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COVID-19 and spinal cord injury and disease: results of an international survey

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Abstract

Study design An online survey.

Objectives To query the international spinal cord medicine community's engagement with and response to the novel coronavirus (COVID-19) pandemic and to assess pandemic-specific information needs and patient concerns.

Setting An international collaboration of authors and participants.

Methods Two near-identical surveys (one English and one Spanish language) were distributed via the internet. Responses from those questions shared between the surveys were pooled then analyzed; four questions' responses (those not shared) were analyzed separately.

Results A total of 783 responses were submitted from six continents. Few participants (5.8%) had tested their outpatients with SCI/D for COVID-19; only 4.4% reported having a patient with SCI/D with the virus. Of respondents who worked at an inpatient facility, 53.3% reported that only individuals with symptoms were being screened and 29.9% said that no screening was occurring. Participants relayed several concerns offered by their patients with SCI/D, including vulnerability to infection (76.9%) and fragility of caretaker supply (42%), and those living in countries with guaranteed health care were more likely to report widespread availability of COVID-19 testing than were those living in countries without universal care, $\chi^2 (3, N = 625) = 46.259, p < 0.001$.

Conclusion There is substantial variability in the rehabilitation medicine community in COVID-19 screening practices and availability of screening kits. People living with SCI/D are expressing legitimate and real concerns about their vulnerability to COVID-19. More and rapid work is needed to address these concerns and to standardize best-practice protocols throughout the rehabilitation community.

Introduction

The earliest articles on the novel coronavirus (COVID-19) characterized affected patients' demographics and presenting symptoms, environment exposures that were associated with infection, and rates of clinical endpoints including

intensive care unit admission and death [1, 2]. At the time of the drafting of this manuscript, 465,915 people worldwide have been diagnosed with COVID-19 and 21,031 have died from it [3].

Given that the literature concerning COVID-19 is emerging, no authors have addressed the virus' impact on people with spinal cord injury and disease (SCI/D). As SCI/D is often associated with need for caregiver support, the regular use of equipment, and vulnerability to pulmonary infection [4, 5], this subset of individuals requires special planning, attention, and consideration.

We developed a survey meant to investigate how health care professionals involved in the care of people with SCI/D are assessing, screening, and treating their patients with potential COVID-19 infections. We further queried whether respondents felt that their patients with SCI/D and they, themselves, have been offered sufficient information about

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risk factors for infection and appropriate preventive measures.

Methods

The authors developed an online survey (Appendix) and distributed it to an international cohort of clinicians who care for individuals with SCI/D. The survey was developed based on the authors' clinical experiences of treating patients with COVID-19 infections and emerging recommendations about screening practices. The survey was distributed via the internet to the authors' colleagues in the field of spinal cord injury medicine with assistance from leaders of the International Spinal Cord Society several affiliated organizations. While the original survey was in English, a similar Spanish language version was drafted and distributed on day 2 of the study period. This version did not include questions seven and eight from the English version and asked two additional questions about outpatient rehabilitation, but was otherwise identical.

The survey was available from the evening of March 23, 2020 through the morning of March 27, 2020, Eastern Standard Time. No identifying details were collected, and consent was implied by participants' having completed the survey. No ethics approvals were sought or believed necessary for this project.

Data analysis was conducted through SPSS version 23. The categorical survey data collected in this study were deemed best suited to Chi Square tests. Participants who did not know if COVID-19 testing is/has been widely available in their country were excluded from this analysis.

Results

The majority of the 783 responses were submitted from Europe and North America (30.4% and 28.1%, respectively), though six continents were represented (South America 17.3%; Asia 14.3%; Australia 6.3%; Africa 3.6%). In the Spanish language survey, 17.5% were from Central America and 7.6% were from the Caribbean. Sixty-seven percent of participants were rehabilitation physicians, 13.1% were therapists, 8.0% were nurses, and 5.7% were researchers, with the remaining 7.4% identifying as "primary care physicians/general practitioners," "other physicians," or "psychologists/mental health professionals." Respondents worked in nations with a variety of economies (developed 46.5%; transitional 19.5%; developing 34.1%) and health care systems (universal coverage 52.3%; tiered system 28.9%; not universal 15.8%; self pay 3%), and 73.1% provided direct patient care.

When participants were asked if they live in a country in which COVID-19 testing is/has been widely available, 57.4% responded, "yes," 27.4% responded, "no," and the remaining 15.2% responded, "I'm not certain." Only 5.8% of participants had ordered COVID-19 testing for one or more of their outpatients with SCI/D. Among this group, 22% reported that they had not used formal screening guidelines, 9.8% that they had screened "all outpatients," and 65.9% that they had used guidelines published by their government. Only 4.4% of respondents reported that they had had a patient with SCI/D diagnosed with COVID-19 (70.3% had not and 25.3% were not certain). The most commonly listed presenting symptoms were fever (86.2%), shortness of breath (62.1%), body aches/worsening pain (20.7%), sweats (20.7%), and chest pain (13.8%). However, 10.3% reported their patients with SCI/D and COVID-19 had had increased spasticity, 6.9% that they had had rigors, and 6.9% that they had been asymptomatic. When asked which treatments their patients with SCI/D and COVID had been offered, 82.8% replied, "strict isolation/quarantine," 58.6% "emergency room level care/hospitalization," 20.7% "over the counter medications for symptom relief," and 27.6% "hydroxychloroquine and/or azithromycin." Two respondents reported that they had referred their patients to a centralized COVID-19 hospital.

Four hundred and forty-three (64% of the 692 who answered this question) worked in an inpatient rehabilitation facility. When asked on which of their inpatients with SCI/D they were performing COVID-19 screening, 53.3% reported "only patients with symptoms," 5.3% "all patients at time of admission," 1.2% "all patients currently in the facility," and 4.3% "all new admissions AND all patients currently in the facility." Ten percent reported that they did not know if patients were being screened, and 25.9% reported that patients in their facility were not being screened.

We asked participants which changes to their practices they were planning or implementing as a result of the COVID-19 pandemic. Forty seven percent reported increased use of telemedicine, 49% limiting use of therapies, 50.4% promoting the use of home care, and 7.7% were not planning any changes. Just less than 60% (58.4%) felt they had been given enough information about COVID-19 to appropriately counsel and screen people with SCI/D; only 38.8% felt that their patients with SCI/D had been given enough information about COVID-19. When asked whether their patients with SCI/D had contacted them with concerns about COVID-19, 34.1% said they had. Specific concerns that had been relayed included increased vulnerability to infection (76.9%), fragility of caretaker supply (42%), inability to obtain necessary routine supplies (40.2%), inability to be appropriately tested (28.5%),

Table 1 Continent versus availability of COVID-19 testing.

| Continent | Has/is COVID testing widely available? | N (%) |
|---------------|--|------------|
| Asia | Yes | 56 (64.4) |
| | No | 31 (35.6) |
| Africa | Yes | 17 (70.8) |
| | No | 7 (29.2) |
| South America | Yes | 77 (81.9) |
| | No | 17 (18.1) |
| Europe | Yes | 142 (68.6) |
| | No | 65 (31.4) |
| North America | Yes | 91 (55.2) |
| | No | 74 (44.8) |
| Australia | Yes | 39 (88.6) |
| | No | 5 (11.4) |

inability to obtain transportation to health care appointments (21.3%), and inability to self-quarantine (20.7%).

The Spanish language survey asked two questions not included in the English version. When asked about changes in outpatient rehabilitation services, 125 of 223 (56.1%) respondents reported that those services had been discontinued, 18.4% that treatment hours had been reduced, 16.1% that services had been discontinued but replaced with telemedicine, and 9.4% that work had continued without modification. Those respondents whose outpatient facilities had closed were asked at which point that had occurred. Thirty-nine percent responded that it had happened within 1 week of the first reported case in their country, 30.2% within two weeks, and 16.6% after three weeks or more.

The availability of COVID-19 testing was not related to the state of economic development, $\chi^2 (2, N = 625) = 0.249, p = 0.883$, but was related to the continent of origin, $\chi^2 (5, N = 622) = 30.794, p < .001$ (Table 1). However, those living in nations with universal health care were significantly more likely than those living in countries without guaranteed health care to report availability of testing, $\chi^2 (3, N = 625) = 46.259, p < 0.001$ (Table 2).

Discussion

To our knowledge, this is the first survey to have assessed COVID-19-related practices and adaptations among health care professionals working with individuals with SCI/D. While we did not specifically recruit people living with SCI/D, we were able to capture those concerns they have expressed to their care teams.

Few respondents had tested their patients for COVID-19 or reported that they had a patient with the virus, indicating

Table 2 Health care system versus availability of COVID-19 testing.

| Nation's health care system | Is/has COVID-19 testing been widely available? | N (%) |
|---|--|------------|
| Universal/government funded health care | Yes | 253 (75.5) |
| | No | 82 (24.5) |
| Tiered system, basic health care with available private insurance | Yes | 117 (68.8) |
| | No | 53 (31.2) |
| Public/private insurance | Yes | 49 (49.0) |
| | No | 51 (51.0) |
| Self pay for care | Yes | 4 (20.0) |
| | No | 16 (80.0) |

that rehabilitation medicine professionals may not yet have been able to fully engage with the pandemic. This may also relate to a lack of availability of testing, guidelines limiting testing, and an under-appreciation of the benefits of routine testing around the world. However, the large number of respondents who had already modified their outpatient practices to reduce their patients' exposure shows that important actions have already been undertaken, and that there is an awareness of the need to help protect individuals who may be vulnerable to infection. This is an important issue to consider, as the hallmark of inpatient rehabilitation facilities has been rehabilitation participants coming together in gyms and dining areas to join in community. Individuals with COVID-19 can spread the disease before symptoms occur, therefore we advocate for the routine testing of individuals that are newly admitted to or currently in rehabilitation facilities and for use of personal protective equipment (PPE) on all individuals with SCI until test results are available. Visitors to rehabilitation facilities also ought to routinely use PPE.

This survey underscores substantial unmet educational needs, both for rehabilitation medicine professionals and for people living with SCI/D. It additionally reveals the specific and legitimate fears experienced by individuals with SCI/D during this pandemic and during disasters. The vulnerabilities of people with disabilities to a lack of care has recently been highlighted [6], and there is a distinct possibility that people with SCI/D and other disabilities may be denied care in times of crises when lawmakers and health care systems determine who will receive limited services [7]. This pandemic highlights the need to advocate for people with SCI/D and other disabilities as we adapt to an increasing worldwide population, climate change, and more frequent zoonoses and disasters. In addition, it emphasizes the need for educational tools for patients and professionals such as those recently created by John Shepherd at University of Toronto and available in multiple languages

which discuss issues such as maintaining personal equipment and wheelchair hygiene [8].

These results also demonstrate the widespread and rapid implementation of telemedicine around the world, and a relaxation of privacy rules, at least in the United States, to accomplish this. Telemedicine for people with SCI/D has previously been reviewed [9] and has many advantages including saving travel time, limiting the costs of medical transportation, serving as an environmentally sound form of health care, and limiting the spread of infection to a potentially vulnerable population. Case reports have also demonstrated the utility of telemedicine to monitor and adjust home therapy regimens to maintain and improve functional potential [10]. We anticipate that the use of telerehabilitation and telemedicine for people with SCI/D will persist after this pandemic.

Finally, in a small but meaningful way, these results demonstrate the importance of at least basic universal health care. In the United States, which does not offer its citizens guaranteed coverage, testing was not widely available as infection rates soared. At the time of this survey, the United States leads the world with over 100,000 confirmed COVID-19 cases. Respondents from countries with guaranteed care, however, were more likely to have reported that testing supplies had been adequate. Our hope is that this pandemic will expose the need for universal health care and will mobilize public support for its implementation.

Our survey has a number of limitations. Due to its rapid deployment, we omitted questions that would have been meaningful to address such as the availability and routine use of PPE and ventilators. This has increasingly become a concern around the world and will undoubtedly continue to be a concern. Moreover, we did not address the issues of addressing adequacy of staffing at health care facilities and for individuals with SCI/D. The COVID-19 pandemic has and will contribute to professional and caregiver stress, and this ought to be addressed in future surveys. Finally, since the drafting of this manuscript, we have become aware of the repurposing of SCI/D beds as acute care beds. All of these issues will undoubtedly evolve over the next weeks and months and we are, therefore, planning to construct a follow-up survey in 4–8 weeks.

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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