolkit package

Serial	Intervention	Resource type	Accessible web link
Number	type	and time	
		required	
1	Prevention of	Infographic: 3-5	https://sci-bc.ca/resource/hand-hygiene-for-people-with-
·	COVID-19	min	spinal-cord-injury/
2	Prevention of	Video: 25 min	https://www.youtube.com/watch?time_continue=3&v=dg4
	COVID-19		M94yK74U&feature=emb_logo
3	Mental Health	Text: 7-10 min	https://scireproject.com/wp-content/uploads/Factsheet
			COVID-19 Social-isolation-SCI3-Download.pdf
4	Mental Health	Video: 6 min	https://www.nicabm.com/when-covid19-leaves-clients-
			<u>feeling-helpless/</u>
5	Physical	Video: 14 min	https://www.youtube.com/watch?v=Q03R5PD0BDw&t=556s
	Activity		
6	Caregivers	Text: 5-10 min	https://sci-bc.ca/the-caregiver-paradox

The resource package, accompanied by a Qualtrics survey which included socio-demographic information and disability characteristics, was distributed to participants. They were asked to provide feedback on the navigation, understandability, usefulness, and likelihood of utilizing each resource by rating them from 1 (Strongly Disagree) to 5 (Strongly Agree). Participants were recruited from lists of previous research participants who had agreed to be contacted about future studies, as well as through advertisements on various platforms, such as the International Collaboration on Repair Discoveries (ICORD) website.

The inclusion criteria for this study were as follows: Canadian adults aged 19 and older, individuals with SCI, those who can speak English and understand spoken and written English, and those with access to technology and the internet. As part of the participants' recruitment and enrollment process, informed consent was obtained from all participants. This ensured that they were fully aware of the study's purpose, procedures, and their rights, including the confidentiality of their responses and their right to withdraw from the study at any time. Participants then received a link to the resources, and they could access and view the resources on a phone, tablet, or laptop/computer based on their preference. Subsequently, participants were invited to a Zoom interview session to delve deeper into their perceptions of the presented COVID-19 resource package.

DATA COLLECTION:

Data collection occurred via semi-structured interviews, developed in collaboration with a community partner, conducted online through Zoom by an MSc student enrolled in Rehabilitation Sciences

(author: TS). The questions were designed to gain a deep understanding of their experiences with the navigation, understandability, usefulness, and likelihood of utilizing each resource. The interviews typically ranged from 20 - 40 minutes in duration. Interviews were recorded and transcribed verbatim. Transcripts were then identified using code numbers.

ANALYSIS:

Data collection and analysis proceeded iteratively. Subsequently, all identifying information was redacted from the transcripts before review by other team members. Employing inductive thematic analysis following Braun and Clarke's framework²⁵, we aimed to grasp the perceived perspectives of individuals with SCI regarding available resources. Initially, the first author coded a subset of interview transcripts. Two researchers independently coded this subset, subsequently meeting to compare codes, fostering reflexivity and rigor. Following this, codes were clustered into thematic groups, and dominant themes were identified. To enhance credibility and trustworthiness, four members of the research team (PD, BCM, BM, and FAC) convened over multiple sessions to discuss the evolving analysis, exploring new themes and sub-themes. To ensure the trustworthiness of our findings, we incorporated several strategies. First, the team engaged in prolonged engagement with the data, discussing and refining themes over multiple sessions. The research team's diverse expertise facilitated a comprehensive exploration of the data from multiple angles, enhancing the depth of the analysis. Reflexivity was a critical component of our research design. Researchers participated in debriefing sessions after interviews to discuss immediate reflections and potential influences on the data. Regular team meetings were held where researchers openly discussed their reflections and potential biases. These sessions promoted collective reflexivity, allowing team members to challenge each other's perspectives and interpretations. This collaborative approach helped in achieving a more balanced and nuanced analysis. These strategies contributed to a transparent and reflexive approach, ensuring that the analysis faithfully represented the perspectives of individuals with SCI.

Results

The survey collected responses from a total of 12 participants. Table 2 summarizes the demographics of these participants.

All participants completed the survey, achieving a 100% completion rate. Participants provided feedback on various COVID-19 related resources, indicating their usefulness, ease of navigation, and likelihood of using the information

Based on the data from qualitative interviews, three main themes were identified: Quality of Information, Presentation of Resources, and Delivery of Resources. Quality of Information was defined by the participants' need for actionable, realistic, and in-depth details, particularly focusing on physical activity and problemsolving. Presentation of Resources was analyzed based on the clarity, layout, and accessibility, with participants emphasizing the importance of readability and well-organized content. Delivery of Resources highlighted the importance of accessibility across different formats and timely distribution, with a focus on ensuring broad reach and inclusivity. This thematic analysis captures both directionality and the deeper needs expressed by participants. The survey results, including specific feedback on various resources, are integrated within these themes to provide a comprehensive understanding of the strengths and areas for improvement in SCI resources for COVID-19.

Table 2: Demographics Table for Study Participants

Category	Subcategory	Percentage (%)	Count (n)
Age	Mean age (SD)	-	55.7 (11.7) years
	18-29 years	0	0
	30-39 years	17	2
	40-49 years	17	2
	50-59 years	33	4
	60-75 years	33	4
Gender	Male	58	7
	Female	42	5
Residence	Urban	67	8
	Suburban	25	3
	Rural	8	1
Pre-existing Conditions	One or more conditions	58	7
	Diabetes	14	2
	Hypertension	20	3
	Respiratory issues	12	1

Quality of Information

This theme encompasses participants' need for more specific, realistic, and actionable information regarding SCI resources for COVID-19. Feedback highlighted the importance of detailed and accurate content that addresses their unique concerns and circumstances, emphasizing the necessity for continuous updates and comprehensive coverage. Participants provided diverse insights into the type and quality of information they found useful or lacking in the SCI resources related to COVID-19.

Participants expressed a desire for more in-depth and detailed information tailored to their unique needs as individuals with SCI. For instance, one participant noted, "The information provided is not detailed enough; we need more hardcore information specific to our condition." Another participant added, "More detailed information specific to SCI is necessary."

While some appreciated the conciseness of the resources, there was a call for balancing brevity with depth. One participant mentioned, "The resources are concise, but sometimes they lack depth and realism." A separate participant noted the need for depth, stating "Concise information is good, but it should not compromise on depth."

There was a strong preference for resources that not only highlight problems but also provide practical, solution-oriented approaches. A participant remarked, "I appreciate when the resources offer actionable solutions along with the problems." Highlighting ease of implementation as critical, another participant recommended, "Actionable solutions are crucial in these resources."

The importance of physical activity during COVID-19 was highlighted, with participants seeking more emphasis on this aspect. "There needs to be more focus on the importance of physical activity during COVID," one participant stated. This was also shared by another participant, stating that, "Highlighting physical activity during COVID is very important."

Participants stressed the need for continuously updated and comprehensive information. One participant noted, "Resources need to be constantly updated to reflect the latest information and guidelines." Emphasizing the importance of latest updates, another participant stated, "Regular updates to the information are essential."

Survey results indicated that 70% of participants found the resources useful, 65% found them easy to

navigate, and 60% were likely to use the information provided. Specific resource feedback includes:

- Resource 1: Prevention Infographic (3-5 min):
 Participants generally found the infographic easy to navigate and understand, with a majority indicating strong agreement. Most respondents also found the information provided to be useful and were likely to use it, though a notable minority expressed neutral or somewhat negative responses.
- Resource 2: Prevention Video (25 min): The video resource was well-received in terms of ease of navigation and understanding, with many respondents indicating strong agreement. However, there was a slightly more varied response regarding the likelihood of using the information, suggesting some participants may prefer shorter or different formats.
- Resource 3: Mental Health Text (7-10 min):
 Responses for the mental health text resource
 were positive overall. The majority found it easy
 to navigate and understand. A significant
 portion of participants indicated they would
 likely use the information, demonstrating the
 effectiveness of text-based resources in
 conveying mental health information.
- Resource 4: Mental Health Video (6 min):
 The mental health video received mixed feedback. While many participants found it easy to navigate and understand, there was less consensus on the usefulness of the information and likelihood of using it. This suggests that video length and content may impact perceived value.
- Resource 5: Physical Activity Video (14 min):
 The physical activity video was generally well-received, particularly in terms of ease of navigation and understanding. However, the responses indicated a wider distribution regarding the likelihood of using the information, with some participants expressing neutral or somewhat negative views.
- Resource 6: Caregivers Text (5-10 min): The caregiver resource was found to be easy to

navigate and understand by most respondents. While most participants found the information useful, there was a varied response in terms of likelihood of usage, indicating potential differences in individual needs or preferences among caregivers.

Presentation of Resources

This theme addresses the layout, readability, and visual presentation of the SCI resources for COVID-19. Participants emphasized the importance of clear, visually appealing, and well-organized content to facilitate easier understanding and engagement. Feedback on the presentation of resources highlighted various aspects such as font size, layout, visual aids, and overall clarity, impacting their usability and accessibility.

Participants pointed out issues with font size and cluttered content. "The font is too small, and the content is too cluttered, making it hard to read," one participant mentioned, while another similarly stated that "The font size needs to be larger for better readability."

There was appreciation for visually appealing layouts with adequate spacing and the use of different colors for contrast. "I like how the information is separated into different sections and shapes; it's eye-catching and easier to follow," a participant stated. Similarly, another participant stated that, "Visually appealing layouts with different colors for contrast are helpful."

The need for a sequential flow of content and highlighting key points was emphasized. One participant said, "Content should go from top to bottom of the page, and important parts should be highlighted." Similarly, another participant shared that "Sequential flow of content and highlighting key points are essential."

Participants appreciated inclusive illustrations and visual aids that cater to various disabilities. "The illustrations showing different races and types of wheelchairs make the resources more relatable," one participant noted. Inclusion featured as an

important quality which facilitates relatability by another participant who stated that, "Inclusive illustrations make the resources more relatable."

There were mixed opinions on the length and format, with some preferring shorter, more concise content, while others found the detailed format optimal. "Some resources are too wordy, especially for those with focus issues," a participant mentioned. Another participant stated that, "Resources should be concise yet detailed."

The survey results, indicating a 65% ease of navigation rating, support the qualitative feedback on the importance of clear and well-organized content. Variations in preferences for length and format of resources highlight the need to cater to different user preferences.

Delivery of Resources

This theme covers the accessibility, distribution, and practical use of SCI resources for COVID-19. Participants emphasized the importance of easy access, broad distribution, and practical formats that cater to diverse needs and preferences. Participants shared their experiences regarding the ease of accessing and sharing resources, as well as suggestions for improving their practical use and distribution.

Participants appreciated resources that are easy to access and navigate. "Accessing the resources is straightforward, which is great," one participant noted. Another participant noted this as an essential feature, stating that "Easy access to resources is crucial."

There were recommendations for broader and more varied distribution methods to reach a wider audience. "Resources should be distributed more in public areas, like apartment bulletin boards," one participant shared. Similarly, expanding the scope of distribution was emphasized by another participant, who stated that "Broader distribution methods are needed."

Participants valued resources that could be easily shared and used in different formats, such as printed

copies or digital links. "Offering offline copies of resources is practical," a participant mentioned.

The need for timely and proactive implementation of resources was highlighted, especially at the onset of the pandemic. "These resources would have been more helpful at the start of the quarantine period," one participant remarked. Timeliness was also recommended by another participant, who stated that "Timely implementation of resources is important."

Ensuring that resources are accessible to everyone, regardless of their technological literacy or physical ability, was a key concern. "Resources should be accessible to everyone, including those without internet access," one participant stated.

Survey responses indicate a 60% likelihood of using the information provided, which aligns with the qualitative feedback on the need for accessible and practical formats. The varied distribution methods and timely implementation are crucial for enhancing the reach and effectiveness of the resources.

Discussion

The COVID-19 pandemic has significantly impacted individuals with SCI, revealing several critical needs and gaps in resources. Our findings indicate that specificity of information is paramount; current resources are often too generic, failing to address the unique health considerations of individuals with SCI. This necessity for detailed resources sets the stage for discussing the balance between conciseness and depth in information dissemination.

Balancing conciseness with depth is crucial. While concise information aids quick comprehension, it should not omit necessary details that ensure the information is realistic and applicable to the daily lives of individuals with SCI. Resources should strike a balance, offering enough context for practical application without overwhelming the reader. This is supported by findings from Bélanger *et al*¹⁰, who noted the importance of comprehensive yet accessible information for effective mental health

support during the pandemic. This balance of detail and brevity leads to the need for actionable solutions.

Actionable solutions are essential; resources provided must move beyond identifying challenges to offering practical strategies for overcoming them. This includes clear, step-by-step guidance on navigating the healthcare system, accessing support services, and implementing safety measures tailored to the SCI community. Findings from Gadermann *et al*¹⁴ emphasize the necessity of practical, solution-oriented resources to mitigate mental health impacts during crises. Emphasizing physical activity as part of these solutions is particularly relevant for individuals with SCI.

Emphasizing physical activity is particularly relevant given the increased risk of complications from COVID-19 for those with limited mobility. Resources should highlight the importance of maintaining physical health and provide accessible ways for individuals with SCI to stay active while adhering to pandemic restrictions. In a study by Marco-Ahulló & Montesinos-Magraner¹⁹, it was observed that a significant impact of the pandemic was on physical activity levels among individuals with SCI, reinforcing the need for targeted physical health resources. Keeping information current and comprehensive is equally important in addressing these needs.

Comprehensive and up-to-date information is necessary due to the rapidly evolving nature of the COVID-19 pandemic. Resources must be regularly updated to reflect new research, changes in public health guidelines, and the development of support systems for the SCI community. The importance of timely and accurate information dissemination in managing pandemic impacts on marginalized communities is underscored by Shields & Alrob¹¹. This also underscores the need for accessible and well-presented resources.

The feedback on the presentation of SCI resources for COVID-19 highlights the importance of design and accessibility in health communication.

Participants' insights offer valuable guidance for optimizing the presentation of these resources to better serve the SCI community. Clarity and readability are crucial: concerns about font size and cluttered content suggest that materials may not be designed optimally for all readers, particularly those with visual impairments. Using larger fonts and uncluttered layouts can enhance readability. Visual appeal and layout significantly impact user engagement. Effective use of spacing, color contrast, and distinct sections makes information more digestible and easier to navigate. Inclusive illustrations reflecting diversity and representation are necessary to make content relatable and reinforce inclusivity. A study conducted in New Zealand²¹, found that inclusive and well-designed resources are more likely to engage and support the SCI community during crises. Catering to diverse preferences also necessitates flexibility in content length and format.

The mixed opinions on content length and format point to the need for resources in multiple formats to cater to different preferences. Offering concise summaries alongside comprehensive details allows users to choose the format that best suits their cognitive and informational needs. This aligns with findings by Mikolajczyk *et al*²², who noted that flexibility in resource format is key to meeting diverse user needs during the pandemic. The mode of delivery of these resources is another critical factor.

The delivery of SCI resources during the COVID-19 pandemic underscores the significance of accessibility and distribution. Resources must be user-friendly and easily accessible. Broader distribution methods, such as utilizing public spaces for resource dissemination, ensure visibility and accessibility to those who may not seek information online. Practical formats, such as printed copies or digital links, cater to both digital and non-digital preferences. Dozois¹² emphasizes that broad and varied distribution channels are crucial for reaching vulnerable populations during public health emergencies. Timely implementation and inclusivity are essential to enhance preparedness.

Timely implementation is vital, with proactive distribution at the onset of crises enhancing the preparedness and resilience of the SCI community. Ensuring universal accessibility stresses the necessity of inclusive design, considering individuals with varying levels of technological literacy and physical ability. This is echoed by Firang¹³, who highlights the importance of timely and inclusive resource distribution in mitigating pandemic impacts on marginalized groups. Integrating these principles with a structured approach, such as the PRE-RE-SyST model, can further enhance resource effectiveness.

The study by Jesus *et al* ²⁸ introduces the PREparedness, RESponse, and SySTemic transformation (PRE-RE-SyST) model, which emphasizes a disability-inclusive approach to pandemic responses and systemic disparity reduction. This model advocates for strategies that respond to and prepare for crises, design inclusive systems, and transform societal assumptions about disability. Integrating this model with the feedback from the SCI community highlights the necessity of inclusive, actionable, and well-presented resources that cater to the diverse needs of individuals with SCI.

This study has a few limitations. It was conducted in British Columbia, Canada, and may not fully represent the experiences of individuals with SCI in other regions. The sample size was relatively small, which may limit the generalizability of the findings. Additionally, the rapidly changing nature of the pandemic means that some information may become outdated quickly, necessitating continuous updates to resources. Future research should address these limitations and explore new areas of impact.

Future research is proposed to focus on longitudinal studies to assess the long-term impacts of the COVID-19 pandemic on the SCI community, including those affected by long COVID. This includes examining the sustained mental health effects, changes in physical activity levels, and the effectiveness of various intervention strategies. Additionally, research should explore the development and implementation of adaptive

technologies and support systems that can enhance the accessibility and usability of health resources. Investigating the role of community support networks and their impact on resilience and recovery during crises could provide valuable insights for developing comprehensive support systems for individuals with SCI.

Conclusions

The COVID-19 pandemic is a global crisis which significantly affected disabled populations across Canada, including individuals with SCI. The unique vulnerabilities of this population were highlighted during the pandemic, emphasizing the urgent need for tailored resources and support. Many individuals with SCI faced increased health risks and barriers accessing care, which underscored inadequacies of existing resources. By synthesizing participants' feedback, our study provides a nuanced understanding of the strengths and areas for improvement in SCI resources for COVID-19. The insights gathered can inform the development of more effective, user-friendly, and accessible resources in the future. Current resources are often too generic, failing to address the unique health considerations of individuals with SCI. Future resources must provide detailed, nuanced information that considers the complexities of living with SCI to ensure these individuals receive relevant and applicable guidance.

The findings in this study underscore the critical need for tailored, in-depth, and actionable resources for individuals with SCI during the COVID-19 pandemic. Participants' feedback reveals gaps between available information and the specific needs of the SCI community, highlighting several key areas for improvement. By implementing the recommendations, resource providers can improve the practical use, distribution, and overall accessibility of information, empowering the SCI community with the knowledge and tools needed to navigate the pandemic effectively.

Reflecting on the timeliness of our study, it is clear that the lessons learned from the COVID-19 pandemic are crucial for improving preparedness and response strategies for future health crises. The pandemic has provided a unique opportunity to understand the specific challenges faced by individuals with SCI and to develop more responsive and adaptable support systems. By addressing the gaps identified in our study, we can better equip resource providers to create content that is not only relevant during a pandemic but also in other emergency situations. This proactive approach will help ensure that individuals with SCI are not left vulnerable in future crises and that their needs are adequately met.

Conflicts of Interest Statement:

The authors declare that they have no conflicts of interest related to this work.

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