



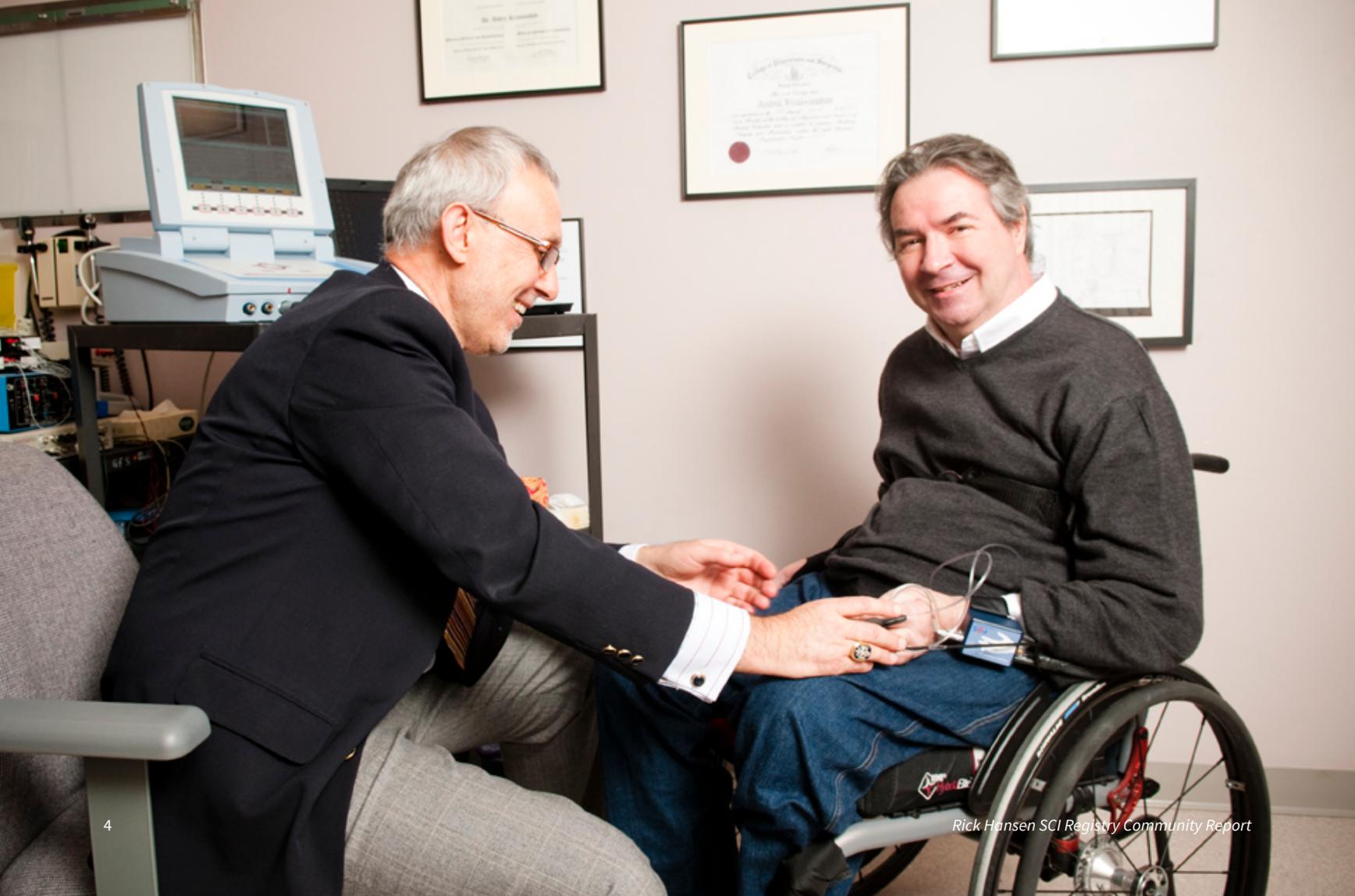
Rick Hansen Spinal Cord Injury Registry

Community Report



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Community Report



Thank you

Thank you to the dedicated clinicians, researchers and coordinators who collect, analyze and input data into the Rick Hansen Spinal Cord Injury Registry (RHSCIR). We also wish to thank the over 7,000 individuals with traumatic spinal cord injuries who have generously contributed their time and experiences to RHSCIR.

The contributions of everyone involved are vital to improving the ability to provide care for those with spinal cord injuries, and maximizing the potential for these individuals to reach his or her fullest recovery possible.

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Spinal cord injury and the Registry

Spinal cord injury (SCI) is a complex, debilitating and costly condition. No two injuries are the same and it can happen to anyone, at any time. For many, SCI also results in loss of independence, poverty and social isolation. In Canada, over 86,000 people live with SCI (43,974 with traumatic SCI).¹ Although it affects fewer individuals when compared to other chronic conditions, the economic burden is near catastrophic. Injuries that are sustained as a result of trauma (also known as traumatic SCI), such as serious vehicle crashes or falls, have an estimated average lifetime cost of \$2 million per individual. For the 1,389 people who sustain a traumatic SCI each year, the annual cost is estimated to be \$2.7 billion (in 2015 Canadian dollars).²



¹Noonan VK, Fingas M, Farry A, Baxter D, Singh A, Fehlings MG, Dvorak MF. Incidence and Prevalence of Spinal Cord Injury in Canada: A National Perspective. *Neuroepidemiology*. 2012;38:219–226.

²Krueger H, Noonan VK, Trenaman LM, Joshi P, Rivers CS. The economic burden of traumatic spinal cord injury in Canada. *Chronic Diseases and Injuries Canada*. 2013;33(3):113-112.

This includes direct costs such as hospital stay and indirect costs such as lost productivity due to disability and premature mortality.

In order to better understand the complex needs of individuals who sustain a traumatic SCI, RHSCIR was created from the vision of two individuals: Canadian icon and Paralympian, Rick Hansen and renowned spine surgeon and researcher, Dr. Marcel Dvorak. With 30 participating facilities in major Canadian cities, RHSCIR includes over 7,000 participants (and counting), making it the largest database that tracks the experiences of individuals living with traumatic SCI in Canada.

RHSCIR is a prospective observational study that collects clinical and demographic data from Canadian acute and rehabilitation hospitals specializing in SCI care and treatment. It collects information from individuals with SCI throughout their lifetime after integrating back into the community. In recent years,



RHSCIR has established international collaborations with pilot studies in China, New Zealand and Israel, making it a truly global study which connects the international SCI research and clinical care communities.

Spinal cord injury and the Registry

The most vital and fundamental component of RHSCIR is its contributors – people with traumatic SCI. Your continued participation determines the value and success of RHSCIR.

Who participates in RHSCIR?

Currently, participants must have an acute (new) traumatic SCI and be an in-patient at a participating RHSCIR-sponsored hospital or rehabilitation facility. An initial interview is conducted during the hospital stay to collect information on health status. Afterwards, follow-ups are conducted during specified time intervals in order to continuously track the experiences of the individual.



How RHSCIR helps people with SCI

How many people sustain a traumatic SCI each year?
What was the cause of their injury and how severe was it?

Ideally, every researcher, clinician and healthcare administrator would have access to this type of information. Questions like these are the reason that RHSCIR was established.

By collecting a person's demographic information (age, date of injury, sex, location, etc.) and clinical data (level and type of injury, admission and discharge dates, complications etc.), it enables researchers and healthcare providers to answer critical questions about care including evaluating how their patients are being treated and helping identify how to improve SCI care at their facility.

With a condition that varies from person to person as much as SCI does, research platforms and registries are one of the only ways to study the many variations, complications and outcomes of such an infrequent, high-cost medical condition. Without such research, there is no way to know how to improve care or bring new therapies into practice.



About this report

The Rick Hansen SCI Registry Community Report analyzes responses from 299 RHSCIR participants who answered a community follow-up questionnaire from April 2014 to February 2017. The questionnaire was **conducted five years after injury**. This report does not present data on all questions. Rather, it highlights responses to key questions to provide a broad perspective on important issues that affect participants in RHSCIR and may also differ from what is reported in the literature. Responses presented in this report represent 299 individuals unless otherwise noted.

In this report, you will find information about patient demographics, life satisfaction, secondary complications and other factors that impact quality

of life after traumatic SCI. This is a small subset of the data that RHSCIR collects; other information collected includes details about surgery and other interventions and detailed diagnosis information.

The report's primary purpose is to serve as a descriptive account with no endorsement of, or recommendations about, policies or programs. However, this report can help inform advocacy, policy and program planning. Data from RHSCIR provides researchers, health care providers, advocacy organizations and decision makers with knowledge that may support strategies to improve SCI care services. To view other RHSCIR reports, visit www.praxisinstitute.org.

“Wow [answering the questionnaire] was really an interesting process. It caused me to reflect on all aspects of my life. My day to day life is so busy coping with specific barriers that I forget about my needs as a whole person. I realize that I need to get out of my home more and pursue recreation and social time.”

– RHSCIR Participant



We welcome feedback or questions on any aspect of this report. Please contact us at RHSCIR@praxisinstitute.org.

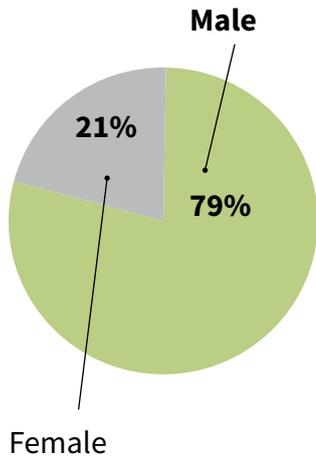


For more information about RHSCIR, please visit www.praxisinstitute.org.

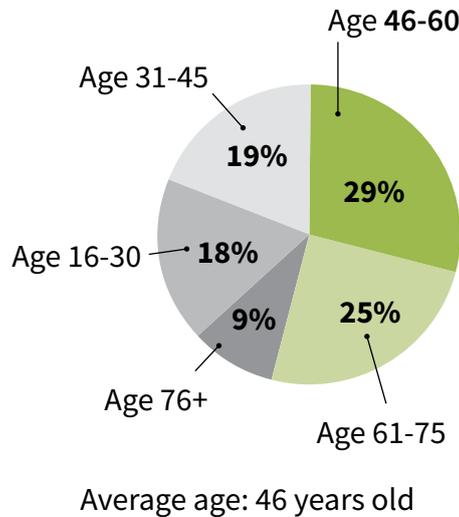


An overview of the population

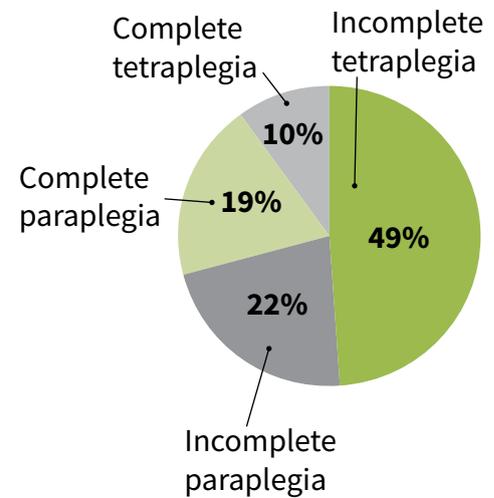
Sex N = 299



Age (at 5 years post-injury)



Injury Type



Causes of Injury



Transportation 38%
Avg. age: 47 years old



Sports 15%
Avg. age: 47 years old



Other traumatic causes 7%
Avg. age: 52 years old



Fall 37%
Avg. age: 58 years old



Assault 3%
Avg. age: 43 years old

**All averages calculated as means.*

Spinal cord injury (SCI)

The impairment of sensory and/or muscle function due to damage of the nerves in the spinal cord.

Tetraplegia or quadriplegia

Complete or partial loss of sensation and/or movement in the arms, and typically in the trunk and legs. It is caused by an injury to the spinal cord in the neck.

Paraplegia

Complete or partial loss of sensation and/or movement in the legs and often in part of, or the entire trunk. It is caused by an injury to the spinal cord in the thoracic (trunk) or below.

Complete injury

An injury where there is no sensory and motor function (ability to feel, touch or move) preserved in the last nerves leaving the spinal cord (sacral 4th and 5th nerves). This usually results in a total lack of sensory and motor function below the level of the injury.

Incomplete injury

An injury where there is some sensory or motor function (ability to feel, touch or move) below the level of the injury. This must include the last nerves leaving the spinal cord (sacral 4th and 5th nerves).



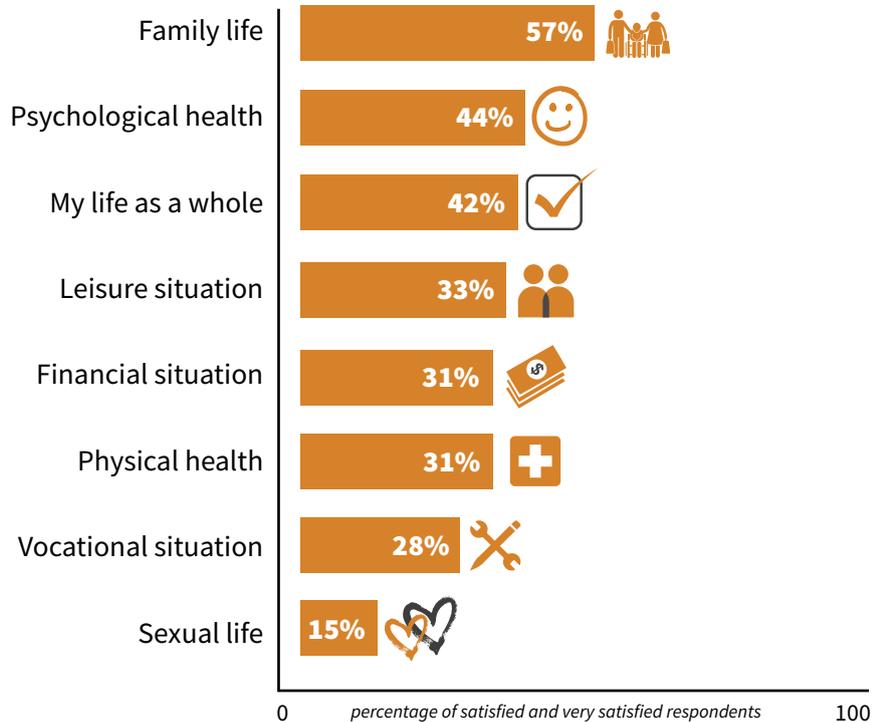
Life satisfaction

Life satisfaction is a way to express quality of life. For SCI clinicians and researchers, a way to quantify how individuals feel about their quality of life is by measuring it through the Life Satisfaction Questionnaire (referred to as LiSAT-11). If you participate in RHSCIR, you may remember responding to questions about vocation, finances, relationships and overall well-being when completing the five-year follow-up. LiSAT-11 is based on a six-point scale (1 = very dissatisfying to 6 = very satisfying).



Highlights from LISAT-11

Responses recorded in the graph below represent individuals who rated each area as “satisfying “ or “very satisfying”.



My name is Michael and I am 81 years old. While walking down some stairs in the morning when it wasn't quite at full light, I miss-stepped and fell down three steps. It took about 10 minutes before anyone arrived at which point I realized I had sustained a spinal injury. I was required to have surgery at the hospital where they performed a spinal fusion, leaving me an incomplete tetraplegic. I now require assistance to do many things that I was able to do independently before.

– Michael

Employment & income

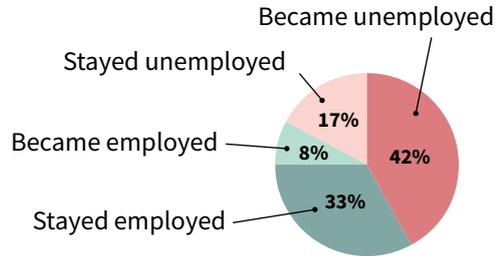
Depending on factors such as age and level of injury, many individuals are ready to re-enter the workforce after they have adjusted to their new life after injury. For people with SCI, it can be difficult to work to their full potential due to a variety of circumstances such as health complications, changes in physical ability or lack of employment opportunities for individuals with disabilities. However, employment is important because it provides tangible financial gains such as earning an income and receiving extended health benefits. It also provides other benefits such as interacting with others, improving self-esteem and improving overall life satisfaction. Many organizations across Canada provide employment services and supports for individuals with SCI.



You can read more about one such organization in the Partner Spotlight on page 17.

Change in employment status

Employed vs. Unemployed (N=210)



* This graph includes only those individuals who were younger than 65 years old at the time of their injury (i.e. should have been eligible for employment)

More than **1 in 2** individuals were unemployed at 5 years post-injury.

Income also changed after injury depending on income levels. The poverty level in Canada varies based on location and number of people in the household; a household income of \$30,000 is a good benchmark for determining an individual's ability to provide basic means such as food, shelter and clothing for their family.

PARTNER SPOTLIGHT: ABILITY NEW BRUNSWICK

“The individuals with a spinal cord injury (SCI) who we work with have a desire to work and New Brunswick needs human resources to sustain our economy. Yet a disconnect in connecting people with an SCI and employers often exists. Through our services, Ability NB helps remove the roadblocks to employment such as negative attitudes, myths and stereotypes about persons with a disability held by many employers, managers and supervisors. We also address the lack of knowledge by employers about accessible work spaces, the duty to accommodate,

job customization, and successful return to work strategies.

Eliminating these roadblocks and good communication consistently leads to successful employment for New Brunswickers with an SCI.”



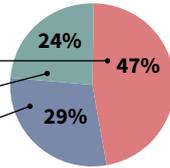
– Haley Flaro,
Executive
Director, Ability
New Brunswick

Employment & income continued

Change in household income (N=167)

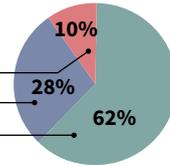
\$30,000 + per year (N=146)

- Had a decrease in income
- Had an increase in income
- Had no change in income



\$0 to \$29,000 per year (N=21)

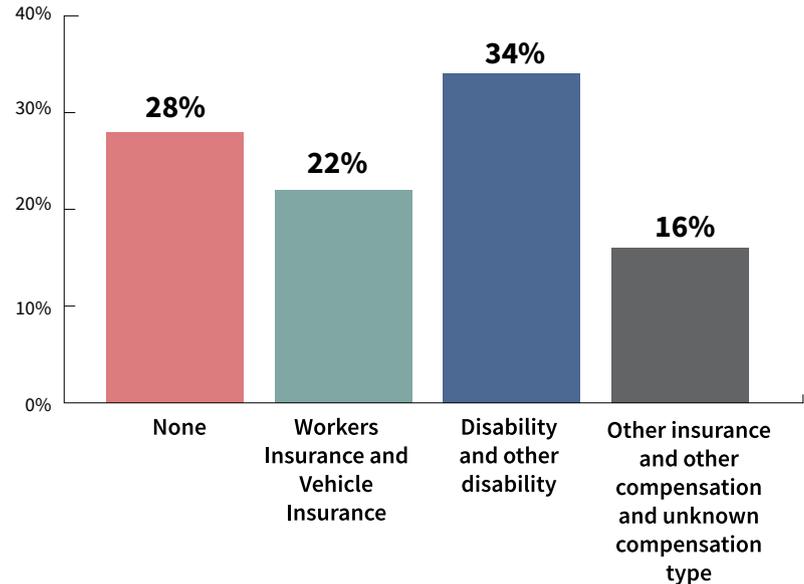
- Had a decrease in income
- Had no change in income
- Had an increase in income



For individuals whose household income was more than \$30,000, almost half (**47%**) saw a decrease in income. For individuals who earned less than \$30,000 before injury, **62%** had an increase in income. This may be due to sources of household income other than employment, such as disability insurance, workers' compensation or vehicle insurance. Some types of disability insurance focus on those who earn the least, which may explain why those who earned the least before injury showed an increase in household income.

Below is a breakdown of compensation types. Workers insurance and vehicle insurance tend to provide the most support. All types of insurance vary in their coverage of medical equipment, home support and allied health or nursing care. These factors can affect quality of life as well as the financial strain placed on the individual with SCI and their family.

Compensation type





Secondary health complications

Secondary health complications refer to a range of conditions that occur after sustaining the initial injury. People with spinal cord injuries often experience multiple complications after their injury. These complications can diminish quality of life, negatively

impact living in the community and if left untreated, can lead to re-hospitalization for urgent care or result in death. More than 8 out of 10 respondents (83%) reported at least one secondary health complication in the last year.

Below are the **top 5 most common secondary health complications** and the percentage of respondents who reported the condition in the year prior to completing the questionnaire (shown in table as “percentage of respondents affected”).

Secondary complication	What it is	Percentage of respondents affected
Spasticity 	Spasticity is usually experienced as involuntary muscle contractions, increased muscle tone, and overactive reflexes. Spasticity can contribute to a number of potential problems such as: pain, reduced mobility and function, skin breakdown, bladder and bowel accidents and sleep problems.	60%

Secondary complication	What it is	Percentage of respondents affected
<p>Neuropathic pain</p> 	<p>Pain from the nerves is called neuropathic pain. Neuropathic pain can be felt anywhere in the body, including below the level of SCI, even when there is no other feeling in the area. A recent study showed that neuropathic pain is four times more common in people with SCI than any other traumatic injury.² Of the 58% of respondents who reported neuropathic pain, more than 6 in 10 (61%) reported that it limits their activity.</p>	<p>58%</p>
<p>Fatigue</p> 	<p>Fatigue can have a negative impact on physical, emotional and mental well-being. It can be from many causes, such as added physical strain from supporting your body with your arms or requiring more effort to perform a certain activity, and can be compounded by other secondary complications such as pain or spasticity.</p>	<p>56%</p>
<p>Constipation</p> 	<p>Constipation is common after SCI because movement of stool through the bowel is slow, which dries out the stool. The stool may also be difficult to pass if the anal sphincter muscles do not relax enough (called stool retention). You can read more on bowel function on page 26.</p>	<p>44%</p>
<p>Sexual dysfunction</p> 	<p>Because of the emotional, physical and sensory changes after SCI, the experience of sexuality can be quite different after SCI. This has implications for quality of life and can strain partner relationships as well.</p>	<p>41%</p>

² Daoust R, Paquet J, Moore L, et al. Early Factors Associated with the Development of Chronic Pain in Trauma Patients. Pain Res Manag. 2018;2018:7203218. Published 2018 Jan 30. doi:10.1155/2018/7203218

Secondary health complications continued

“Sexuality is an area of great joy and pleasure, but also an area of great suffering and there is a significant unmet need for services and support. This topic is often ignored because of people’s discomfort in talking about it, but it doesn’t have to be this way. We need to get more clinicians trained on treating sexual health after SCI and talking to their clients about it. The best advice I can give someone dealing with these issues is to maximize what you have with your own body, adapt to it and be open to new experiences or interventions that may help increase your sexual satisfaction.”



– Stacy Elliott, MD
Sexual Health Clinician,
Vancouver Coastal Health



Another common complication was depression or mood problems. **Two in five** of the respondents reported this issue, but just over **one in four** (27%) were receiving treatment for it. The experience of severe levels of distress which can accompany disability can potentially lead to depression, which may worsen quality of life and is associated with increased health care utilization, costs and poorer patient outcomes.



Living arrangements

After spending weeks or months in a hospital or rehabilitation facility, many individuals who have sustained an SCI look forward to returning home. For many individuals, living at home is important because it gives them a sense of familiarity and comfort after enduring a life-altering change. Place of residence (private residence compared with nursing home) is an objective measure of community reintegration, and an indicator of successful outcome for SCI care. While home renovations or additional support may be required in order to adapt to a new home life after SCI, the vast majority of respondents were able to successfully return to living in a private residence.

Living Arrangements (N=248)



9 in 10 reported living in a private residence five years after their injury.

Of those living in a private residence



27% reported receiving in-home support or healthcare.



80% live with another person.

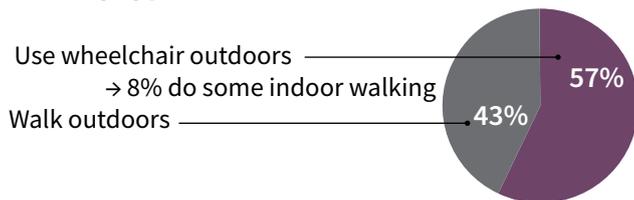


20% live alone.

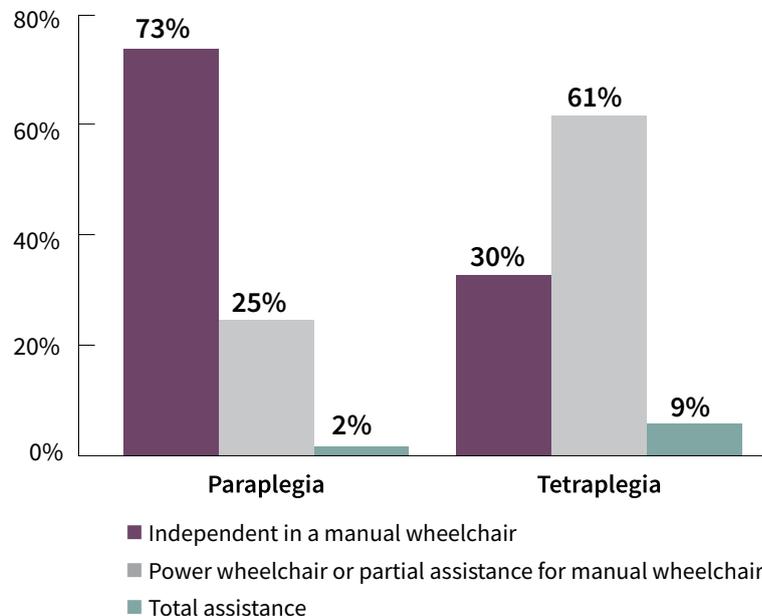
Mobility

The ability to get outside the home independently is a significant measure of an individual's ability to participate in their community. It is also informative for researchers and policy makers to understand how much assistance individuals with SCI need. For example, if you need total assistance, you cannot leave the house without someone with you, whether that is paid assistance, a family member or a friend.

Mobility types



Outdoor Wheelchair Users N=211



Bladder & bowel management

Bladder and bowel care are two high priority areas for individuals with SCI. Bladder and bowel routines that suit an individual's needs and lifestyle can have a profound impact on that individual's feelings about independence and overall life satisfaction.



According to the responses analyzed for this report, **41%** of individuals used an intermittent catheter when they left the hospital— a medical device inserted several times a day to empty the bladder. Five years later, this number decreased to **23%**. This may be due to individuals regaining some control over their bladder or using alternative bladder emptying methods.

41%



23%



For **one out of four** respondents, fecal (bowel) incontinence is a serious problem; **25%** reported having one or more bowel accidents per month.



Accidents can be accompanied by feelings of shame and fear of going out, which will decrease quality of life.





**PARTNER SPOTLIGHT:
SCIRE COMMUNITY**

SCIRE (Spinal Cord Injury Research Evidence) Community is a free, evidence-based website that provides information about spinal cord injury research that is written in everyday language. Its goal is to help ensure everyone has access to information based on the latest science to help them understand spinal cord injury, manage health conditions and live a healthy and fulfilling life. SCIRE Community covers a variety of topics including information on health services, treatments and common health issues, like bowel and bladder care. Visit www.scireproject.org/community.

Healthcare utilization

After sustaining an SCI, individuals can expect to see an increase in healthcare utilization – in other words, how much time they spend at the hospital or saw a family physician, specialist or other health care provider. Of the respondents (N=227), **22%** spent at least one night in the hospital in the past year and spent an average of **15.5 nights** in the hospital.

Urologists were the most commonly seen specialists.

One in three people had a urinary tract infection within the last year. Regular follow-up visits help to monitor bladder function and manage issues for people with SCI.



Top 5 most common health professionals seen in the last year:

Family physician	58%
Urologist	26%
Nurse	21%
Physical therapist	20%
Physiatrist (rehab physician)	14%

Interestingly, only **4%** saw a peer support person, **2%** saw a sexual health clinician and **1%** saw a vocational counselor.

A NEW APPROACH TO COMMUNITY FOLLOW-UP

Rick Hansen SCI Registry researchers in Alberta partnered with local community advocacy organization, Spinal Cord Injury Alberta, to conduct RHSCIR follow-up interviews. The team modified the questionnaire as well as the data collection process for the follow-up interviews and as a result, are better able to address individuals' concerns in real time, incorporate specific research interests and improve participant retention. Today, a staff member from SCI Alberta (usually a social worker) conducts interviews with participants. If any concerns are raised during the interviews, SCI Alberta staff team are able to directly handle the concerns or connect patients with the appropriate clinical supports.

“[This approach] enhances the number of unique individuals that data is gathered from so that research and services can be strengthened and policies can be better informed.”

- Teren Clarke,
Former Executive Director, Spinal Cord Injury Alberta



Summary of findings



9 in 10 live in a private residence

(91%, N=285)



Over 1 in 2 individuals were unemployed

at 5 years post-injury (59%, N=210)



42% are satisfied or very satisfied with their life, post-injury as a whole



2 in 5 reported depression or mood problems limit their activity (40%)



15% of individuals reported their sexual health to be satisfying or very satisfying



1 in 4 reported having one or more bowel accidents per month (25%)



83% reported at least one secondary health complication (e.g. spasticity, neuropathic pain) as a result of their SCI



The work continues...

The findings of this report highlight the need for further research and resource development in the areas of sexual health, optimizing bowel and bladder management, vocational support, as well as supporting psychosocial and emotional health. We encourage people with SCI, community groups and researchers to contact us to use the data in the RHSCIR to advocate for change.

In the near future, RHSCIR will collect clinical data on people with non-traumatic SCI (injuries caused

by disease, infection or congenital disorders) which represents approximately half of people with SCI in Canada.

Thanks to support from the federal and provincial governments, the work of RHSCIR continues.

Questions about this report?

Contact us at RHSCIR@praxisinstitute.org.



Additional Resources

National Organizations

Spinal Cord Injury Canada
www.sci-can.ca

Spinal Cord Injury Research Evidence (SCIRE)
www.scireproject.com

Provincial Organizations

Spinal Cord Injury Alberta
www.sci-ab.ca

Spinal Cord Injury British Columbia
www.sci-bc.ca

Canadian Paraplegic Association (Manitoba) Inc.
www.cpamanitoba.ca

Ability New Brunswick
www.abilitynb.ca

Spinal Cord Injury Newfoundland and Labrador
www.sci-nl.ca/

Canadian Paraplegic Association Nova Scotia
www.thespine.ca/

Spinal Cord Injury Ontario
www.sciontario.org

Spinal Cord Injury Prince Edward Island
www.sci-pe.ca

Moelle Epinière et Motricité Québec
www.moelleepiniere.com

Spinal Cord Injury Saskatchewan
www.spinalcordinjurysask.com

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Definitions on pages 20-21 sourced from SCIRE Community. www.scireproject.com/community



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