










## Research Article

# The Impacts and Vulnerabilities for People Living with Spinal Cord Injury and Their Service Systems of the COVID-19 Pandemic in Queensland, Australia

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As part of a larger study examining the perceived impacts of health system stress in Queensland, Australia, caused by the COVID-19 pandemic, this study explored the experiences and perspectives of a sample of people with spinal cord injury (SCI) and critical stakeholders to identify secondary complications, access concerns, and potential solutions in the context of the pandemic. This study utilised a multimethods qualitative design. Thirty-four people with SCI completed an online survey between August and November 2021, recruited from an online Spinal Life Australia Peer Support Group. Sixteen SCI expert stakeholders, recruited from the Queensland Spinal Cord Injuries Services, consumer support organisations, and funding agencies, participated in one of two expert stakeholder forums in September 2021, focusing on impacts of the pandemic on the services they provided. Survey and forum results were analysed thematically. Results highlighted service disruption wherein people with SCI faced difficulty accessing health and community services (including rehabilitation) and personal supports. Reduced access led to secondary complications in physical health, psychosocial, and occupational domains. Solutions for safeguarding access to care, including action-ready back-up plans, effective technology and training, collaboration of service networks, and forward planning for system disruption, consumables access, staff support, and advocacy are required to best support vulnerable populations and the supporting staff in times of crisis. In conclusion, COVID-19 disrupted access to specialist SCI and mainstream health, rehabilitation, and social care services, resulting in functional decline and physical and psychosocial complications. While people with SCI and their service providers attempted to innovate and solve problems to overcome service access barriers, this is not possible in all situations. Improved planning and preparation for future system disruptions mitigates risks and better protects vulnerable populations and service providers in times of severe system stress.

## 1. Introduction

Managing a spinal cord injury (SCI) is challenging even in usual circumstances. It is a medically complex condition that requires timely care, support, and diligent self-management

to promote wellbeing and prevent serious secondary complications (SCs; [1–3]). Undoubtedly, system disruptions created by the COVID-19 pandemic have substantially exacerbated the challenges of living with SCI. This study explores the experiences and perspectives of people with

spinal cord injury (SCI) and critical stakeholders, to identify secondary complications, access concerns, and potential solutions in the context of the pandemic.

Health systems have been experiencing severe stress as they redistribute resources to manage COVID-19 outbreaks [4, 5]. For people with SCI, this has curtailed routine healthcare, rehabilitation, and outpatient services, with earlier discharge from inpatient rehabilitation for people who are COVID-negative and suspended or temporarily reduced admissions [4, 6, 7]. The use of telemedicine/tele-rehabilitation and home care has increased to support people at home [4, 8], but further evidence is required to assess comparability with in-person consultations across a range of clinical interactions [9, 10]. Additionally, changes in service delivery and system capacity have negatively impacted on social and mental wellbeing of staff and the social contact between people with SCI, their families, and health professionals [4].

Unsurprisingly in this scenario, SCs are occurring in physical, psychosocial, and occupational domains for people living with SCI. This includes increased vulnerability to infection and respiratory complications [5, 7]; significantly decreased physical activity including recreational and occupational pursuits [11]; and markedly increased spasticity, pain, and discomfort [7, 12, 13]. These SCs were attributed to pandemic-related social restrictions resulting in reduced walking, extended sitting in wheelchairs or confinement to bed, and insomnia-related pain or discomfort. Symptom re-emergence and increased spasticity were also attributed to the postponement of treatments such as botulinum toxin type A injections [12].

In the psychosocial domain, lost access to personal supports such as family, personal networks, and formal support workers increased social isolation and complicated access to healthcare information [4–7, 13, 14]. Lower resilience and quality of life have also been reported, with increased depression and anxiety, particularly around accessing services [6, 14, 15].

In the occupational domain, social restrictions have reduced access to recreational activities [11]. It is also more difficult to access essential assistive technology, other necessary equipment, repairs, routine medical supplies (i.e., medications, protective consumables), groceries, and transport for healthcare appointments [5, 6, 14]. The financial concerns and impacts have also been substantial [14].

While Australia limited the spread of COVID-19 in the first two years of the pandemic through widespread lockdowns, COVID-19 mandates, leave payments (to enable COVID-positive workers to remain at home), and job-keeper supports (a fortnightly wage subsidy, designed to support the economy during the COVID-19 pandemic by helping to keep businesses trading and people employed), health and social care system functionality was still significantly compromised, impacting on all members of the community including people with SCI and other disability. Since restrictions began to ease in late 2021 including reopening of international borders in February 2022 (to

vaccinated tourists and other visa holders), COVID-19 has spread rapidly. By July 2022, Australia had recorded 9,235,014 cases and 11,387 deaths [16]. Queensland initially minimised the spread of COVID-19 through border closures, strict isolation/quarantine mandates, societal restrictions, and lockdowns. The state only returned to a close to normal situation, when achieving a 90% vaccination rate [17]. Practical guidelines were published to protect the rights of Australians with disability under pandemic-related restricted access to health services, including mobility aids, communication options, visitor and family access, and involuntary hospital discharge [18]. Implementing some of these strategies potentially placed additional demand on already limited service resources, thus challenging service delivery for providers and recipients across primary, secondary, and tertiary healthcare sectors.

Severe pandemic-related disruption to SCI services warrants investigation of (a) the personal impacts and how the disruptions are managed by people living with SCI, health professionals, and services; and (b) identification of system enhancements to better protect people with SCI and other disability from future pandemic waves or other causes of system disruption.

This study is part of a larger program of research which examines the impact of health system stress caused by the COVID-19 pandemic on SCs and access to health and rehabilitation services by comparing people with SCI discharged prior to and during the pandemic in Queensland, Australia, using data linkage and survey data. The aim of this component of the research was to examine the perspectives of a sample of people with SCI and SCI expert stakeholders regarding disruptions in their access to health and rehabilitation services, impact on SCs, and examples of problem solving and innovation in response to service disruption and personal impacts for people with SCI. It was assumed that study participants would report reduced health service capacity and increased SCs due to the pandemic, particularly in the first several months of the pandemic.

## 2. Method

*2.1. Design.* The present study utilised a multimethods qualitative design comprised of a qualitative online survey of people living with SCI, and expert stakeholder forums (ESFs) with experienced SCI clinicians, as well as representatives from community-based SCI consumer organisations (including some who were people living with SCI), and other community services providing services to people with SCI such as compensation agencies. Examining multiple perspectives enabled a comprehensive understanding of the impacts from all critical stakeholders in the SCI rehabilitation journey to be gained. The survey identified issues of importance to respondents living with SCI, and the forums enabled key issues to be explored in-depth to generate insights of value to all concerned.

The study setting was the Queensland Spinal Cord Injuries Service which provides state-wide specialist SCI services along a life-long continuum of care that comprises of

acute management and primary rehabilitation, outpatient follow-up, as well as transitional and community rehabilitation, and outreach services.

*2.2. Participants.* The research was advertised via the Peer Support Facebook Group of Spinal Life Australia, the largest member-based SCI community services provider in Queensland. Survey respondents were recruited over a period of six weeks by regular advertisements posted to this group where participants followed a link to the online survey if interested. The group is a by-invitation social media platform community of over 2000 members with a SCI or their family members (approximately 1600 members at the time of recruitment) and the moderator was a member of the research team. Eligible participants were aged 18 years and older, lived in Queensland, and had a SCI. The survey participants comprised of a convenience sample. The ESFs comprised a convenience sample of representatives of health, disability, and other organisations experienced in providing services to people with SCI, with the aim of providing a diverse range of perspectives. Using a snowballing approach to recruitment, key organisations were identified by members of the project steering committee and invited via email to nominate an appropriate person/persons to represent them in the ESFs based on their knowledge, skills, and leadership experience in SCI rehabilitation and consumer organisations. Invitations were sent via email by a member of the research team to the nominated multidisciplinary clinicians and to representatives of consumer and community support organisations. Some participants may have known one another before the study and some may have been known to the ESF facilitators. While this may potentially introduce bias, any pre-existing relationships could add value to the quality of interaction and dialogue during the ESFs.

*2.3. Measures and Procedure.* Prior ethical clearance was obtained from Human Research Ethics Committees at Metro South Health and Griffith University. An opt-in consent was used for the online survey, whereby participants consented to participate by completing the survey. ESF participants were introduced to the study and its purpose and provided written consent prior to the forum.

*2.3.1. Data Collection.* The survey collected demographic data regarding current age, age at injury, years post-injury, gender, marital status, living situation, employment, level of injury, and cause of injury. This was followed by eight open-ended questions which explored the impacts of the pandemic on service access, psychosocial and health outcomes, and opportunities for problem-solving and coping solutions (Appendix A). These questions were developed collaboratively and iteratively by the co-investigators, members of the project's steering committee, and members of the project's clinical advisory group which included people with SCI. The online survey was delivered via Microsoft Forms and data collection occurred between

August and November 2021. While the spread of COVID was relatively low during this period, Queensland experienced COVID-19 restrictions including social distancing measures, mask mandates, snap lockdowns, vaccination mandates, and international and inter-state border closures all introduced to lessen the spread. For the ESFs, a set of open-ended questions (Appendix B) was developed to explore perspectives on (a) pandemic-related service disruption, (b) impacts of disruption for people with SCI and SCI specialist services, (c) the broader opportunities and challenges of alternative modes of service delivery and personal support, and (d) the implications for service delivery, state-wide planning, and advocacy. These questions were developed collaboratively and iteratively by the co-investigators, members of the project's steering committee, and members of the project's clinical advisory group which included people with SCI. To maximise opportunities for participation, two in-person forums were held in a wheelchair-accessible meeting room in the Spinal Injuries Unit at the study site in September/October 2021, with a virtual attendance option to the venue through videoconferencing technology which included speakers, microphone, and cameras. This enabled all attendees to see, hear, and contribute to the conversation during a period of active COVID-19 restrictions. Discussion was led by facilitators experienced in qualitative research (MF and LB) and accustomed to suspending any personal assumptions during data collection and analysis while motivated by academic interest in the topic. The ESFs were audio-recorded in-person by a professional stenographer for verbatim transcription.

*2.3.2. Data Analysis.* Descriptive analyses were used to summarise the demographic characteristics of survey respondents. Qualitative content analysis [19] was used to summarise the information provided in the survey responses to the question topics. This enabled the development of a comprehensive and coherent summary of respondents' views regarding the topics of interest. Frequency distributions were used to provide an overview of responses, structured to align with the open-ended survey questions. The analysis was conducted independently by two team members (LB and CH), followed by a meeting to progress the findings. Minor differences were identified and resolved through discussion to ensure consistency. The forum transcripts were analysed thematically [20], following five key steps: familiarisation with the data, identifying a coding framework, indexing the data, charting to identify patterns, and mapping and interpretation. A framework approach was adopted to enable prespecified questions to be addressed [21, 22]. Thus, the key themes were structured deductively from the four question topics (disruptions; impacts; opportunities, challenges, and innovations; and implications for service delivery planning and advocacy) and inductively from the comments of participants. Two forum participants agreed to read the findings, and both confirmed that they accurately represented what was discussed.

### 3. Results

The survey was completed by 34 people with SCI (Table 1). No information was available regarding nonrespondents or their reasons for nonparticipation. The mean time since injury was approximately 20 years.

A total of 16 SCI expert stakeholders participated in one of two forums and all but two opted to attend in person. Participants comprised ten clinicians representing specialist inpatient and community SCI services, as well as representatives from three key consumer organisations (including two representatives with SCI) and one compensation agency. The duration of ESFs was 90 minutes and 120 minutes, respectively.

Due to the complementarity of findings from the online survey and ESF, the results are presented as a single unified narrative regarding the impact of the COVID-19 pandemic on physical and mental wellbeing, access to services and supplies, and the use of workarounds to mitigate adversity. Table 2 summarises the survey results. Comments were selected from the survey responses and forum transcripts to shed light on the study results. In this section, “respondent” refers to a person who completed the survey (individual with SCI), and “participant” refers to a person who participated in the forum discussion.

*3.1. Impact on Physical and Psychosocial Wellbeing.* Unwanted physical impacts were a common concern for SCI survey respondents early in the pandemic, with only two (6%) reporting no physical impact. The most frequently reported problems were a lack of physiotherapy and no hydrotherapy, followed by lack of exercise and gym access since facilities were shut down or respondents were confined to their home. Another commonly reported concern was muscle stiffness linked to reduced physical activity. The impact on physical wellbeing was discouraging, as one forum participant observed:

“When you know what they’re capable of and how hard they’ve worked to get there, and then you’re watching that just go backwards and then losing independence and function. . . that was tough to watch” [ESF1, P1].

Another participant noted:

“[Some] just stopped services altogether and we found some reluctant to go to doctors, to physios, to whatever services – other services they might need. And, yes, it’s just been that when they get to a point where they absolutely have to go, they’re dealing then with a pressure wound or something that is a whole lot worse than it needed to be, had they gone out early” [ESF1, P5].

A forum participant explained that “a lot of the community services that people relied on [were] gone almost, very quickly” [ESF2, P6].

Undesirable impacts on mental health were reported by most SCI survey respondents. The majority ( $n = 24$ , 71%) identified isolation as a mental health issue, and nine (26%) reported experiencing isolation and mental health issues ( $n = 8$ , 24%). Anxiety, worry, or stress were reported by a substantial minority ( $n = 14$ , 41%). Others identified fear, boredom, frustration, and a lack of concentration as

TABLE 1: Demographic information for online survey respondents ( $n = 34$ ).

Characteristics	<i>n</i>	% (rounded)
Sex		
Male	18	53
Female	16	47
Age		
Mean age: 52 years (range: 25–76 years)		
Mean age at injury: 32 years (range: 0–57 years)		
Mean years post-injury: 20 years (range: 1–76 years)		
Level of injury		
Paraplegia	21	62
Tetraplegia	13	38
Cause of injury		
Traumatic	20	59
Nontraumatic	14	41
Relationship status		
Married/de facto relationship	16	47
Never married	10	29
Divorced/widowed	8	24
Living arrangement		
Living at home with family	20	59
Living at home alone	11	32
Other	3	9
Employment status <sup>a</sup>		
Full-time	2	6
Part-time	6	18
Casual	4	12
Unemployed	6	18
Self-employed	1	3
Volunteer	5	15
Retired	6	18
Home duties	4	12

Note: <sup>a</sup>Total > 100% due to rounding on small percentages.

a concern. Only six (18%) respondents reported no impact on their mental health. For example, one reported being “very bored [and] we all became depressed due to lack of human contact” [R2]. One individual living with SCI described impacts in terms of injury, “immense stress. . . pain, and exhaustion” [R12] for his wife who had become his sole caregiver. In contrast, however, another respondent noted “liv[ing] rurally, so nothing much changed” [R20]. ESF participants had noted “significant increases for the majority in DASS [depression, anxiety, and stress] scores” [ESF1, P1], and reduced mental wellbeing.

“We know that social connection is such a protective factor, and it completely dropped off for a lot of people . . . Mental health has been the big issue and big concern” [ESF1, P6].

One SCI survey respondent reported a relationship breakdown, and the partner of another was diagnosed with mental illness. A participant noted that it is not surprising that there would be significant impacts on family, given that access to professional support workers was often challenging and that even “getting support

TABLE 2: Survey results summarised and stacked by the number of responses.

	<i>n</i>	%
<i>Early pandemic</i>		
<b>Physical impacts</b>		
Lack of physical activity due to reduced service/community/therapy access and home confinement		
Lack of physiotherapy/no massage therapy	10	29
No gym access/lack of exercise	7	21
No hydrotherapy/unable to go swimming	8	24
No sport	3	9
Only land-based physiotherapy appointments	1	3
Confined to home/yard	1	3
Locked down in apartment and no exercise facilities	1	3
Confined to bed	1	3
Muscle stiffness due to physical inactivity		
Increased stiffness/legs became very tight	3	9
Unwanted secondary impact on health and wellbeing of lay carer		
Injury, pain, and exhaustion (carer)	1	3
No impact		
No physical impact	2	6
<b>Impact on mental health (incorporating family and social interaction)</b>		
Isolation significant impact on mental health		
Isolation (both physical and social)	24	71
Specific mental health symptoms and concern for emotional wellbeing		
Anxiety	8	24
Worry/stress	6	18
Depression	4	12
Fear/post-traumatic stress disorder (PTSD)	4	12
Boredom	2	6
Frustration	1	3
Lack of concentration	1	3
Concern for wellbeing	1	3
Impact on relationships and family		
Separation from partner	1	3
Diagnosed mental illness (spouse)	1	3
No impact		
No impact on mental health	6	18
<b>Impact on usual health and community services</b>		
Decline in access to usual services and community		
Cancellation or reduction in support services	28	82
Difficult or no access to appointments	25	74
Virtual communication difficulties		
Difficulties with telehealth and virtual communication	8	24
Positive impacts		
Easier access, traffic, and disabled-only supermarket times	1	3
Short distance travel if less traffic and easy shop access	1	3
No impacts		
No problem with carers	1	3
No impact on usual services	6	18
<i>Whole pandemic</i>		
<b>Complications due to issues regarding COVID-19 or health and community services</b>		
Secondary complications: physical		
Worse mobility, flexibility, and spasticity	3	9
Loss of upper limb/body strength	2	6
Oedema and leg tightening	2	6
Major skin breakdown/pressure sores	2	6
Weight gain	2	6
Urinary retention	1	3
Increased neurological symptoms causing a seizure	1	3
Progression of transverse myelitis/chronic inflammatory demyelinating polyradiculoneuropathy, shingles, and gastro-oesophageal reflux disease	1	3
Blood pressure	1	3
Deterioration, had to work on to get back	1	3

TABLE 2: Continued.

<i>Early pandemic</i>	<i>n</i>	<i>%</i>
Physical impacts		
Secondary complications: psychosocial		
Social isolation	9	26
Mental health issues including lack of mental health support	8	24
Government/administrative impositions (i.e., challenges with Centrelink and National Disability Insurance Scheme)	4	12
PTSD has worsened to suicidal thoughts	1	3
Loss of employment	1	3
No impact		
No complications	13	38
Problems getting usual personal/home support, community access, or healthcare		
Difficulty accessing home support and community		
Yes/yes with all of the above/extremely difficult	15	44
No support or difficult to find	13	38
No or restricted access to community	12	35
Difficulty accessing health care or conflicting health information		
No access to therapies, surgery, tests, consultations, and exercise	4	12
Concerns regarding COVID-19 vaccination rates and efficacy	2	6
Difficulty accessing vaccination	1	3
No impact		
No problems	8	24
Problems regarding technology and equipment/consumables including repairs		
Delays or difficulty accessing equipment/consumables and increased cost		
Difficulty/delays accessing equipment and parts	8	24
Difficulty accessing consumables/cost	6	18
Delays and slower delivery	4	12
Yes/yes all of the above	2	6
Difficulty with budget	1	3
No impact		
No problems	11	32
New solutions or workarounds developed to manage the impact of the pandemic		
Adoption of technology		
Telehealth/virtual appointments	6	18
Online shopping, home deliveries, and less frequent shopping	6	18
Individual exercise		
Self-directed or solo exercise	6	18
New supports		
Planned for and sourced alternative support	8	24
New routines and strategies		
Restored or developed new home/work routines	4	12
Used or developed new personal strategies	7	21
Unable to identify solutions		
No solutions	8	34
Resigned to things that cannot be changed	3	9

worker training sessions together is difficult” [ESF1, P2]. This left family or others assuming the lay support worker role in the undesirable situation of extra responsibilities to fill service gaps without necessarily being equipped for it. Conversely, another participant found that “the lockdown for me was quite good. I quite enjoyed having family at home” [ESF1, P8].

**3.2. Impact on Access to Usual Health and Community Services.** Service cancellations or reductions were reported by most SCI survey respondents ( $n = 28$ , 82%) early in the pandemic, when access to appointments was also limited or

difficult. The specialist SCI outpatient clinic was rapidly converted to a COVID-19 Fever Clinic at several points in the pandemic. Forum participants also noted:

“[T]he last-minute cancellations of clinics, having to contact people after hours for change - it all adds [up] to angst in those people you can't get on to” [ESF2, P2].

The number of people with SCI who experienced difficulties was marginally lower ( $n = 26$ , 76%) by a year later. Although several ( $n = 6$ , 18%) reported no impact on their usual services, almost half ( $n = 15$ , 44%) reported difficulty in general, and more than a third ( $n = 13$ , 38%) reported that no support was available or that it was difficult to find. A similar number ( $n = 12$ ) reported restricted community access.

Specialist SCI inpatient and ambulatory services were variably impacted through the course of the pandemic. Survey respondents noted that they were unable to “access. . .GP, hospital, and specialist care” [R17] or “attend my regular SCI rehabilitation sessions” [R22]. In the early stages, the need to create hospital inpatient capacity resulted in very rapid discharge planning for existing patients and consequently increased responsibility and stress on specialist SCI community services:

“I think the early discharges, whether they are by the health system wanting people to be discharged, or people wanting to be discharged themselves, the fallout is just that we're seeing bigger problems at home” [ESF2, P6].

Later, as all community services were increasingly curtailed, discharge from inpatient services was often delayed, for example by inability to get home modifications completed by community service providers in a timely manner:

“If we're all on lockdown or there are restrictions, then you don't get your home mod[ifications] started. You can't discharge; you have a backlog for people coming in the front door if people can't get home” [ESF2, P2].

One of the forum participants noted that delayed discharges also meant that others needing specialist spinal rehabilitation were placed in “acute wards or other hospitals” [ESF2, P3]. Another remarked that a down-side of being able to go out into the community again after a long-delayed discharge from the Spinal Injuries Unit was that, for people with SCI who “have been in a cocoon for six months, twelve months”, this *freedom* also generated fear around “How vulnerable am I?” [ESF1, P4].

A minority of SCI survey respondents experienced lack of flexibility in their interactions with government agencies such as Centrelink (which delivers income support payments and services) and the National Disability Insurance Scheme (NDIS), and one had to pay a fee for cancellation of support during a snap lockdown. Lack of access to therapy, surgery, consultations, and exercise remained a problem as the pandemic continued. One SCI survey respondent reported difficulty accessing vaccinations, while two were concerned about challenges accessing clear information around the limits of COVID-19 vaccination including efficacy. Another reported that it was helpful that supermarkets “had disabled-only times” [R18] and access was easier with “less road traffic” [R18], but such benefits were not experienced by those “unable to access shopping and chemist” [R7]. In contrast, almost a quarter of respondents ( $n=8$  people with SCI, 24%) reported no problems with obtaining personal or home support or community access during the entire pandemic.

**3.3. Impact on Equipment, Consumables, and Repairs.** For some SCI survey respondents, the cost of consumables was a problem ( $n=6$ , 18%), and an equal number reported difficulties with delays and deliveries. Access to equipment and parts was difficult for almost a quarter of respondents ( $n=8$ , 24%). For example, one respondent “waited 9 months for parts for an essential item (hoist) to be repaired” [R9] while others had problems “from almost day 1 with

continence supplies” [R29] or being “unable to purchase examination gloves” or to attend “massage [fortnightly] and hydro[therapy][twice a week]” [R21]. In contrast, six identified no problems with equipment or consumables.

One ESF participant provided further insight into such disruptions, “[W]e had to get special permission for all of our suppliers to come in to provide equipment. . .we had to keep communicating and highlighting that as it impacted on people's rehab[ilitation] and potentially length of stay to ensure that the expectation was understood, that things couldn't move as quickly as we would normally move them” [ESF1, P9].

Another forum participant noted:

“That's been a massive problem getting [equipment and aids], getting [allied health]. . .to the people, getting equipment to the people, ordering the equipment. And that goes with telehealth as well with getting - suddenly - iPads, computers, technology” [ESF2, P6].

A minority of SCI survey respondents ( $n=6$ , 18%) identified no problems with technology. Despite its potential advantages, technology was problematic for several respondents who struggled with virtual communication. In contrast, some ESF participants “found telehealth to be a nice escalation pathway now” [ESF1, P2]. Positive impacts were also identified, including easier, disability-friendly access to shops, because “at times less road traffic allow [ed] safer short distance travel, easier access at shopping centres” [R16].

**3.4. Secondary Complications.** A substantial minority of survey respondents ( $n=15$  people with SCI, 44%) reported a diverse range of physical complications due to pandemic-related restricted access to services, including muscular deterioration, skin problems, weight gain, neurological problems, and hypertension. For example, “physiotherapy services shut and my legs ended up becoming very tight” [R28]. Consistent with these reports, an ESF participant described seeing:

“[S]ituations where the person has not been able to come to get the acute treatment necessary, post-injury. They have been remotely hospitalised and very quickly they developed. . .UTIs, pressure injuries, sepsis. . .[They lack] expertise in managing SCI. . .By the time they get to the Spinal Injuries Unit. . .they've got to get extended medical treatment, which delays rehabilitation” [ESF2, P1].

The diversity of experience with COVID-19 or service-related complications is reinforced by the absence of complications for a substantial number of respondents ( $n=13$  people with SCI, 38%), in contrast with the SCI respondent who disclosed suicidal thoughts, and another who lost employment. For one respondent, the COVID-imposed isolation was intensified by “marriage breakdown and separation” [R17].

**3.5. Solutions and Workarounds to Mitigate Negative Impact.** Almost a quarter of respondents ( $n=8$  people with SCI, 24%) were unable to identify any solutions, and three had

resigned themselves to their circumstances. Six (18%) SCI respondents regarded technology as a solution, and a similar number reported that shopping less frequently and shopping online were solutions. Six respondents (18%) tried a self-directed approach to exercise, eight planned for and sourced alternative supports (24%), four restored or developed new work or home routines (12%), and seven (21%) used or developed new personal strategies including avoiding watching the news, relaxation techniques, and increased hobby activities. For some respondents, workarounds were not necessarily positive, as one “had to move into a tense living arrangement with my ex-partner” [R7], and another reported “confusion about access to medical services unrelated to my SCI” [R6], while acknowledging that “phone consultations and telehealth were most welcome” [R6]. Solutions were also constrained by undercurrents of financial concerns such as having “lost my job and hav[ing] no personal income” [R7] or concerns about personal choice regarding vaccination mandates, with “no supplies in our area” [R5] or “the mandate to have our health workforce vaccinated. . .and staff leaving” [R22]. ESF participants were more positive in recognising the opportunities and challenges of imposed change:

“[It’s] changing everybody’s expectations. We’ve all come along the journey and had to learn we can’t get everything we want now, although we need it. We can’t get all the services we want; we can’t get it the way we want it. I think the balance of learning that this is new, and we all have to accept it and also learning that everybody, emotionally and mentally, are heightened. . .balancing that as well has been difficult, but that includes everybody. That’s the service users, the service providers who are also humans with a family in this pandemic” [ESF2, P6].

#### 4. Discussion

To our knowledge, this is one of the first Australian studies to examine the impact of COVID-19 pandemic-related health system stress on a sample of people with SCI. It also reveals how service providers and people living with SCI in the community have innovated in attempts to mitigate the impact of pandemic-related disruptions. The survey and forum results together contribute to our understanding of these impacts for people living with SCI in three ways. Firstly, people with SCI experienced *service disruption*, particularly to health and community services and personal supports. Secondly, the impacts of the disruptions were measured by *secondary complications* in physical health and psychosocial domains. Lastly, people with SCI and those who support them, accommodated and generated change, to try to find *solutions* for ensuring access to care during the pandemic. These impacts were evident in the beginning of the pandemic and stayed relatively stable over the prolonged period created by widespread restrictions, lockdowns, and other pandemic responses.

The scale, complexity, and duration of disruption to healthcare, rehabilitation, and community support services, and to the supply of equipment and consumables has been unprecedented and is consistent with international research

[4, 6, 23, 24], as is the finding of disrupted in-home personal support [5]. In addition to closed, delayed, or rationed services, participants were confronted with their own self-preservation instincts of not wanting to interact with services for fear of contracting COVID-19 [7]. Although intended to alleviate concerns about loss of face-to-face interactions, the rapid growth in telehealth consultations was found to generate new challenges related to unfamiliar or unreliable technology, as well as safety concerns, for example when undertaking physical therapy virtually [4, 5, 8]. Service users and providers were challenged by the scarcity and higher cost of supplies and by uncertain service accessibility and safety.

Disruption led to multiple concurrent and intersecting impacts. Isolation was implicated as a key contributor to SCs in physical and psychosocial domains, particularly poor mental health. Supporting previous research [6, 14, 15], respondents reported increased anxiety, worry, and stress, and one disclosed suicidal ideation. The impact also extended to quality of life and wellbeing, with respondents reporting increased fear, boredom, frustration, poor concentration, relationship breakdowns, and increased burden on family members/support workers. It was almost inevitable that hard-won levels of physical health suffered because of pandemic-related disruption, with the reporting of increased muscle stiffness, loss of strength and mobility, increased pain/discomfort, and other medical complications, consistent with previous research [7, 11–13, 15]. These results all support the study assumptions.

Coupled with the pressure of ongoing needs, the large number of impacts compelled people to respond. However, it is noteworthy that for more than three quarters of respondents attempts to innovate were unsuccessful, which seems consistent with their reported frame of mind. Despite working in survival mode, providers continued to explore and test alternatives to ensure adequate support was reaching those who needed it, with some success, including increased use of telehealth. The limitations of technology as an alternative means of communication are not new, especially for inexperienced users [4].

Taken as a whole, the results of this study demonstrated resilience in people with SCI and in the health professionals who care for them. They were confronted by new large-scale challenges and at least attempted to resolve them in ways to preserve quality of life and progress with rehabilitation. Nonetheless, some respondents clearly experienced unwanted physical and mental health impacts, reduced or disrupted access to usual services and community, increased SCs, and difficulty accessing support and equipment. In contrast to many natural disasters, the COVID-19 pandemic is a marathon, which adds endurance as a further need. This has implications for all concerned, including those who may have used alternative sources of support to mitigate or delay the development of SCs.

**4.1. Implications.** Since some issues arising early in the pandemic failed to resolve, new and collaborative approaches are needed to manage complex issues that resist or overwhelm usual strategies. The pandemic provides a new



opportunity to develop and evaluate crisis management plans and strategies, and to add them to standard resources as valuable action-ready back-up plans in any future disruptions to the supply chain and coordination of health care and support. If online solutions become standard options, work is needed to improve the low (less than 20%) effectiveness of technological solutions (i.e., telehealth) reported by the study participants and to now shift the focus of education and training away from health professionals and service providers to the end users. We suggest that this population who prize their independence and resilience [25, 26] would welcome training initiatives to improve their technological capacity. Training in telehealth and technology for delivering care and rehabilitation would require significant investment in materials, hardware, and training for both people living with SCI and healthcare personnel. While some face-to-face attendance is non-negotiable due to the hands-on nature of physical rehabilitation (i.e., physiotherapy and hydrotherapy), the integration of technology in health-related care could have great benefits for this population in many other aspects (i.e., general check-ups and mental health support), particularly those with limited mobility.

A key priority is to conserve and consolidate the team of specialised health care and support workers who carry the burden of bridging gaps between needs and resources. There is opportunity to build on the peer support and cross-pollination that exists within this network. Exchanging ideas can contribute practically to what is being learned. The composition of partnerships could be explored in a brief that enables new thinking to enter the process.

In summary, forward planning is needed on multiple levels. State-wide planning for service delivery during prolonged periods of disruption is needed to safeguard the availability of resources as well as specialised healthcare and support workers able to care for vulnerable populations. Centralised planning is needed to enable consumables to be stockpiled, with simpler access to products and equipment. Decentralised planning is needed to proactively ensure local back-up plans are in place. Finally, multilevel advocacy and planning is needed to protect the capacity and availability of healthcare and support workers and to maintain cohesion between these workers and community organisations. The core implication is that we must work together to avoid the scenario in which vulnerable people who depend on specialised health care and support fail to receive them, only to inadvertently develop complications that isolate them further from the quality of life that is their right and increase the need for access to the very services which are restricted.

**4.2. Strengths and Limitations.** This small study provides rich insights into the daily realities of pandemic-related disruptions to specialised services that are needed long-term by people with SCI. The results identify and explore the complexity of multiple interconnected factors that have affected the health and well-being of people with SCI. They

also highlight the motivation that generates important strategies to protect and sustain adequate care under unprecedented ongoing conditions that interrupt the timely delivery of needed services. These initiatives reveal exceptional use of human characteristics such as resilience, autonomy, and resourcefulness in seeking to close gaps that can lead to adversity for people with SCI.

However, the study is limited by convenience sampling and small sample sizes, which may have resulted in some potential bias. For example, the proportion of female respondents does not match the gender distribution in the SCI population. Additionally, the timing of the study meant that COVID had not yet spread widely throughout the community due to the pandemic-related restrictions and vaccination mandates. Therefore, the findings may relate to the impact of the lockdown restrictions themselves versus the impact of the rapid spread of the virus. Data saturation is unlikely to have been reached, although there were common themes from both ESFs. Therefore, it is important to note that these study results provide insights from one small population of people with SCI who are linked to services provided by one tertiary hospital and the network of community services that continue to support people with SCI beyond discharge from hospital. While some results will be generalisable, the experiences of provider and user groups in other geographic settings and health systems may vary, leading to different implications.

## 5. Conclusions

This multilevel, multimethods, qualitative study provides valuable insights that a survey or single-level qualitative inquiry alone could not provide. The results present the nature of pandemic-related disruption, its impact, solutions, and implications, which may inform future rehabilitation practice and research in the study setting and elsewhere. While the research was conducted during the early stages of the pandemic in Queensland, Australia, when COVID-19 cases were relatively low, future research should examine the disruptions and implications of the pandemic in more recent times now that lockdowns are a thing of the past and almost all pandemic-related restrictions have been lifted but where COVID-19 is widespread in the community, to ascertain if the impacts vary in type or significance.

## Appendix

### A. Online Survey

#### *Demographic Questions*

- (1) What is your current age?
  - \* Please answer in years
- (2) How old were you when you had your injury?
  - \* This includes both traumatic and nontraumatic damage.
  - \* Please answer in years
- (3) What is your marital status?

- (i) Married/*De facto*
  - (ii) Never Married
  - (iii) Divorced/Widowed
- (4) What is your gender?
- (i) Male
  - (ii) Female
  - (iii) Other
- (5) What is your employment status?
- (i) Full-time
  - (ii) Part-time
  - (iii) Casual
  - (iv) Unemployed
  - (v) Self-employed
  - (vi) Volunteer
  - (vii) Retired
  - (viii) Home duties
- (6) What is your current living arrangement?
- (i) Living at home with family
  - (ii) Living at home alone
  - (iii) Living in a share house
  - (iv) Other
- (7) What is your level of injury?
- (i) Paraplegia
  - (ii) Tetraplegia/Quadriplegia
- (8) What is your cause of injury?
- (i) Traumatic
  - (ii) Nontraumatic
- Impact of COVID-19*
- This section will ask about the lived experience of the impacts of the COVID-19 pandemic on people's health and ability to access their usual services.
- (9) Remembering back to the early stages of the COVID-19 pandemic and the lockdown period (first half of 2020), what were the main ways in which you and your family and caregivers were impacted physically?
- (10) Remembering back to the early stages of the COVID-19 pandemic and the lockdown period (first half of 2020), what were the main ways in which you and your family and caregivers were impacted in regard to mental health?
- (11) Remembering back to the early stages of the pandemic and the lockdown period (the first half of 2020), did you have any problems getting your usual health and community services? Which services were most affected?
- (12) Considering the whole of the 2020/21 pandemic period, did you develop any health or other complications which you relate directly to the pandemic or your inability to access services or the community? What were those complications?

- (13) Considering the whole of the 2020/21 pandemic period, did you have problems with getting your usual support services or other help in the home or with getting out of your home and accessing the community as you usually would?
- (14) Considering the whole of the 2020/21 pandemic period, did you have problems related to assistive technology or equipment or consumables, for example purchasing or delivery of equipment of consumables or repairs and maintenance of equipment?
- (15) Despite the disruption and difficulties caused by the pandemic, many people developed their own solutions to help them cope during that time. What new ways of doing things or workarounds did you develop to help you manage the impacts of the pandemic?
- (16) Considering the whole of the 2020/21 pandemic period, are there any other impacts that you would like to mention?

## **B. Expert Stakeholder Forum Discussion Guide**

### *General comments*

- (1) Let us start off with some general comments about any changes in the provision of service and support as a result of the pandemic.
- (a) What have you noticed in your setting?
  - (b) What concerns have these changes raised for you regarding your capacity and responsiveness to people with SCI?

### *Disruptions*

Let us now look more specifically at disruptions.

- (2) Tell us about something you have seen or experienced during the pandemic that disrupted the previous flow of service and support.
- (a) What kind of problems have you mostly seen?
  - (b) What kind of disruptions were most problematic for you in relation to your core work with people with SCI?

### *Impacts on people, SCI specialist services and the community*

Turning now to the impact of these COVID-19-related disruptions.

- (3) In your view what are some of the key flow-on effects?
- (a) For people who depend on services and support?
  - (b) For people who care for them?
  - (c) For people who provide services and support?

### *Opportunities and challenges of alternative modes of service delivery and personal support*

Thinking now about alternative ways to provide services and support.

- (4) What kind of opportunities has the pandemic opened up for the service that you are involved in?
- Tell us how you developed these opportunities.
  - How would you envisage assessing the place of these new initiatives in your ongoing suite of services in the longer term?
- (5) We are also interested to hear about the other side of innovation during the pandemic, i.e., any challenges.
- How did you become aware of challenges?
  - How did you tackle them, in terms of weighing up the pros and cons of investing effort into fixing them vs. discarding the service MO that had difficult challenges?

*Implications for service delivery, state-wide planning and advocacy.*

The final key topic we want to discuss tonight is an important one.

- (6) How have you scoped the implications of pandemic-related changes in services and support?
- What do the COVID-19-imposed changes mean for the practicalities of delivering services, in the short-term? In the longer-term?
  - How have the pandemic-related changes in services and support been influencing the State-wide planning process? What influence might they have? Is that a good thing?
  - Tell us about any implications for the work of advocacy for people with SCI.

*Other points*

That brings us to the end of our prepared questions, but there may be other issues that need to be discussed.

- (7) Have we missed anything?

## Data Availability

The deidentified survey and forum data used to support the findings of this study are available upon request from Prof Timothy Geraghty (timothy.geraghty@health.qld.gov.au).

## Conflicts of Interest

The authors declare that they have no conflicts of interest.

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## References

- Callaway, L. Barclay, R. McDonald, L. Farnworth, and J. Casey, "Secondary health conditions experienced by people with spinal cord injury within community living: implications for a National Disability Insurance Scheme," *Australian Occupational Therapy Journal*, vol. 62, no. 4, pp. 246–254, 2015.
- S. L. James, A. Theadom, R. G. Ellenbogen et al., "Global, regional, and national burden of traumatic brain injury and spinal cord injury, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016," *The Lancet Neurology*, vol. 18, no. 1, pp. 56–87, 2019.
- M. A. Van Loo, M. W. M. Post, J. H. A. Bloemen, and F. W. A. van Asbeck, "Care needs of persons with long-term spinal cord injury living at home in The Netherlands," *Spinal Cord*, vol. 48, no. 5, pp. 423–428, 2010.
- P. Boldrini, C. Kiekens, S. Bargellesi et al., "First impact of COVID-19 on services and their preparation Instant paper from the field" on rehabilitation answers to the COVID-19 emergency," *European Journal of Physical and Rehabilitation Medicine*, vol. 56, no. 3, pp. 319–322, 2020.
- M. D. Stillman, M. Capron, M. Alexander, M. L. Di Giusto, and G. Scivoletto, "COVID-19 and spinal cord injury and disease: results of an international survey," *Spinal Cord Series and Cases*, vol. 6, no. 1, pp. 21–24, 2020.
- E. Felix, J. V. Alvarado, N. Miranda-Cantellops, and S. Jackson, "Access limitations and level of psychological distress during the covid-19 pandemic in a sample of individuals with spinal cord injury," *Archives of Physical Medicine and Rehabilitation*, vol. 102, no. 4, pp. e5–e6, 2021.
- J. H. Hearn, E. J. Rohn, and K. R. Monden, "Isolated and anxious: a qualitative exploration of the impact of the COVID-19 pandemic on individuals living with spinal cord injury in the UK," *The Journal of Spinal Cord Medicine*, vol. 45, no. 5, pp. 691–699, 2021.
- N. A. Dean, A. Marwaha, M. Grasdahl et al., "Perspectives from the spinal cord injury community with teleSCI services during the COVID-19 pandemic: a qualitative study," *Disability and Rehabilitation: Assistive Technology*, 2022.
- D. Barrows and B. Goldstein, "Virtual care in the veterans affairs spinal cord injuries and disorders system of care during the COVID-19 national public health emergency," *Physical Medicine and Rehabilitation Clinics of North America*, vol. 32, no. 2, pp. 207–221, 2021.
- K. Brehon, J. Carriere, K. Churchill et al., "Evaluating the impact of a novel telerehabilitation service to address neurological, musculoskeletal, or coronavirus disease 2019 rehabilitation concerns during the coronavirus disease 2019 pandemic," *Digital Health*, vol. 8, Article ID 205520762211016, 2022.
- A. Marco-Ahulló, L. Montesinos-Magraner, L. M. González, J. Morales, J. A. Bernabéu-García, and X. García-Massó, "Impact of COVID-19 on the self-reported physical activity of people with complete thoracic spinal cord injury full-time manual wheelchair users," *The Journal of Spinal Cord Medicine*, vol. 45, no. 5, pp. 755–759, 2021.
- K. Gumussu and B. Erhan, "Spasticity management of individuals with spinal cord injury in era of societal restrictions due to COVID 19 pandemic," *Toxicol*, vol. 190, pp. S30–S31, 2021.

- [13] M. Matsuoka and M. Sumida, "The effect of the COVID-19 pandemic on the health-related quality of life in home-based patients with spinal cord injuries in Japan," *The Journal of Spinal Cord Medicine*, vol. 45, no. 5, pp. 760–764, 2021.
- [14] B. Mikolajczyk, C. Draganich, A. Philippus et al., "Resilience and mental health in individuals with spinal cord injury during the COVID-19 pandemic," *Spinal Cord*, vol. 59, no. 12, pp. 1261–1267, 2021.
- [15] A. Garcia-Rudolph, J. Sauri, J. Lopez Carballo et al., "The impact of COVID-19 on community integration, quality of life, depression and anxiety in people with chronic spinal cord injury," *The Journal of Spinal Cord Medicine*, vol. 45, no. 5, pp. 681–690, 2021.
- [16] Department of Health and Aged Care, "Coronavirus (COVID-19) case numbers and statistics," 2022, <https://www.health.gov.au/health-alerts/covid-19/case-numbers-and-statistics#covid19-situation-overview>.
- [17] Queensland Government, "Queensland COVID-19 statistics," 2022, <https://www.qld.gov.au/health/conditions/health-alerts/coronavirus-covid-19/current-status/statistics>.
- [18] Australian Human Rights Commission, *Guidelines on the Rights of People with Disability in Health and Disability Care during COVID-19: August 2020*, Australian Human Rights Commission, New South Wales, 2020, <https://humanrights.gov.au/our-work/disability-rights/publications/guidelines-rights-people-disability-health-and-disability>.
- [19] M. Sandelowski, "Whatever happened to qualitative description?" *Research in Nursing and Health*, vol. 23, no. 4, pp. 334–340, 2000.
- [20] V. Braun and V. Clarke, "Using thematic analysis in psychology," *Qualitative Research in Psychology*, vol. 3, no. 2, pp. 77–101, 2006.
- [21] J. Ritchie, L. Spencer, and W. O'Connor, "Carrying out qualitative analysis," in *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, J. Ritchie and J. Lewis, Eds., pp. 219–262, Sage, Washington, DC, USA, 2003.
- [22] D. J. Ward, C. Furber, S. Tierney, and V. Swallow, "Using framework analysis in nursing research: a worked example," *Journal of Advanced Nursing*, vol. 69, no. 11, pp. 2423–2431, 2013.
- [23] C. M. O'Connell, I. Eriks-Hoogland, and J. W. Middleton, "Now, more than ever, our community is needed: spinal cord injury care during a global pandemic," *Spinal Cord Series and Cases*, vol. 6, no. 1, pp. 18–22, 2020.
- [24] A. E. Schwartz, E. G. S. Munsell, E. K. Schmidt, C. Colón-Semenza, K. Carolan, and D. L. Gassner, "Impact of COVID-19 on services for people with disabilities and chronic health conditions," *Disability and Health Journal*, vol. 14, no. 3, Article ID 101090, 2021.
- [25] K. A. Bailey, K. L. Gammage, C. van Ingen, and D. S. Ditor, "It's all about acceptance": a qualitative study exploring a model of positive body image for people with spinal cord injury," *Body Image*, vol. 15, pp. 24–34, 2015.
- [26] R. Kornhaber, L. Mclean, V. Betihavas, and M. Cleary, "Resilience and the rehabilitation of adult spinal cord injury survivors: a qualitative systematic review," *Journal of Advanced Nursing*, vol. 74, no. 1, pp. 23–33, 2018.