



Original Research

Living With Cervical Spinal Cord Injury During the COVID-19 Pandemic: A Qualitative Study



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KEYWORDS

Caregivers;
COVID-19;
Rehabilitation;
Spinal cord injuries;
Vulnerable populations

Abstract Objective: To understand how COVID-19 has affected the daily lives of people living with cervical spinal cord injury (SCI).

Design: Cross sectional qualitative study.

Setting: Academic medical center in the Midwestern United States.

Participants: Ten community-dwelling individuals (8 men, 2 women), average 11.6 years post-mid-cervical level SCI (N=10).

Interventions: Not applicable.

Main Outcome Measures: Semistructured interviews were completed by phone. The research team used thematic analysis and inductive strategies to analyze the data in this exploratory investigation.

Results: People with cervical SCI living in the United States during the spring of 2020 experienced changes to their daily lives. Participants described how interactions with caregivers for activities

List of abbreviations: COVID-19, coronavirus of 2019; SCI, spinal cord injury.

Data availability: Data are available from the corresponding author upon request.

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Ethical approval: All study procedures were approved by the institution review board at Washington University School of Medicine in St. Louis. We certify that all applicable institutional regulations concerning the ethical use of human volunteers were followed during the course of this research.

Disclosures: none.

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of daily living were complicated by fear about contracting and/or transmitting COVID-19. The pandemic limited this population's access to medical care and adversely affected their mental and physical health. Telemedicine was seen as a helpful alternative to in-person visits. Some participants felt that their previous life-altering experience (SCI) better prepared them to cope with the pandemic and "roll with things."

Conclusions: Learning about how people with SCI cope, persevere, and survive to overcome adversity during the pandemic should inform future research to support those with SCI. Improving telemedicine and rewarding and recognizing caregivers for their role in maintaining health are important first steps. We must continue to be creative about improving our health care systems and access for people with disabilities, particularly during this and future public health crises.

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COVID-19 has magnified the profound inequities and shortcomings in the U.S. health care system and society.^{1,2} Socio-economically disadvantaged populations may have greater morbidity and mortality when infected and lack the advantages to mitigate risk and exposure.³ By contrast, little is known about how the pandemic affected other populations such as people with disabilities. There is limited information about how the pandemic has affected people living with spinal cord injury (SCI): individuals who need regular access to medical supplies and care, may not be as physically able to follow precautions such as donning a mask or washing hands, and are commonly dependent on caregivers for basic activities of daily living.⁴⁻⁶

Early in the pandemic the American Association on Health & Disability conducted an online survey of people with mobility disorders (defined as serious difficulty in walking/climbing stairs). Data were collected from over 663 respondents between April 17 and May 1, 2020. Findings indicated that (1) 58% had disrupted access to necessary regular medical care and (2) 67% were unable to maintain safe distances from their caregivers.⁴ Similarly, the Paralyzed Veterans of America organization conducted a survey of its membership (between March 26 and 29, 2020; >1000 respondents) and found that people living with SCI had limited knowledge about how to access clinical care safely and no backup plan for caregiver assistance.⁷

Many have argued the need to investigate the experiences of these populations during COVID-19.^{1,8} How did people with SCI try to maintain health yet mitigate risk? Drawing on the experience and knowledge of people with disabilities will provide information on how to better prepare for disasters and deliver health services to those who are most dependent on them.²

We had established relationships with over 30 people living with cervical SCI who were previously enrolled in a longitudinal mixed methods investigation in which participants completed semistructured interviews and standardized surveys before and after surgery to restore upper extremity function. The purpose of this new study was to understand how COVID-19 has affected the daily lives of individuals with cervical SCI. Our existing research relationship supported the collection of meaningful in-depth and potentially sensitive information on the experiences of this population in the emerging pandemic.

Methods

Participants provided informed consent for study data collection after institutional review board approval.

Setting and participants

The study was carried out at Washington University in St. Louis, a large academic tertiary care center in the Midwestern United States. Participants were people living in the community with cervical level SCI followed within a separate existing study. They were invited to participate in an additional phone interview and were compensated with a nominal store gift card (\$20). To obtain timely information, we recruited participants in our existing cohort. Twelve individuals were contacted to participate (the research coordinator called individuals on our existing study phone list) and the first 10 people who responded were included; none were excluded. The interviews were conducted between May and July 2020.

Data collection and analysis

One-on-one semistructured phone interviews lasting between 30 and 60 minutes were completed. We sought to better understand how the pandemic altered the daily activities and quality of life of people with cervical SCI and focused on domains related to social interactions and relationships, accessing health care, well-being, and strategies for dealing with the pandemic and related restrictions. Development of the interview guide (see online supplement, available online only at <http://www.archives-pmr.org/>) was informed by the literature and previous qualitative studies interviewing people with SCI.⁹⁻¹¹

Interviews were carried out by C.K., a research coordinator well known to participants but not part of the medical treatment team. This allowed us to quickly achieve rapport and trust in the phone interviews. Data were transcribed verbatim and de-identified, and socially appropriate pseudonyms were assigned.

Thematic analysis, which acknowledges the underlying assumption that data are co-constructed between the participant and researcher, was undertaken.¹²⁻¹⁴ The team also acknowledges that multiple interpretations of the data are

possible and addressed the experiences of the research team through reflexivity.¹⁵ Data interrogation was carried out using inductive coding.¹⁵ This study took an exploratory approach aiming to provide a rich description of the participants' experiences in an area where little information exists. This exploratory study will lay the foundation for future research.

The first 5 interviews were individually and then collaboratively examined by A.L., E.H., I.F., and C.K. to expand and develop the interview guide and develop an initial set of codes, which were defined in a codebook. A.L. then reviewed the remaining interviews and iteratively modified the codebook. The codebook was finalized after team review and applied to all transcripts by A.L. A selection of transcripts was also independently coded by I.F. and E.H. and agreement was checked to enhance credibility and trustworthiness of the codes. Coded text was reviewed to infer themes in the data through a team-based process to reflect position and interpretation of team members with different disciplinary and experiential perspectives. Analysis was facilitated via NVivo qualitative data analysis software.^a

Reflexive diaries were maintained by E.H., A.L., C.K., and I.F. to record and challenge any assumptions, differing perspectives, or interpretations of data. The diaries were regularly reviewed and discussed within the research team to encourage critical reflexivity and were considered during thematic discussions. The goal was to encourage our own and others' interpretations of the data and did not form part of the data set for analysis. For more detail on our procedure, please refer to the online supplement.

Results

Context

During our ongoing study assessing upper extremity function in surgical and nonsurgical patients with SCI, we made several observations. In our practice environment in the Midwestern United States, accessing restorative upper extremity functional surgery in SCI can require a herculean

effort by the patient and provider to patch together a safe perioperative care package. Individuals travel great distances for access to specialty care, have comorbidities that make decision making more complex, and often do not have the best type of health insurance that allows them choice of care and the fullest extent of support. Beginning in March 2020, the onset of the COVID-19 pandemic further stressed this fragile network of care. Individuals missed surgery follow-up visits and therapy. This study further highlights emerging challenges such as difficulty with caregiver support, access to medical care, and the inability to follow public health guidance around COVID precautions.

Demographic characteristics

Participants had mid-cervical level SCI (shoulder and elbow flexion function were present; wrist and elbow extension were variably present and hand function, aside from tenodesis, was absent). Eight of 10 participants were male, 9 had an accident resulting in SCI, and 2 were under the age of 30. Demographic characteristics are described further in [table 1](#). A core shared experience in the group was the sudden and permanent life-altering event and change in independence after SCI. To protect the confidentiality of participants, we do not link detailed demographic or injury data to the individual quotes.

Summary

Participants described their experiences living with cervical SCI during the COVID-19 pandemic. Primary themes highlighted how reliant individuals with SCI are on caregivers ([table 2](#)), the effect of COVID-19 on mental and physical health ([table 3](#)), and the role of telemedicine in advancing health care access ([table 4](#)).

Caregiving

COVID-19 affected study participants in different ways, but most described a need for hands-on close-proximity

Table 1 Participant demographics

Study ID and Pseudonym	Age Range (y)	Sex	Race	Years Since SCI	Highest Level of Education	Employment Status	Mechanism of Injury
1. Kelsey	30-39	F	White	3	Bachelor's degree	On disability	Nontraumatic spinal cord lesion
2. Jeff	30-39	M	White	16	Associate's degree or trade school	Employed	Sports/recreation
3. Derrick	20-29	M	African American	6	Some college, no degree	On disability	Vehicular
4. Jim	30-39	M	White	15	Master's degree	Employed	Sports/recreation
5. Zane	20-29	M	White	9	Bachelor's degree	Student	Vehicular
6. Tammy	40-49	F	White	7	Some college, no degree	On disability	Vehicular
7. Paul	30-39	M	White	19	Master's degree	Employed	Vehicular
8. Bill	40-39	M	White	8	Not reported	Employed	Sports/recreation
9. Joseph	30-39	M	White	14	Bachelor's degree	On disability	Sports/recreation
10. Ted	30-39	M	White	19	Not reported	Employed	Vehicular

Abbreviations: F, female; M, male.

Table 2 Effect of COVID-19 on caregiving—illustrative quotes

Short-term loss of caregiver (choice of person with SCI)

“I think if it wasn’t so stressful with my wife trying to handle work, I probably would have asked [my caregiver] to just, you know, stay out. We were, we’re kind of on the same page with that. Like, she wanted to come back but, you know, she kind of, you know, in a perfect world, she wouldn’t of had to, but she wanted to come back. I kind of wanted her back and so now she’s back, but we’re just playing it by ear.”—Jeff, without a caregiver for 3 weeks.

In need of care but chose not to seek out new paid caregiver due to COVID-19

“When COVID hit, we were looking for a new home health care aide and we just kind of decided, ‘Hey, this isn’t the right time to be bringing somebody else in the house with everything else going on.’ So that’s probably the biggest impact for us right now is that I just—I usually had an aide come in, in the morning for about 2 and a half hours and help me get up and my wife has been doing that over this period.”—Jim

Unable to socially distance from caregivers

“So they reduce their clientele. One lady only works with me now and wears a mask, but you don’t—we’re not able to keep social distancing obviously, but she, like, she only works for me, so that’s part of it. The other lady never worked with anybody else to begin with, so that wasn’t much of a change for her.”—Bill

caregiving due to their SCI that was nonnegotiable and stressful to navigate during the pandemic:

I would just go back to the, me needing help more than a normal person. . . . With my spinal cord injury and having someone that has to be around me every day . . . that’s been the most stressful part about it. Just knowing that if I was to catch it . . . if someone was to catch it, how, and they were helping me, how could they still help me. Yeah, that’s been like the biggest, the biggest stressor, the most stressful thing.—Derrick

Caregivers were a necessary part of life for participants living with cervical SCI, and the pandemic highlighted challenges that can be inherent to the use of caregivers (table 2). Participants experienced both temporary and long-term changes to caregiving because both they and their caregivers wanted to limit exposure to other individuals. Six of the 10 participants had changes to caregiver arrangements due to the pandemic. Many participants needed to continue working with nonfamily external caregivers. Participants described how they tried to carefully negotiate their increased exposure risk, particularly with caregivers who

Table 3 Effect of COVID-19 on mental and physical health—illustrative quotes

Mental Health

Family-related stress

“[My] wife’s a schoolteacher, so she’s home [. . .] I work from home; I’m used to being here by myself. [. . .] So she’s scrambling to try to figure out how to work from home, and it’s a little chaotic. [. . .] Two college-age kids who are back home now as well because of the situation. [. . .] There’s just more stress and more messes and it’s just, you know, definitely been feeling the impact of that on top of the added anxiety about the illness itself.”—Jeff

Missing socialization and desire for a return to normalcy

“I’m tired of it. I want it to be over and, yeah, a little bit stressed because now I’m living with both mom and dad all the time, not getting out and just, yeah, there’s some anxiety and I guess a little bit of depression just not being able to go see people like you would normally.”—Joseph

Physical Health

Impaired hand function makes it difficult to wash hands and put on masks

“My mom does it all for me. Puts the mask on. [. . .] I had no hand function basically at all, so my mom—I’ve got, I’ve grown used to mom there, mom or dad or somebody doing all that for me.”—Ted

Canceling and/or need to continue attending medical appointments

“I’m due for a bone density test and my renal ultrasound and KUB, but I’m putting those off because I don’t want to go to the hospital for that. My—I do go in there monthly or every 5 weeks for my tube change. That’s an appointment where I have to go and my baclofen pump every 6 months, and I had to go like right near the beginning of quarantine for that, but those are the only medical appointments that I’ve gone to.”—Paul

Limited access to supplies affected ability to follow precautions and meet SCI-specific needs

“I put orders in for masks several months ago and it took them a very long time to come in, like right when the whole thing was starting. So that took a long time. Yeah, just general cleaning supplies whenever it first hit. All that was really hard to find. I use rubbing alcohol for cleaning out all my urinary bags and rubbing alcohol was very hard to find for a while.”—Paul

Abbreviation: KUB, x-ray of the kidneys, ureters and bladder.

Table 4 Perceptions of telemedicine—illustrative quotes

Telemedicine visits promoted feelings of safety during the pandemic

“I’m a little anxious and a little anal because if I, you know, I’m one of the high riskers that really shouldn’t be around it, so if my doctors are still giving me the option to do teleconference or over the phone, I’m going to take it probably. It’s way more convenient—I swear. I want to do all my appointments that way!” —Kelsey

Reduced barriers to health care

“Yeah, [telehealth visits are] okay. It’s better in person. I guess it depends on exactly what you need. If you don’t need to actually leave and you can get it done over the phone, then that helps. But not having to leave the house for a visit—I take public transportation, so it can be a hassle getting out for something that you can get done over the phone.”—Derrick

Telemedicine is recommended to address basic health care needs

“I mean, I will use telemedicine if I need, if I have a cold or, you know, something like that and I need—I just want, you know, something prescribed [. . .] for stuff like that. If it’s, you know, you’re trying to get, you know, something that’s relatively basic.”—Jim

Certain types of health care are less conducive to telemedicine visits

“If it was more of a surgical operation, something like getting ready to do a nerve transplant, I would not feel comfortable enough just talking, I guess, through a Zoom meeting. I would want to be hands-on and in an office probably.”—Joseph

work with multiple clients or had vulnerable family members in their own homes. Paul described how his caregiver’s risk changed the support he received:

My one evening girl, though, her husband has a lot of respiratory issues anyway, so near the beginning of it, they were all freaked out about it and so she stopped working here. So I’ve been down one personal assistant. So I’m still kind of looking for a new PA.—Paul

Others chose to stop working with external caregivers, at least temporarily, but this increased demands on family members such as spouses and parents. The added stress this created was too difficult for some to sustain and they had to bring back an external caregiver out of necessity (table 2).

Participants could not socially distance from their caregivers and acknowledged that their exposure risk was likely higher as a result. Participants also lacked control over various facets of their caregivers’ daily lives such as who they interacted with and how strictly they adhered to COVID-19 precautions outside of their client/caregiver relationship. Additional vulnerability around the dependence on family caregivers was also a concern with some family members engaging in activities the participant perceived as high risk for COVID-19 transmission. Negotiating trust among caregivers and family was particularly hard for those who had family and caregivers who worked outside the home.

Effect of COVID-19 on mental health

Increased vulnerability, stress, and isolation

The pandemic increased participants’ feelings of physical vulnerability, which affected their mental health. Participants described their perceived high risk of COVID-19 and how this increased anxiety. Kelsey described how concerns about contracting COVID-19 affected her daily life:

I’ve been a hermit, to be honest. I, if I would contract it and I would have the respiratory issues, my diaphragm is not strong enough to handle it. I’d be on a ventilator and

likely die, so I’ve been super serious about not going out at all.

Anxiety about contracting COVID-19 was heightened when participants felt they had less control over how others in their environment adhered to precautions, thus potentially increasing their exposure risk. Concerns spanned from interactions with immediate family members to individuals in the workplace or medical environments. Feelings of stress and anxiety were not only linked to risk of contracting COVID-19. Participant experiences highlighted stress related to new dynamics within the family due to altered living arrangements, more people working at home, and changes to work schedules (table 3). Stress related to caregiving was prominent and was discussed in the prior theme.

The necessity of minimizing risk of exposure led to feelings of isolation and loneliness:

The main thing would be the just kind of isolation aspect of it. . . . At the beginning of it, I was more concerned about the like, actually possibility of contracting it. [But now] I’ve been more affected just by having to stay home and not really been able to see, see anyone. . . . Yeah, I would say just more kind of isolation.—Zane

Many participants described how their lack of social interaction negatively affected their mental health, and some discussed feelings of depression. This cohort described their desire to return to normalcy and resume interacting with others (table 3).

Coping

Two participants explicitly outlined how their SCI had equipped them with coping strategies that were advantageous for coping with COVID-19:

In some ways I almost feel like it’s easier. . . . We’re a little bit more . . . sort of prepared for life changing events. We’ve had big stuff happen to us and world disruptions

and that kind of stuff and so . . . I think it maybe prepares you a little bit to sort of . . . roll with things?—Jim

Effect of COVID-19 on physical health

SCI can affect the ability to follow COVID-19 precautions

SCI and resultant limitations in hand function make mask donning/doffing and frequent hand hygiene difficult or, for some, impossible (table 3):

I do wheel around in the wheelchair a lot so, and it's hard being—actually washing my hands as much as a normal person, just because it's just a little more difficult, so. Yeah, it's, it has been kind of stressful. Added a lot more stress, I guess.—Derrick

Challenges in following precautions were an added stressor unique to this population due to their limited hand function. These challenges did not necessarily limit participants from doing things but rather made the specific tasks of hand washing and mask use more difficult.

COVID-19 affected access to medical care and supplies

Participants discussed their need to routinely interface with the medical system to meet SCI-specific needs (eg, monthly suprapubic tube change, weekly therapy). The pandemic further restricted access to health care services and supplies for participants. Some individuals discussed balancing the exposure risk to COVID-19 with delaying medical care.

I have been putting that [medical issue] off. I probably would have gone already, but I'm pretty confident at the same time that it's not like, I'm not in dire need. You know, I don't have to go right away.—Jeff

Telemedicine

Telemedicine promoted feelings of safety during the pandemic for some and decreased barriers to care (eg, transportation issues). Telemedicine was valued by participants for routine appointments such as visits to a primary care physician or getting a prescription (table 4). Participants expressed less enthusiasm for telemedicine for specialized medical care (eg, surgical consultations) and appointments that needed to be more hands-on (eg, hand therapy). Overall, participants expressed that telemedicine supported continued access to health care, and some strongly proposed wider access:

I think telemedicine is vital, especially for any kind of consult, consultative health care, vital. Yeah. Kind of examples of that: behavioral health, internal medicine, family medicine. Those are all visits that could be done via telemedicine.—Bill

Though many positive aspects of telemedicine were discussed, 1 individual acknowledged that she was “not good at the technology thing” and was concerned about managing a virtual appointment. When her visit shifted to a phone call,

she reported that she was glad and was able to easily manage this mode of technology.

Discussion

People with cervical SCI living in the United States during spring 2020 experienced changes to daily activities. Key findings included the following: (1) interactions with caregivers for activities of daily living were complicated by fear about contracting and/or transmitting COVID-19; (2) mental and physical health were adversely affected; and (3) telemedicine was a helpful and acceptable alternative to in-person visits.

Although preliminary reports suggest that people with SCI who contract COVID-19 do not have greater mortality,^{5,16-18} our participants felt at high risk of adverse outcomes. They also worried about the deleterious socioeconomic and mental health effects on themselves, their families, and society as a whole. At the same time, several expressed their unique learned skill to “roll with it.” They drew on resilience learned from surviving an SCI to adapt to and overcome this new challenge. They felt, in some ways, that they were better psychologically prepared for living in a pandemic than the general population.

This psychological strength does not mitigate the complex health needs of these individuals living with SCI. Our findings highlight the lack of a health care safety net in the United States. Though resources will likely be allocated to pandemic response strategies and global health in the short term, improving public health, universal health coverage, and primary health care is intertwined and must be integrated to imagine a better future.¹⁹

One already profound alteration to the health care system in the United States has been use of telemedicine. This was made possible in part by the following: (1) loosening of the bureaucratic requirements around licensing to provide care for patients outside of the physician's state of practice and (2) improvement of insurance reimbursement for non-in-person visits. The acceptability of telemedicine was discussed by several study participants and is particularly advantageous to those with physical and other disabilities because it can improve access and convenience. Our population found telemedicine useful for routine visits—especially medication checks and counseling. To augment telemedicine, we should study its implementation²⁰ and integrate strategies to successfully provide complex care and virtual physical examination to less technologically adept populations.

Further recognizing caregiving as an important service is another needed advancement. Many participants discussed loss of caregivers, stress around hiring or retaining caregivers, and burden to family members who provided caregiving in addition to full-time employment during the pandemic. Payment for caregiving by family members²¹ and providing better salaries, paid medical leave, and health insurance for caregivers might improve circumstances.⁸ These caregivers are frontline workers who may lack the voice and support of those with professional degrees working in large health care systems. They, along with other nonprofessional providers, need the same access to vaccines,

personal protective equipment, and training in best practices and infection prevention.

Study limitations

Study limitations must be considered when interpreting these findings. The small sample size and homogeneity (with respect to race, sex, and geographic sample) of the population must be acknowledged. This exploratory study aimed to generate preliminary data about the experiences of a subset of individuals living with disabilities and lays the foundation for future investigations. All participants had cervical level SCI, so study findings are likely not generalizable to all individuals with SCI. Additionally, the majority of participants resided in the Midwestern United States, which again limits generalizability given the variability of COVID-19 experiences across the United States and worldwide. However, with the limited data available about the experiences of individuals with SCI during the pandemic, this research adds substantial novel information to the literature.

Conclusions

Learning about how people with SCI cope, persevere, and survive to overcome adversity during the pandemic should inform future research to support those with SCI. Improving telemedicine and rewarding and recognizing caregivers for their role in maintaining health are important first steps. We must continue to be creative about improving our health care systems and access for people with disabilities, particularly during this and future public health crises.

Supplier

a. NVivo v12, QRS International.

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