

Evidence Related to COVID-19 in People Living With Spinal Injury

(summary of publications as of March 27, 2021)

Since the onset of the COVID-19 pandemic, the unknown has caused significant impact in the community living with spinal cord injury (SCI). At the same time, there has been much learning, creation, and gathering of knowledge and resources about this disease to begin to understand the SCI community's health risks in relation to COVID-19. The North American Spinal Cord Injury Consortium (NASCIC) took the initiative to gather and present all current evidence-based information and knowledge about COVID-19 related to those living with SCI. NASCIC collaboratively assessed various resources to provide those living with SCI and the community a thorough understanding of the current situation and, hopefully, quell fears of the unknown related to COVID-19. The evidence that NASCIC has compiled and has included in this report covers:

- the concerns about the pandemic from people with SCI,
- case studies with SCI who have contracted COVID-19, and
- impacts of nationwide lockdowns due to COVID-19.

Research involving COVID-19 and its effect on the community are on-going and NASCIC hopes that this report will help bring awareness and open doors for further conversation and advocacy about the concerns/needs of the SCI community to researchers, policy makers, healthcare providers, and other stakeholders with interest in spinal injury. This report and take-home points will be updated as new, peer-reviewed evidence becomes available.

Published concerns of the community living with SCI

Investigator(s): Dr. Stillman and colleagues

Institution: Thomas Jefferson University

Study Aim: International survey of the SCI medical community's engagement with and response to COVID-19

Results: Those results showed that, during March 23 to March 27, 2020, people with SCI were concerned about:

- their vulnerability to becoming infected (76.9%);
- the fragility of access to caregivers (42%);
- the inability to get needed, routine medical supplies (40.2%);
- the inability to get tested for possible COVID-19 infection (28.5%);
- the inability to access transportation to healthcare appointments (21.3%); and
- the inability to appropriately self-quarantine (20.7%).

Article citation: Stillman MD, Capron M, Alexander M, Di Giusto ML, Scivoletto G. 2020. COVID-19 and spinal cord injury and disease: results of an international survey. *Spinal Cord Series and Cases*. 6:21.

Investigator(s): Dr. Boldrini and colleagues

Institution: Italian Associations of Persons Affected by Different Disabilities

Study Aim: Impact of the initial pandemic and lockdown on people with disabilities, including SCI, across Italy

Results: Those results showed that, during February to May, 2020, people with various neurologic disabilities, including SCI, were experienced:

- decreased access to inpatient services;

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- decreased access to medical specialists;
- worsening of coordination of care;
- worsening of access to home based and community services;
- increased social isolation and feelings of loneliness and discrimination;
- increase in bureaucratic burden to obtain assistive devices; and
- concern about availability of resources in future 'waves' of the pandemic.

Article citation: Boldrini P, Garcea M, Brichetto G, Reale N, Tonolo S, Falabella V, Fedeli F, Cnops AA, Kiekens C. 2020. Living with a disability during the pandemic. "Instant paper from the field" on rehabilitation answers to the COVID-19 emergency
Eur J Phys Rehabil Med. 56:331-334.

Investigator(s): Dr. Gustafson and colleagues

Institution: Thomas Jefferson University

Study Aim: 2nd International survey of the SCI medical community's engagement with and response to COVID-19

Results: Those results showed that from the beginning of the pandemic through June 2020, people with SCI experienced:

- decreased access to therapy;
- fear of in-person visits;
- decreased access to transportation and caregivers;
- lack of access to in-person visits when needed;
- inadequate access to telehealth;
- decreased access to supplies, equipment repairs, and medications.

Article citation: Gustafson K, Stillman MD, Capron M, O'Connell C, Di Giusto ML, Tyagi N, Scivoletto G. 2021. COVID-19 and spinal cord injury and disease: results of an international survey as the pandemic progresses. *Spinal Cord Series and Cases.* 7:13.

Investigator(s): Dr. Monden and colleagues (including recruitment and collaboration with NASCIC)

Institution: University of Minnesota

Study Aim: To understand the initial impact of COVID-19 on the SCI community

Results: Preliminary results (in the process of being published) are the following:

- Medical rationing & discrimination: Thirty percent of participants reported being concerned about medical discrimination and being denied access to a ventilator if hospitalized with COVID-19. Participants also reported feeling moderately concerned about being denied access to medical care due to their disability status.
- Impact on care in the home and medical supplies: The majority of participants (60%) reported that the pandemic has had a negative impact on the care they receive in their homes. Similarly, approximately 60% of participants reported the pandemic has negatively impacted their access to medical supplies.
- Impact on overall and mental health: The majority of participants (68%) reported that the pandemic has had a negative impact on their overall health and 71% reported a negative impact on their mental health. Additionally, participants reported feeling moderately bothered by social isolation and highly concerned about future social isolation.

Published cases of COVID-19 in people with SCI

In theory, there are several legitimate reasons to expect that a person with SCI would experience severe-level symptoms if they develop COVID-19. Weakness and/or paralysis of the abdominal and trunk muscles results in people with SCI having weaker lungs. With weaker lungs, people with SCI are unable to produce a productive cough. Being unable to produce a productive cough has some serious implications, and as a result people with SCI can experience chronic respiratory infections. Additionally, evidence suggests that people with SCI have weaker immune systems and have a higher risk of developing cardiometabolic diseases like diabetes and high blood pressure, which are all known risk factors for having greater problems with COVID-19.

As COVID-19 remains as a relatively new disease, it is very important to learn from case studies of people with SCI who have experienced COVID-19. In response to the pandemic, the clinical community has been quite responsible in publishing this information in a rapid fashion. We have collected published cases of people with SCI and COVID-19 as of the time of this report. Presented below is a brief description (i.e. SCI characteristics, experience symptoms, take-home points) of the published cases of people with SCI and COVID-19 at the time this report was shared.

Study Aim/Title: Description of the first reported case of COVID-19 in a person with spinal cord injury

Investigator(s): Drs. Righi and Del Popolo

Country: Italy

Date: March 2020

Injury Characteristics: 1st reported case of a person with cervical SCI; a 56-year-old male with C4 AIS A spinal injury for 7 years

Symptoms: Initially developed a fever that was thought to be due to a UTI; antibiotics were given for 2 days at home, then 2 days in the hospital without any change in the fever; a chest x-ray was done and pneumonia was suspected; testing for the COVID virus was positive and anti-viral medications was started; 2 days later the fever went away and the individual went on to recover.

Take Home Points: A cough never developed; COVID-19 testing should be done when a fever is present, regardless of other symptoms; and the symptoms of COVID-19 were not severe.

Article citation: Righi G, Del Popolo G. 2020. COVID-19 tsunami: the first case of a spinal cord injury patient in Italy. *Spinal Cord Series and Cases*. 6:22.

Study Aim/Title: Description of clinical features of COVID-19 in a group of people with spinal cord injury

Investigator(s): Dr. Rodriguez-Cola and collaborators

Country: Spain

Date: April 2020

Injury Characteristics: 7 cases – 5 of which were cervical, 1 upper thoracic, 1 lower thoracic; 5 of 7 were male; 4 of 7 were AIS A; 3 of 7 were less than 3 months' post-injury; average age was 68-years-old, but the range was from 34 to 75

Symptoms: Fever was the most frequent symptom (experienced by 6 out of the 7 people), followed by weakness (4 out of 7); other symptoms were shortness of breath, cough, coughing up sputum from the lungs (experienced by 3 out of 7 for each symptom). The COVID infection was considered severe in 5 out of 7, but only 3 required oxygen treatment and none needed to be put on a ventilator or admitted to an intensive care unit.

Take Home Points: Despite having severe infections, the symptoms experienced were not as severe as expected; all 7 people recovered, but recovery was slower in those people that were older.

Article citation: Rodriguez-Cola M, Jimenez-Velasco I, Gutierrez-Henares F, Lopez-Dolado E, Gambarrutta-Malfatti C, Vargas-Baquero E, Gil-Agudo A. 2020. Clinical features of coronavirus disease

2019 (COVID-19) in a cohort of patients with disability due to spinal cord injury. *Spinal Cord Series and Cases*. 6:39.

Study Aim/Title: Description of challenges screening for COVID-19 in people with spinal cord injury

Investigator(s): Dr. Korupolu and collaborators

Country: USA

Date: April 2020

Injury Characteristics: 1 case – 78-year-old male with T4 incomplete injury

Symptoms: Developed a fever, which was initially thought to be due to a UTI and was treated with antibiotics; a few days later developed a cough; after the fever and cough did not go away, a chest x-ray was performed showing changes in the lungs, which then prompted testing for COVID-19.

Take Home Points: Individuals with SCI may not present with typical symptoms of COVID-19 and they may be confused with other common secondary conditions. Therefore, the criteria for testing should be expanded to ensure the SCI population is appropriately included and provided adequate safety measures.

Article citation: Korupolu R, Stampas A, Gibbons C, Jimenez IH, Skelton F, Verduzco-Gutierrez M. 2020. COVID-19: screening and triage challenges in people with disability due to spinal cord injury. *Spinal Cord Series and Cases*. 6:35.

Study Aim/ Title: Differences in clinical features and evolution of COVID-19 between people with SCI and able-bodied individuals

Investigator(s): Dr. D'Andrea and collaborators

Country: Italy

Date: July 2020

Injury Characteristics: 15 cases – 8 were cervical, 5 thoracic, 2 lumbosacral; 10 of 15 were male; age ranged from 49 to 70 years old; time post-injury ranged from 2 months to 10 years

Symptoms: 5 out of 15 experienced no symptoms; of the 10 that experienced symptoms, none had significantly different symptoms or disease severity as compared to non-SCI individuals experiencing COVID at the same time in the same hospital, even though many of the individuals with SCI had underlying cardiometabolic disease.

Take Home Points: None of the COVID infections were considered severe, no one required treatment in an intensive care unit, and everyone recovered.

Article citation: D'Andrea S, Berardicurti O, Berardicurti A, Felzani G, Francavilla F, Francavilla S, Giacomelli R, Barbonetti A. 2020. Clinical features and prognosis of COVID-19 in people with spinal cord injury: a case-control study. *Spinal Cord Series and Cases*. 6:69.

Study Aim/ Title: Medical record chart review of United States Veterans with spinal cord injuries and disorders with coronavirus disease 2019 (COVID-19)

Investigator(s): Dr. Burns and collaborators

Country: USA

Date: July 2020

Results: Of 17,452 records of Veterans with traumatic and non-traumatic SCI, 140 had tested positive for COVID-19 (this equals 0.8%). Of those 140 individuals who tested positive, 26 had died (19%). The average age of those 140 individuals with SCI who tested positive was 67-years-old.

Limitations: This was a review of medical records after the fact, not a monitoring of symptoms in real time as they occurred. Individuals who may have been infected with COVID-19, but were not experiencing symptoms were not accounted for as well as individuals who may have experienced mild symptoms but

were never tested. Additionally, the US Veteran population living with SCI tends to be older and have more underlying complications than other SCI populations around the world.

Take Home Points: Reviewing large medical record sets can be helpful in providing preliminary information about SCI and COVID-19, and in particular here that US Veterans with SCI may be more vulnerable to severe infections and fatality. Caution is still very important in order to minimize the risk of getting COVID-19.

Article citation: Burns SP, Eberhart AC, Sippel JL, Wilson GM, Evans CT. 2020. Case-fatality with coronavirus disease 2019 (COVID-19) in United States Veterans with spinal cord injuries and disorders. *Spinal Cord*. 58(9):1040-1041.

Study Aim/Title: Brief description of COVID-19 in 4 cases of people with spinal cord injury

Investigator(s): Drs. Sanchez-Raya and Sampol

Country: Spain

Date: July 2020

Injury Characteristics: 4 cases – 3 of which were cervical, 1 mid thoracic; 3 chronic and 1 acute; ages ranged from 41 to over 80

Symptoms: The 3 cervical injuries were all chronic. Two of those individuals experienced severe disease and passed away. They were both over the age of 80 with similar risk factors as the general population for severe COVID. The other chronic cervical SCI was 57 years old with no relevant risk factors; symptoms experienced were severe difficulties swallowing, which required temporary tube feeding that recovered over time. The 1 acute injury was T5 AIS B, age 41, who developed pneumonia that required oxygen treatment. This individual recovered.

Take Home Points: Suggests that advanced age and similar risk factors experienced by the general population are better indicators of how people with SCI will experience COVID-19.

Article citation: Sanchez-Raya J, Sampol J. 2020. Spinal cord injury and COVID-19: some thoughts after the first wave. *Spinal Cord*. 58:841-843.

Study Aim/ Title: COVID-19 outbreak in the largest specialized spinal injury rehabilitation center in Nepal

Investigator(s): Dr. Dhakal and collaborators

Country: Nepal

Date: December 2020

Injury Characteristics: Total outbreak 103/238 patients/caregivers/hospital staff tested positive; 43 were inpatients with SCI

Symptoms: All individuals had mild symptoms, most commonly mild fever and overall weakness or discomfort; one individual with a high cervical injury also had a UTI with a blocked catheter and required a higher level of care, however recovered without complications or the need for oxygen within 2 weeks. Of all 103 case, only 1 required referral to a designated COVID-19 hospital for treatment.

Take Home Points: People with SCI did not have as severe COVID-19 disease course, no one had any lasting medical problems due to COVID-19 at that point, and everyone recovered.

Article citation: Dhakal R, O'Connell C, Gurung JB, Shah RP, Ashikari HP, Chandi N, Groves CC. 2021. A team effort in Nepal: Experiences from managing a large COVID-19 rehabilitation hospital outbreak. *Spinal Cord Series and Cases*. 7:5.

Study Aim/ Title: Case series description of disease course of COVID-19 in Veterans with SCI

Investigator(s): Dr. Galea and collaborators

Country: USA

Date: January 2021

Injury Characteristics: 7 cases; all male; 5 cervical; 5 AIS A; average age 60 years; 3 with chronic pulmonary disease; 3 with chronic kidney disease; 6 were obese

Symptoms: The most common symptom was fever. Each case had a different disease course. Four recovered. The 3 individuals that experienced severe disease and passed away had pre-existing conditions including high blood pressure, diabetes, and chronic pulmonary disease.

Take Home Points: Injury level and completeness are not risk factors for severe COVID-19 disease course. Pre-existing conditions that are risk factors in the general population, such as chronic kidney disease and chronic pulmonary disease, are better predictors of the likely severity of COVID-19.

Article citation: Galea MD, Gelman MA, Galea VP, Raulkar KP, Kornfeld S, Johnson-Kunjukutty S, Li G, Brau N. 2021. COVID-19 in spinal cord injury patients at a veterans administration hospital: A case series. *J Spinal Cord Med*. DOI: 10.1080/10790268.2020.1871254.

Take home messages about COVID-19 in people with SCI*

1. People with SCI are not at a higher risk of getting infected with the COVID-19 virus; they are a higher risk of exposure if they require daily care and cannot isolate when needed.
2. The early symptoms people with SCI experience can often be confused with UTI.
3. Cough may not be as severe as compared to people who have COVID but do not have SCI.
4. The severity of symptoms and disease course of COVID-19 in people with SCI, so far, is not as bad as initially expected.
5. Age appears to be an important risk factor, as well as secondary conditions that are risk factors for the general population.
6. It is very important to get vaccinated and to minimize the risk of exposure to COVID-19 by washing hands, wearing a mask, and social distancing.

*These take home messages are based on the published, peer-reviewed evidence as of March 27, 2021.

Impact of COVID-19 lockdown on SCI Community

Investigator(s): Dr. Felix and collaborators

Institution: University of Miami

Study Aim: A survey conducted of people living with SCI in south Florida during the peak in COVID-19 cases from August to September 2020

Preliminary Results presented at a conference in October 2020:

- 51 people with SCI were interviewed by telephone; these individuals were part of the South Florida SCI Model System.
- Compared to the general non-SCI population during that time, the individuals with SCI had similar levels of depression and lower levels of anxiety.
- During the COVID-19 isolation, however, the individuals with SCI had more depression symptoms, less resilience, and greater difficulty accessing healthcare information and services, food/groceries, and personal protective equipment in comparison to pre-COVID isolation.

Poster citation: Felix ER, Alvarado JRV, Miranda-Cantellops N, Jackson SN. Access Limitations and Level of Psychological Distress During the Covid-19 Pandemic in a Sample of Individuals with Spinal Cord Injury. American Congress of Rehabilitation Medicine 97th Annual Conference.

Investigator(s): Dr. Schladen and collaborators

Institution: MedStar National Rehabilitation Network and the Bridging Bionics Foundation

Study Aim: A survey one month into the COVID-19 lockdown to try to understand the impact of removing access to physical therapy and exercise at community fitness centers.

Preliminary Results presented at a conference in October 2020:

- 40 individuals with SCI, multiple sclerosis, cerebral palsy, Parkinson's disease, or stroke who had been regularly exercising at two community fitness centers completed the survey one month into the lockdown.
- Individuals reported:
 - Reduced social connectedness (72.5%), increased feelings of depression/anxiety (60%), worsened attitude (42.5%), decreased mental outlook (35%), reduced emotional wellbeing (32.5%), and a decline in physical health (22.5%).
 - All individuals attempted physical activity at home.
 - Despite trying to remain active, many reported decreased range of motion (57.5%), increased muscular (52.5%) and neuropathic pain (50%), worsened spasticity (50%), worsened balance (37.5%), worsened sleep (30%), and increased falls (20%).
- The study emphasizes the whole body role of regular and personally adapted physical activity when dealing with chronic neurological disability in the community.

Poster citation: Schladen M, Weidemann D, Pizzino K, Cassetty T, Grufstedt M, Martinez B, Boxel AC. Changes in physical activity, health, and wellness experienced by persons with neurologic impairments during the COVID-19 pandemic. American Congress of Rehabilitation Medicine 97th Annual Conference.

Current initiatives ongoing (results not yet published)

Prospective, multicenter observational study in Italy of all people with SCI that get COVID-19

- Ongoing, 6 units enrolling

The International Spinal Cord Society (ISCoS) is creating an SCI COVID-19 registry:

- It will enroll people with SCI that test positive from around the world;
- It will include demographics, risk factors, symptoms, complications, treatments, outcomes.

The World Health Organization (WHO) is developing a protocol to identify mid- and long-term consequences of COVID-19 infection.

Abilities Centre and the Canadian Disability Participation Project at the University of British Columbia "COVID-19: Identifying and Addressing the Needs of Ontarians with Disabilities"

- This study aims to: 1) Measure the impact of social isolation on physical and psychosocial well-being among people with disabilities and their families; 2) Identify the imminent COVID-19 related needs of people with disabilities and their families in Ontario; 3) Evaluate resources and services that are being used to address these COVID-19 related needs of people with disabilities and their families in Ontario.
- The findings will provide important information to help Canadian communities ensure that COVID-19 response strategies meet the needs of people of all abilities.

The Reeve Foundation is funding a study being led by Drs. Spungen and Bryce in New York City. They are creating a regional collaboration of major SCI centers in the tri-state area to understand the medical, physiological, psychosocial, and environmental impacts of COVID-19 on individuals with SCI and their caregivers. This knowledge will enable them to plan to meet the immediate needs of the SCI community

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as the course of the pandemic surges and wanes. This information will also be important for other SCI centers across the US and will help the SCI community better prepare for future pandemics and natural disasters. While this will be started as a regional project, their intention is to invite other regions of the country to input data and share their experiences.

Conclusion

NASCIC's objective for this report was to gather and present current evidence-based information and knowledge to understand the SCI community's health risks in relation to COVID-19. People with SCI were concerned that they were at an increased risk of experiencing severe COVID-19 if contracted compared to the able-bodied population. **Based on the review presented here of the evidence available at the time of publishing, it is fair to say that so far the SCI community does not necessarily experience more severe symptoms and mortality if COVID-19 is contracted compared to the rest of the population.**

However, due to the SCI community's need for personal care, they do face an added risk in being exposed to the virus. Personal care attendants may not be able to socially distance themselves when assisting individuals, and thus create an added-risk in transmitting or contracting the virus. This added risk can be reduced through appropriate usage of personal protective equipment (PPE). Hand washing and personal safety with PPE are an absolute priority, as it can help lower risk of spread. It is also very important to get vaccinated. This provides the most significant protection against experiencing COVID-19. Lastly, like everyone experiencing the pandemic, mental and emotional health are impacted. Hence, it is a great time to virtually connect with one's family and friends, and find new support groups online to help cope with isolation.

Further conversation and continuous advocacy for the SCI community is NASCIC's focus during this unprecedented time. NASCIC encourages meaningful engagement and further education as we endure this pandemic. We look forward to sharing the results of ongoing and future studies that are being conducted that address the impact of COVID-19 on the SCI community.

Citation: North American Spinal Cord Injury Consortium, Evidence Related to COVID-19 in People Living With Spinal Injury. Niagara Falls, NY. 2020.