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COVID-19 and spinal cord injury and disease: results of an international survey as the pandemic progresses

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Abstract

Study design An online survey.

Objectives To follow-up with and re-query the international spinal cord community's response to the Coronavirus Disease 2019 (COVID-19) pandemic by revisiting questions posed in a previous survey and investigating new lines of inquiry.

Setting An international collaboration of authors and participants.

Methods Two identical surveys (one in English and one in Spanish) were distributed via the internet. Responses from both surveys were pooled and analyzed for demographic and response data.

Results Three hundred and sixty-six respondents were gathered from multiple continents and regions. The majority (63.1%) were rehabilitation physicians and only 12.1% had patients with spinal cord injury/disease (SCI/D) that they knew had COVID-19. Participants reported that the COVID-19 pandemic had caused limited access to clinician and support services and worsening medical complications. Nearly 40% of inpatient clinicians reported that "some or all" of their facilities' beds were being used by medical and surgical patients, rather than by individuals requiring inpatient rehabilitation. Respondents reported a 25.1% increase in use of telemedicine during the pandemic (35% used it before; 60.1% during), though over 60% felt the technology incompletely met their patients' needs.

Conclusion The COVID-19 pandemic has negatively impacted the ability of individuals with SCI/D to obtain their "usual level of care." Moving forward into a potential "second wave" of COVID-19, patient advocacy and efforts to secure access to thorough and accessible care are essential.

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Introduction

Nearly 7 months have passed since Coronavirus Disease 2019 (COVID-19) was declared a public health emergency of international concern (i.e., a global pandemic) [1] and just over 5 months have passed since publication of one of the first reported cases of the disease in a person with spinal cord injury or disease (SCI/D) [2]. As of October 3, 2020, there have been 34,737,092 confirmed cases of COVID-19 across the world. The United States has had the most cases (7,368,452) followed by Europe, the Eastern Mediterranean, South-East Asia, Africa, and the Western Pacific [3]. As we are nearing what is expected to be a second wave of infections [4], the medical community must recognize the potential for the virus to disproportionately impact persons who are vulnerable to respiratory compromise and who have limited access to caregivers, medical supplies, and health services [5]. In response to potential inequities and care

Table 1 Participant demographics.

Demographics		<i>N</i> (%)
What is your primary professions	Rehabilitation physician	229 (63.1)
	Primary care physician (PCP)/ generalist physician	3 (0.8)
	Other physician specialist	12 (3.3)
	Nurse	13 (3.6)
	Psychologist/mental health professional	3 (0.8)
	Therapist	69 (19.0)
	Other	34 (9.4)
Describe your nation's economy	Developed	192 (53.6)
	Transitional	45 (66.2)
	Developing	121 (33.8)
Describe your nation's health care	Universal/government funded health care	185 (54.1)
	Tiered system basic health care with available private insurance	62 (18.1)
	System of public/private insurance	85 (24.9)
	Self-pay for care	10 (2.9)
On which continent/in which region do you live?	Asia	21 (6.2)
	Africa	19 (5.6)
	South America	53 (15.5)
	Europe	149 (43.7)
	North America	51 (15.0)
	Australia or New Zealand	20 (5.9)
	Central America	23 (6.7)
Caribbean	5 (1.5)	

gaps, SCI clinicians have collaborated virtually and internationally to better understand how COVID-19 has uniquely affected people with SCI and to proactively support and care for them.

In March, 2020, we reported the results of an international survey of 783 clinicians in which respondents emphasized concerns over how COVID-19 has and would affect their patients with SCI [6]. In the 6 months since that publication, incident cases in some regions of the world have continued to climb, though they have “flattened” in others [3]. Recurrent outbreaks of COVID-19 are expected, and as the reality of our “new normal” sets in, the collective experience of spinal cord colleagues from around the world will assist in informing and guiding our care and management strategies [7]. As such, we report the results of a follow-up international survey of SCI clinicians detailing how the COVID pandemic has impacted their clinical and academic practices and their perceptions of how the virus has affected the care of individuals with SCI.

Methods

The initial survey was developed by two of the authors (KG, MS), then edited and finalized by the entire working group. A total of 39 questions (38 multiple choice and one free text) were written to assess respondents' experiences with, knowledge of, and concerns regarding the COVID-19 pandemic. The survey (Appendix) was written first in English then translated into Spanish, and both versions were distributed via an emailed solicitation with an embedded SurveyMonkey link. The survey was disseminated with assistance from International Spinal Cord Society, American Spinal Injury Association, and the Praxis Spinal Cord Institute. The authors also distributed the survey to their professional colleagues around the world. Participants could access the survey from May 21, 2020 through June 10th, 2020.

Analysis of survey data consisted of descriptive statistics regarding the frequencies of responses. Qualitative review of the open response question was performed by the authors. No institutional review of the instrument was sought, and none was considered necessary.

Results

Among our 366 respondents, the largest plurality (43.7%) hailed from Europe, with 22.2% from Central and South America, 15.0% from North America, and the remainder from Asia and Africa (Table 1). Over six in ten participants (63.1%) were rehabilitation physicians, 13.5% were therapists, 5.5% were researchers, 3.6% were nurses, 0.8% were psychologists or mental health professionals, 0.8% were primary care physicians, and the remainder self-identified as “other,” which included social workers, consumers, and educators. Just over half (53.6%) worked in countries with developed economies, 33.8% were from developing nations, and 21.6% were from countries with transitional economies. The majority (54.1%) stated that their nation of origin had universal or government funded health care, 24.9% said there was a system of public and private insurance without universal coverage, 18.1% said there was basic health care with available private insurance, and 2.9% said there was only a system of self-pay for health care.

When asked whether their community had been widely impacted by COVID-19, 81.9% replied “yes,” but only 32.2% considered it to be a “hot spot.” Over three-quarters of respondents (75.6%) lived in a community in which COVID-19 testing has been widely available, with 21.0% reporting that screening has been universally available and 54.6% reporting that screening has been available only to people with symptoms. Only 31.7% of participants had

been tested for COVID-19 (3.1% had tested positive), though 26.1% said they would like to be tested.

Only 12.1% of respondents reported that they had had a patient diagnosed with COVID-19 (64.3% “no”; 23.6% “not certain”). The most frequently cited presenting symptoms were fever (7.9%), shortness of breath (6.8%), sweats (1.6%), increased spasticity (1.6%), worsening pain (1.4%), rash/peripheral lesions (1.4%), and anosmia (1.1%). When asked whether or not they had ordered COVID-19 testing on one or more outpatients, only 14.4% replied “yes,” and among those who had, 48.8% had used screening guidelines set forth by their governments, 34.9% had used their own clinical judgment, and 16.3% reported that “all outpatients were being screened.”

Just over eighty percent (80.3%) worked at an inpatient rehabilitation facility. Only 25.6% were not accepting patients with COVID diagnoses to their facilities (42.4% were accepting them after a negative antigen test; 22.7% were accepting them even with a positive test; 9.3% were accepting them “after a certain time period had passed”), and 81.1% were performing COVID screenings in those facilities (40.2% on all patients at admission; 23.1% on inpatients with symptoms; 8.9% on new admissions with symptoms; 5.9% on all new admissions and all inpatients; 3.0% on all inpatients). When asked whether they had had difficulties with availability of personal protective equipment (PPE), 50.9% of respondents replied “yes” and 49.1% replied “no.” The PPE items participants had had the most trouble securing were N95 respirator masks (29.5%), face shields (17.5%), and basic surgical masks (13.9%). Others, however, noted inadequate access to selected powered air-purifying respirators (PAPR) (12.0%) and gloves (7.1%).

Over sixty percent (60.1%) of respondents said they now utilize telemedicine, but only 35.0% had done so prior to the COVID-19 pandemic. Over eight in ten of participants using telemedicine (81.2%) said they had intentionally transitioned their practice to include more telemedicine visits and fewer in person visits, yet only 39% reported that they had been educated in appropriate use of the technology and felt confident in using it (46.3% said they had not been trained and felt they needed it; 14.7% had not been trained and did not feel they needed it). Among respondents who had transitioned their practices to include more telemedicine, the majority felt the technology incompletely meets their patients’ needs. Over six in ten (63.2%) reported that “some needs are met, but we need to further develop protocols to ensure privacy, safety, and best practices,” while 32.2% felt that most of their patients needs were met through using telehealth. Only 3.4% felt that telehealth allowed them to meet all their patients’ needs, and 1.1% felt that physicians should not be using it for patient care.

Among the 175 respondents who worked at an inpatient facility, 67.5% reported that the COVID-19 pandemic had

resulted in fewer admissions with SCI (50.9% described the decrease as “substantial”; 16.6% as “minimal”). A sizeable minority (38.7%) reported that “some or all of [their] facility’s inpatient beds [were] being used by medical or surgical patients,” and among those respondents, 37 (56.9%) found it difficult to provide the “usual level of care” to individuals with SCI and 54.7% were concerned that repurposed beds would never revert to rehabilitation beds.

Participants were asked which, if any, barriers to care their patients with SCI had faced as a result of the COVID-19 pandemic. Nearly half cited “decreased therapy availability” and “fear of in person visits” (47.8% and 42.9%, respectively), while others reported decreased availability of transportation and caregivers (33.6% and 30.6%, respectively), lack of availability of in person visits for medical concerns (27.9%), inadequate access to telehealth (23.5%), and decreased access to supplies (19.1%), equipment repairs (12.8%), and medications (10.9%). Only 2.7% of participants reported that their patients with SCI had not faced barriers to care during the pandemic (Table 2). When asked if their patients with SCI had suffered unexpected complications due to COVID-related barriers to care, 29.0% replied “yes.” The most frequently cited complications were depression or anxiety (9.0%), poorly controlled spasticity (6.6%), skin injuries (6.0%), increased urinary tract infections (3.8%), and poor pain control (3.3%) (Table 2). Offering free text responses, several participants wrote that their patients with SCI had had to delay needed medical procedures and admissions to rehabilitation facilities.

When asked whether the COVID-19 pandemic had affected their ability to receive and participate in continuing and professional education, 54.2% of respondents replied that it had and only 8.4% were happy with those changes. Among those 54.2% of participants, 50.5% said the pandemic had forced them to engage in online educational sessions, 47.7% that they had been reading more articles, one-third (33.3%) that they had not been able to attend in person educational sessions, and 24.0% that they had been prevented from attending remote meetings. Nearly two-thirds (66.0%) intended to attend meetings in the future that require travel, but only 24.2% of that cohort predicted that their frequency of travel would be unaffected by COVID-19. Among the 103 respondents who were affiliated with an SCI research program, only 22 (21.4%) said the pandemic had not affected their investigative work. Fifty (48.5%) said that it had, and that they were not worried about restarting the program, while the rest (30.1%) said that it had and that they were concerned about future impacts.

Participants were asked to identify their greatest professional needs as the medical community prepares for a potential second wave of COVID-19. Of the 249 participants who answered this question, a majority stated they

Table 2 Barriers to care and unexpected medical complications during COVID-19.

Table name		N (%)
In recent months, which of the following barriers to care have your SCI patients faced	Fear of in person visits for medical concerns	157 (42.9)
	No availability of in person visits for medical concerns	102 (27.9)
	Decreased therapy availability	175 (47.8)
	Decreased availability of transportation	123 (33.6)
	Decreased availability of caregivers	112 (30.6)
	Decreased availability of supplies (specific to SCI care)	70 (19.1)
	Decreased availability of medications	40 (10.9)
	Inability to have equipment repairs	47 (12.8)
	Lack of technology to provide and/or receive telehealth care	86 (23.5)
	None	10 (2.7)
Have any of your patients had unexpected complications or increased morbidity due to new barriers because of COVID	Yes	73 (29)
	No	179 (71)
Which categories would the unexpected complications or increased morbidity fall into?	Skin injury	22 (30.1)
	Increased urinary tract infections	14 (19.2)
	Depression or anxiety	33 (45.2)
	Poorly controlled spasticity	24 (32.9)
	Pain control	12 (16.4)
	Respiratory (not COVID related)	7 (9.6)
	Other	13 (17.8)

needed more education about how COVID impacts people with disabilities (69.5%), how COVID impacts patients' rehabilitation (61.0%), how to adapt their practice to the changing environment in the wake of COVID (58.6%), and education about telemedicine (53.0%). A minority also requested education about advocating for patients (39.0%) and education about self-care as a provider (33.3%).

Discussion

This study yielded a wealth of insights into how the COVID-19 pandemic has impacted the SCI medical community's practice patterns and ability to provide thorough and equitable care to individuals living with SCI. However, several salient findings merit special attention and consideration.

First, while it is understandable that inpatient rehabilitation beds have been "repurposed" during this pandemic to house and care for medical patients, it is notable that this has resulted in fewer rehabilitation admissions of people with SCI and an inability of SCI providers to offer their patients the "usual level of care." The spread of

COVID-19 has required flexibility in allocation of both inpatient and outpatient health care resources, but professionals in SCI Medicine and advocates for individuals with SCI must monitor this redistribution of rehabilitation beds and advocate for an eventual return to their original purpose.

Second, while it is known that over 40% of people have delayed or avoided medical care due to COVID-19 [8], there has been virtually no documentation to date of reduced access to care by individuals with SCI nor of how that has impacted and exacerbated medical complications of injury. As the medical community prepares for a second wave of infections and considers how to care for vulnerable individuals during this pandemic, creative solutions incorporating case management, telemedicine technologies, and home-based care must be sought. Now that we know that COVID-19 has substantively limited persons with SCI's access to therapy, transportation, medical supplies, and medications, we must advocate to ensure they receive the care they require in the safest possible manner.

Finally, this survey offers important insights into the adoption and limitations of telemedicine technologies.

While our data indicate a dramatic shift toward utilization of telemedicine during the COVID-19 pandemic among SCI providers, they also reveal concerns about its utility in seeing to patients' needs. This stands in contrast to a recent survey of primary care providers, the majority of whom felt that telehealth allowed them to meet most of their patients' care needs [9]. It is not clear why SCI clinicians seem to be more concerned than PCPs about the utility of telemedicine. It is possible that the complex care needs of many individuals with SCI expose the inherent limitations of remotely-delivered health care, or that clinicians caring for people with altered and/or diminished sensation depend more on physical examination to determine diagnoses than do clinicians caring for non-injured individuals. While studies and case reports have demonstrated the utility of telemedicine to adjust medical regimens and improve function among individuals with SCI [5, 10–13], more work is needed to determine how telemedicine best fits into management of the complex care needs of people with SCIS.

This work has several important limitations. First, the survey was distributed to a self-selecting group of respondents; namely, those with professional connections to the authors and/or who are members of one of several international SCI organizations. Second, clinicians working in Asia and Africa were relatively under-represented in this work. Hence, our results may not fully or adequately represent how the COVID-19 pandemic has affected individuals with SCI in a variety of economies and care settings. Third, we did not inquire about how individuals with SCI and SCI clinicians have addressed care deficiencies during the pandemic, nor the role of rehabilitation teams in allowing people to maximize recovery after infection with COVID-19 [14]. This being said, our findings demonstrate that individuals with SCI have suffered from reduced quality of and access to care during the pandemic, and underscores a need for enhanced services and advocacy during a potential “second wave” on infections.

Data availability

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

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