

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

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 (NASCI) took the initiative to gather and present all current evidence-based information and knowledge about COVID-19 related to those living with SCI. NASCI 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 NASCI 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.

NASCI additionally highlights preliminary best-practices people with SCI can take to stay safe and healthy (physically, mentally, and emotionally) as they live through the pandemic. Research involving COVID-19 and its effect on the community are on-going and NASCI 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.

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%).

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

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.

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.

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.

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.

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.

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: In the process of being published in November 2020

Injury Characteristics: 44 cases – 37 were inpatients with SCI, 7 were trainees or staff with SCI

Symptoms: All individuals had very 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.

Take Home Points: People with SCI did not have as severe COVID-19 disease as seen in people without SCI, no one had any lasting medical problems due to COVID-19, and everyone recovered.

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.
2. The early symptoms people with SCI experience can often be confused with UTI.
3. Cough and fever 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 and underlying secondary conditions may still be risk factors, more information is needed.
6. **It is still very important to minimize the risk of exposure to COVID-19 by washing hands, wearing a mask, and social distancing.**

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.

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.

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. Survey Link - <https://abilitiescentre.org/disabilitysurvey>
- 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 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. 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.

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Resources Available for SCI Community

Version 2 25 March, 2020

HAND HYGIENE FOR PEOPLE WITH SPINAL CORD INJURY

PREVENTING COVID-19

This advice is meant to address the COVID-19 pandemic. Certain supplies may be limited but you can still protect yourself and prevent infection using whatever is available to you; soap and water is always better than nothing.

1 HAND HYGIENE BASICS

- Soap and warm water: **20 seconds**, all parts of hand (front & back, under nails, between fingers, wrists), or
- Sanitizer (70% alcohol): cover **all parts of hand** (front & back, under nails, between fingers, wrists).
- Take care when you dry your hands; use single-use paper towels in a public place or a clean towel at home.

The coronavirus (that causes COVID-19) can live for **hours or even days** on a variety of materials; be especially careful of **surfaces in public areas** that are touched by many people (elevator/door buttons, keypads, handrails, touchscreens, etc.).

2a MANUAL WHEELCHAIR USER

- Wash your hands frequently and whenever you enter your living space.
- Remove gloves first; clean your gloves with whatever non-damaging cleaning product is available.
- After you wash your hands, be **careful about touching your tires**; if you need to transfer, you may want to use paper towels or cloths to cover your tires.
- Clean your **pushrims** as well, since you're constantly touching them... anything that gets on your pushrims is very likely to get on your hands.
- Clean your **brake handles, push handles** and any other parts of your wheelchair that anyone touches with their hands.
- Clean your tires regularly, and try to **avoid making contact** between your hands and your tires when you're pushing.

2b POWER WHEELCHAIR USER

- Wash your hands frequently and whenever you enter your living space.
- If you're not able to wash your hands, get **someone to help you** clean them with soap and water or sanitizer.
- Clean your **joystick** and any other **controls** (while taking care not to damage the electronics)
- Clean your **armrests, tray**, and any other parts of the wheelchair that your hands touch.

3 EVERYONE

- Clean your **cell phone** or other mobile device, and any parts of a **bag or backpack** that you touch.
- Clean your **keys, wallet**, and any **cards** you use in public places.

4 OTHER ASSISTIVE DEVICES

- Clean all parts of any **splints, cuffs, braces, or reachers**, or any other assistive device that you touch with your hands.
- Clean the handles of your **cane or crutches**.
- Clean the **handgrips and brakes** of your walker or rollator, and any other part that you touch (such as a **storage compartment**).

5 USING YOUR MOUTH

- If you have limited hand function, you may typically use your **mouth** to grasp and hold all kinds of things. Although it may be more difficult, it's a good idea to find **other strategies** (including **asking for help** if necessary) so you can avoid using your mouth, **ESPECIALLY** with any object that **someone else** may have touched.

These measures may seem difficult and time-consuming, but it is **EXTREMELY IMPORTANT** for people living with SCI to prevent infection by the coronavirus. During the current emergency, taking **every possible measure** to protect yourself will help you stay healthy.

More information on COVID-19 and people living with SCI:
www.scientario.org/covid-19-guidance-for-sci-community

SCI & U FOR HEALTHY LIVING

A Research Project of:
Physical Therapy UNIVERSITY OF TORONTO

DESIGNS

SCI Moving Forward – A Response to COVID-19

(<http://www.nasciconsortium.org/scimovingforward.com>)

- 10-episode webinar series which focuses on different topic related to COVID-19 and how they are affecting the SCI community. These episodes are meant to educate and empower the community.

MDIC releases a Patient Discussion Tool for patients considering a medical procedure during COVID-19

(<https://mdic.org/project/patient-resources-during-covid-19>)

- “It is important for patients to feel empowered to make health care decisions, understand the benefits and risks associated with medical procedures, and feel comfortable about receiving healthcare, especially during the COVID-19 pandemic. This discussion tool was developed as a guide for patients, patient advocated, and medical and scientific experts to help you ask relevant questions regarding your care during the pandemic”.

SCIRE Community

<https://scireproject.com/community/covid-19/videos>

- COVID-19: Mental Health Concerns and SCI
- COVID-19: Social Isolation and SCI
- COVID-19: Working Out at Home with an SCI
- COVID-19: Staying Physically Active During Pandemic
- COVID-19: Medical Concerns for Individuals with an SCI

Public Health Ontario

How to Self-Monitor (<https://www.publichealthontario.ca/-/media/documents/ncov/factsheet-covid-19-self-monitor.pdf?la=en>)

- Infographic highlighting symptoms to look for and what to do if these develop

Canadian Ministry of Health

COVID-19 Reference Document for Symptoms

(http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_reference_doc_symptoms.pdf)

- Outlines the symptoms, signs, and clinical features which have been most commonly associated with COVID-19.

Canadian Ministry of Health

COVID-19 Guidance: Home and Community Care Providers

(http://www.health.gov.on.ca/en/pro/programs/publichealth/coronavirus/docs/2019_home_community_care_guidance.pdf)

- Covers screening protocols for care providers and clients, COVID-19 testing, reporting, and occupational health and safety for care providers.

Ontario Ministry of Labour, Training and Skills Development

Health & Safety at Work (https://files.ontario.ca/mltsd_2/mltsd-prevention-poster-en-2020-07-22.pdf)

- Lists the rights and responsibilities of workers, employers, and supervisors.

Canadian Direct Funding Program

Self-Managed Attendant Services

(https://www.dfontario.ca/df_public/MEMO%20Health%20and%20Safety%20-%20October%2023%20%202020.pdf)

- Changes in COVID-19 Home and Community Care Guidance and information about a change in the provincial minimum wage.

Rodrigo Torres-Castro and collaborators shared several respiratory interventions that healthcare workers perform on people with SCI, that may expose them to respiratory droplets. Thus, if the patient has COVID-19, there is a high-risk of contamination.

- Professionals who work with people with SCI and perform respiratory interventions should wear:
 - A waterproof long-sleeved gown
 - Double non-sterile gloves
 - Eye protection
 - N95 mask
- An essential precaution is the use of a mask by the patient
 - Without a mask = cough travels 68cm
 - Wearing a surgical mask = cough travels 38 cm
 - Wearing a N95 mask = cough travels 15 cm

Anja Raab and Franz Michel note that the treatment strategy for COVID-19 is dependent on symptoms and not diagnosis. Therefore, the treatment strategy does not differ from the treatment of other respiratory complications. Due to COVID-19's spread through respiratory droplets, a challenge arises for

respiratory therapist to provide accurate intervention while remaining safe. This article highlights how hygiene and personal safety are an absolute priority during the treatment of respiratory complications.

- Respiratory therapy interventions include:
 - Airway clearance techniques
 - Secretion clearance techniques
 - Mobilization and exercise prescription which may trigger a cough and/or expulsion of mucus
- During therapy:
 - Use appropriate personal protective equipment, including N95/P2 masks, fluid resistant long-sleeved gowns, goggles/face shields and gloves
 - Re-usable respiratory equipment should be avoided
 - Use only the maximal needed equipment for single-patient use
 - Use materials which can be properly decontaminated
- Take-home message – increased reader's awareness of the respiratory therapy with COVID-19 to feel supported during these challenging times

The Canadian SCI community quickly developed a network of researchers, clinicians, healthcare providers, SCI funders, community members nationally to support the SCI community during the pandemic. The committee, comprised of over 40 members was formed in March 2020 to encourage a collaborative approach to share knowledge around pandemic management. Resources are available here <https://onf.org/the-sci-community-responds-to-covid-19/>

Drs James Milligan and Tara Jeji were involved in a series of podcasts with the International Spinal Cord Society (ISCoS) to discuss the implications of exiting the lockdown from the SCI perspective. This is available here <https://onf.org/sci-care-what-really-matters/>

Dr Jamie Milligan led the development of a 'Flu Season' handout for SCI in Ontario which is being widely disseminated and is available here <https://onf.org/new-2020-flu-season-resource/>

Drs James Milligan & Joseph Lee have developed a Mobility Clinic Pandemic Initial Telephone Outreach – Risk Identification flow chart which is a comprehensive list of questions addressed over the phone with patients and is available here <https://onf.org/wp-content/uploads/2020/05/Mobility-Clinic-Pandemic-Outreach.pdf>

In partnership with Dr. Blayne Welk from the Western University Canada, Ontario Neurotrauma Foundation have developed a COVID-19: SCI Urology Guide to inform community members of key considerations as it relates to uro-health. This is available here <https://onf.org/wp-content/uploads/2020/05/SCI-Urology-Guide-final.pdf>