

SPINAL CORD INJURY COMMUNITY SURVEY

Participants Report - Non-traumatic Injuries



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Rick Hansen Institute
Institut Rick Hansen



Moelle épinière
et motricité Québec



Spinal Cord
Injury
Canada

Blessure
Médullaire
Canada

Acknowledgements

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Principal Investigator

Luc Noreau, PhD

Professor, Université Laval and Director, Centre interdisciplinaire de recherche en réadaptation et intégration sociale (CIRRIIS)

Survey Team

Lydia Cartar, MA, Rick Hansen Institute

Erin Cherban, MSc CCRP, Rick Hansen Institute

John Cobb, BSc OT, Vancouver General Hospital

Marie-Eve Drouin, MA, Université Laval

Frederic Dumont, PhD, Université Laval

Phil Giborski, Mustel Research Group Ltd.

Jean Leblond, PhD

Vanessa Noonan, PhD, PT, Rick Hansen Institute

Co-Investigators

Bill Adair, Spinal Cord Injury Ontario (formerly CPA Ontario)

Kathryn Boschen, PhD, University of Toronto

Teren Clarke, Canadian Paraplegic Association Alberta (CPA Alberta)

Geraldine Jacquemin, MD, Institut de réadaptation Gingras-Lindsay de Montréal

Kathleen Martin Ginis, PhD, McMaster University

Mary-Ann McColl, PhD, Centre for Health Services and Policy Research, Queens University

Bill Miller, PhD, University of British Columbia

Dalton Wolfe, PhD, University of Western Ontario

With significant contributions from

Heather Harris-Harper, Rick Hansen Spinal Cord Injury Registry (RHSCIR)

Dan Maceluch, Rick Hansen Institute

Catherine McGuinness, RHSCIR

Gabrielle Nye, Rick Hansen Institute

Claudia Poirier, OT, Université Laval

Julie Tremblay, MA, Université Laval

Carey Yada Lee, Rick Hansen Institute

Jennifer Zander, Rick Hansen Institute

Hongbin Zhang, MSc, MEng, RHSCIR

Interviews and survey website

Mustel Research Group Ltd.

Support with participant recruitment

Nancy Beaton, CPA Nova Scotia

Nathalie Beaupré, Institut de réadaptation en déficience physique de Québec

Ron Burky, CPA Manitoba

Mike Burry, CPA Newfoundland

Teren Clarke, CPA Alberta

Paul Cudmore, CPA Prince Edward Island

Haley Flaro, Ability New Brunswick

Marie-Thérèse Laramée, Institut de réadaptation Gingras-Lindsay de Montréal

Chris McBride, Spinal Cord Injury BC (formerly CPA BC)

Nathalie Michaud, Moelle épinière et motricité Québec

Carol Mishaw, SCI Ontario

Bobby White, SCI Canada (formerly CPA Canada)

Les Wehner, CPA Saskatchewan

Robb Dunfield, Ambassadors Director, Rick Hansen Foundation

Jim Richards, Executive Director, 25th Anniversary Relay

Heather Askes, RHSCIR London

Ish Bains, RHSCIR Calgary

Kim Bertone, RHSCIR Winnipeg

Cathy Craven, RHSCIR Toronto

Heather Flett, RHSCIR Toronto

Cyndi Jones, RHSCIR Ottawa

Garry Linassi, RHSCIR Saskatoon

Darren Nickel, RHSCIR Saskatoon

Colleen O'Connell, RHSCIR Fredericton

Kirby Scott, RHSCIR Edmonton

Ginette Thibault-Halman, RHSCIR Halifax

Andrea Townson, RHSCIR Vancouver

Deborah Tsui, RHSCIR Hamilton

Catherine Wheeler-O'Neil, RHSCIR Halifax

Dalton Wolfe, RHSCIR London

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Non-traumatic Injuries

CAUSED BY ILLNESS OR CONGENITAL CAUSE

(tumour, infection, neurodegenerative diseases, post-surgical complications, spina bifida)

412 people with a non-traumatic injury participated in the survey, just like you.

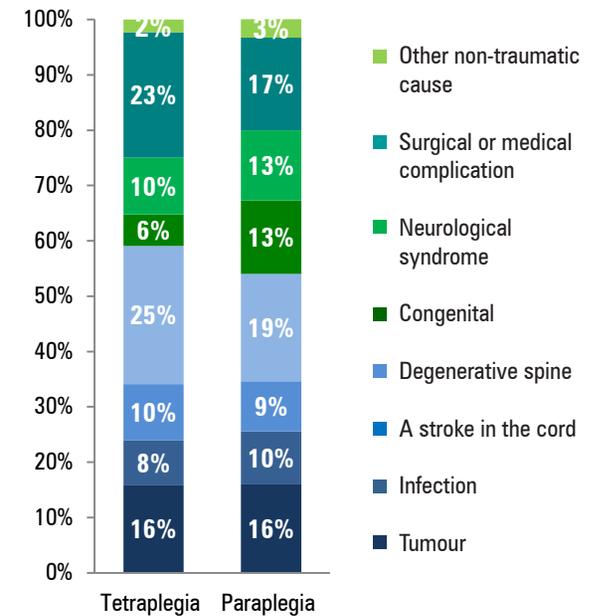


Demographics

Who you are

Are you less familiar with certain terms? Refer to the Glossary at the end of this document.

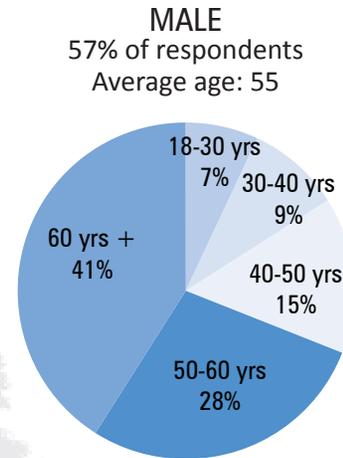
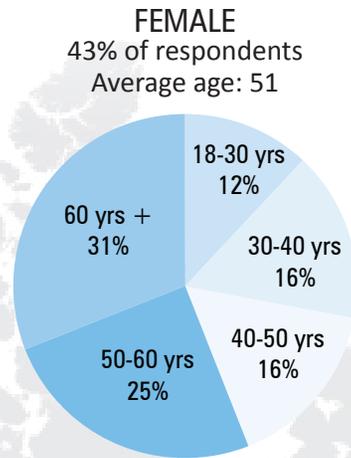
FREQUENCY OF DIFFERENT CAUSES FOR SPINAL CORD INJURY ACCORDING TO IMPAIRMENT TYPE



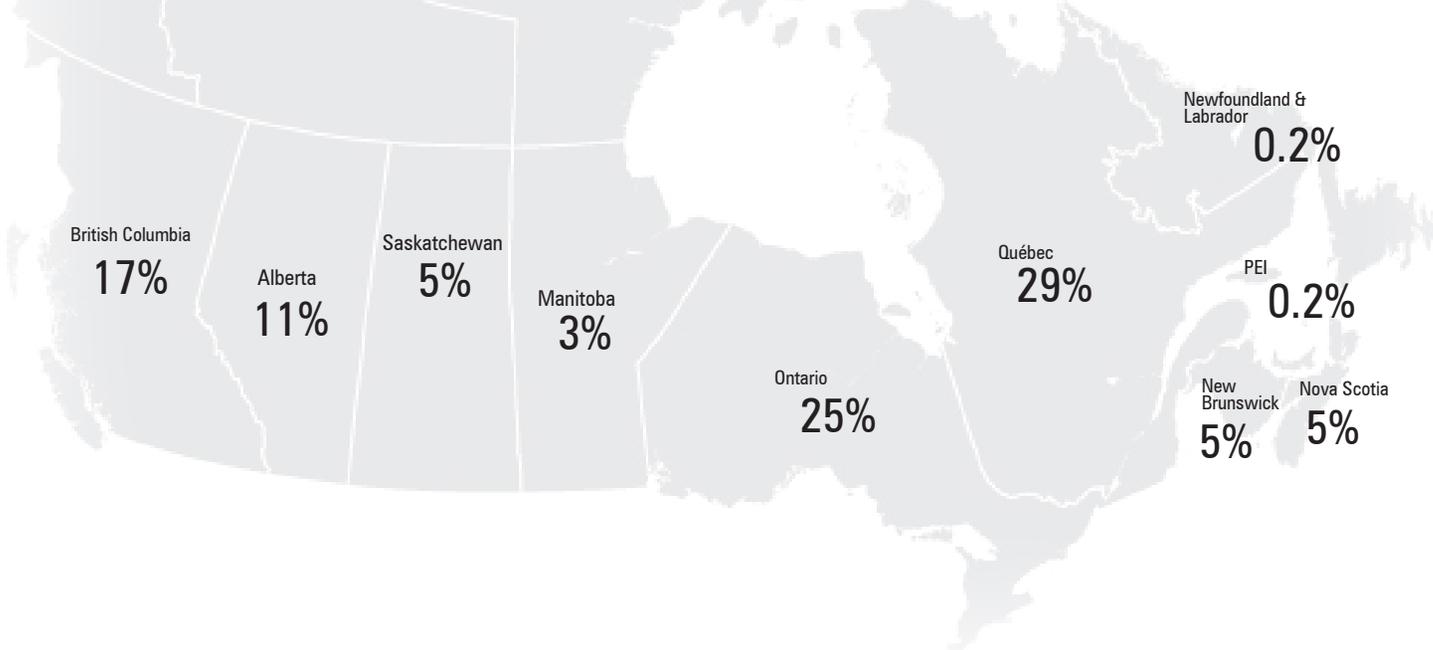
22%
Reside in a city with more than 100,000 inhabitants

58%
Live in an urban setting

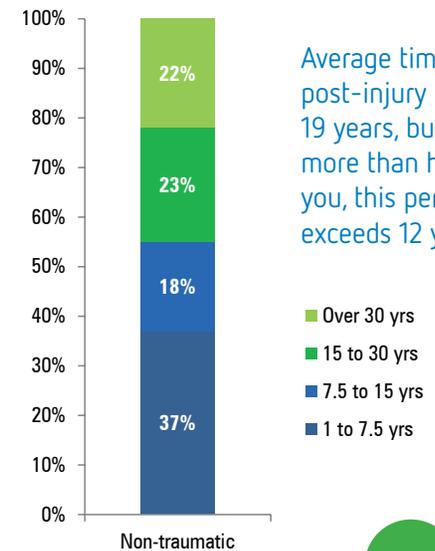
20%
Live in a rural setting



Most participants are between 42 and 64 years of age.



YEARS AFTER INJURY

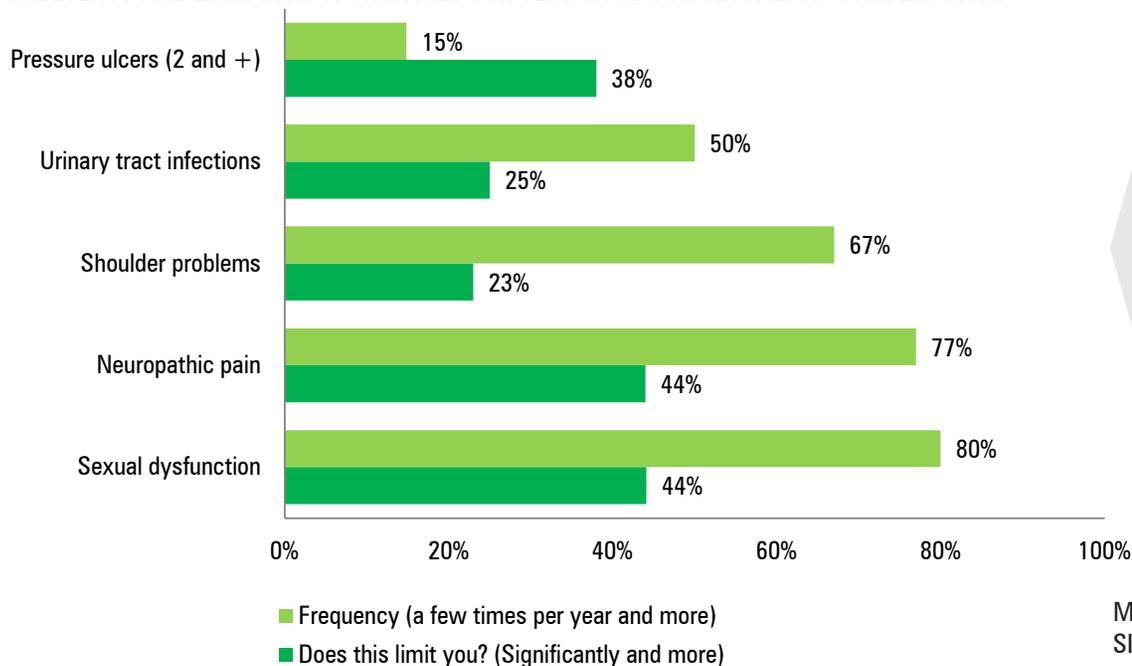


Average time post-injury is 19 years, but for more than half of you, this period exceeds 12 years.

Secondary Complications

A secondary complication is a health problem that can arise after a spinal cord injury. The survey measured the frequency of 21 complications (over the last 12 months) and their impact on daily activities.

FREQUENCY AND LIMITATION OF ACTIVITIES FOR CERTAIN MAJOR SECONDARY COMPLICATIONS



Complications and daily activities

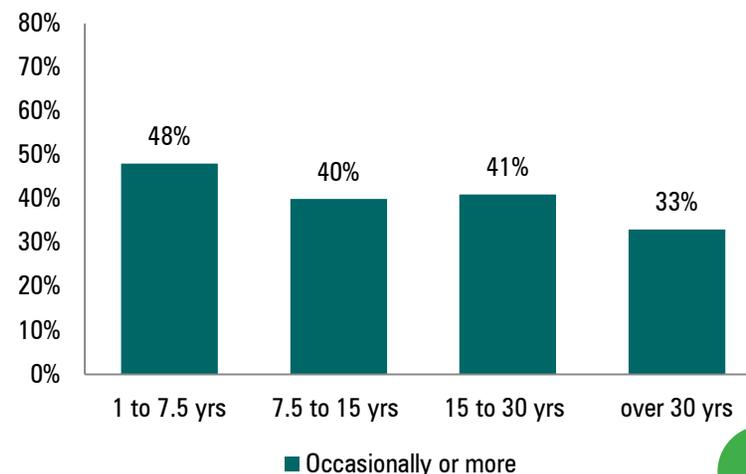
This figure presents the frequency of five significant secondary complications in people with a non-traumatic spinal cord injury.

- *Sexual dysfunction* and *neuropathic pain* are characterized by their high frequency and impact on activities.
- *Pressure ulcers (two or + / last 12 months)* are not among the most frequent (approximately one person in seven or 15%), but greatly limit activities for more than one-third of respondents presenting this complication.

Mood disorders and post-injury time

Mood disorders (occasionally or frequently) are reported by many people, particularly during the first post-injury years. They tend to diminish with time, suggesting better adjustment to the situation.

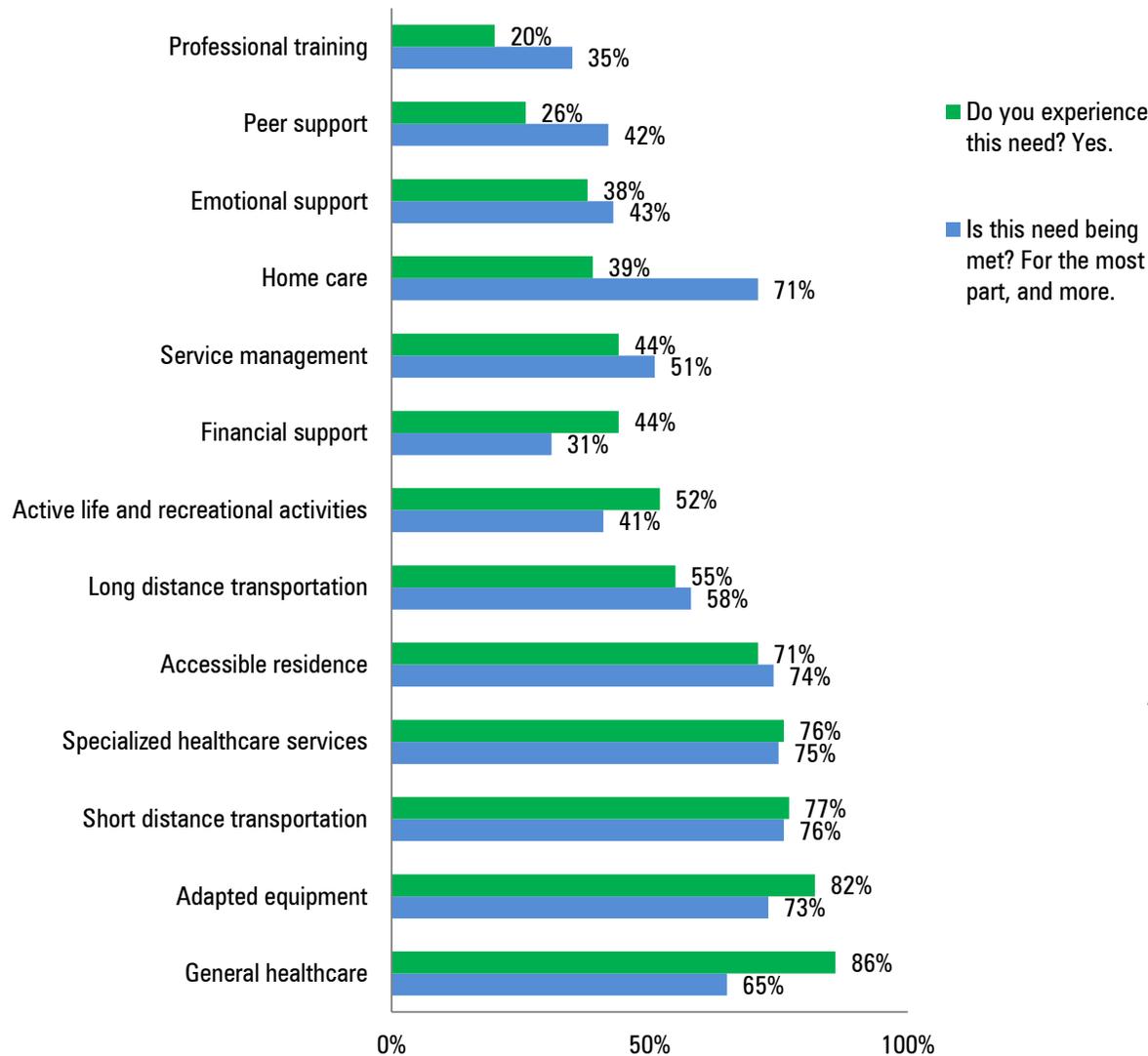
MOOD DISORDERS: LINK BETWEEN THE NUMBER OF YEARS SINCE INJURY AND FREQUENCY



Need for Services

People with a spinal cord injury must have access to services that satisfy their needs. This survey has measured the frequency of 13 needs and the level to which they are currently being met.

SERVICE NEEDS FOR PEOPLE LIVING WITH A NON-TRAUMATIC SPINAL CORD INJURY: FREQUENCY AND RESPONSE TO NEEDS



Importance of the need

The study has enabled us to determine that the needs that are considered most important are also the ones that are the most frequent and the most satisfied.

For example, 86% of people have a need for *general healthcare*. Of this number, approximately two out of three people consider this need is met.

According to the type of injury ...

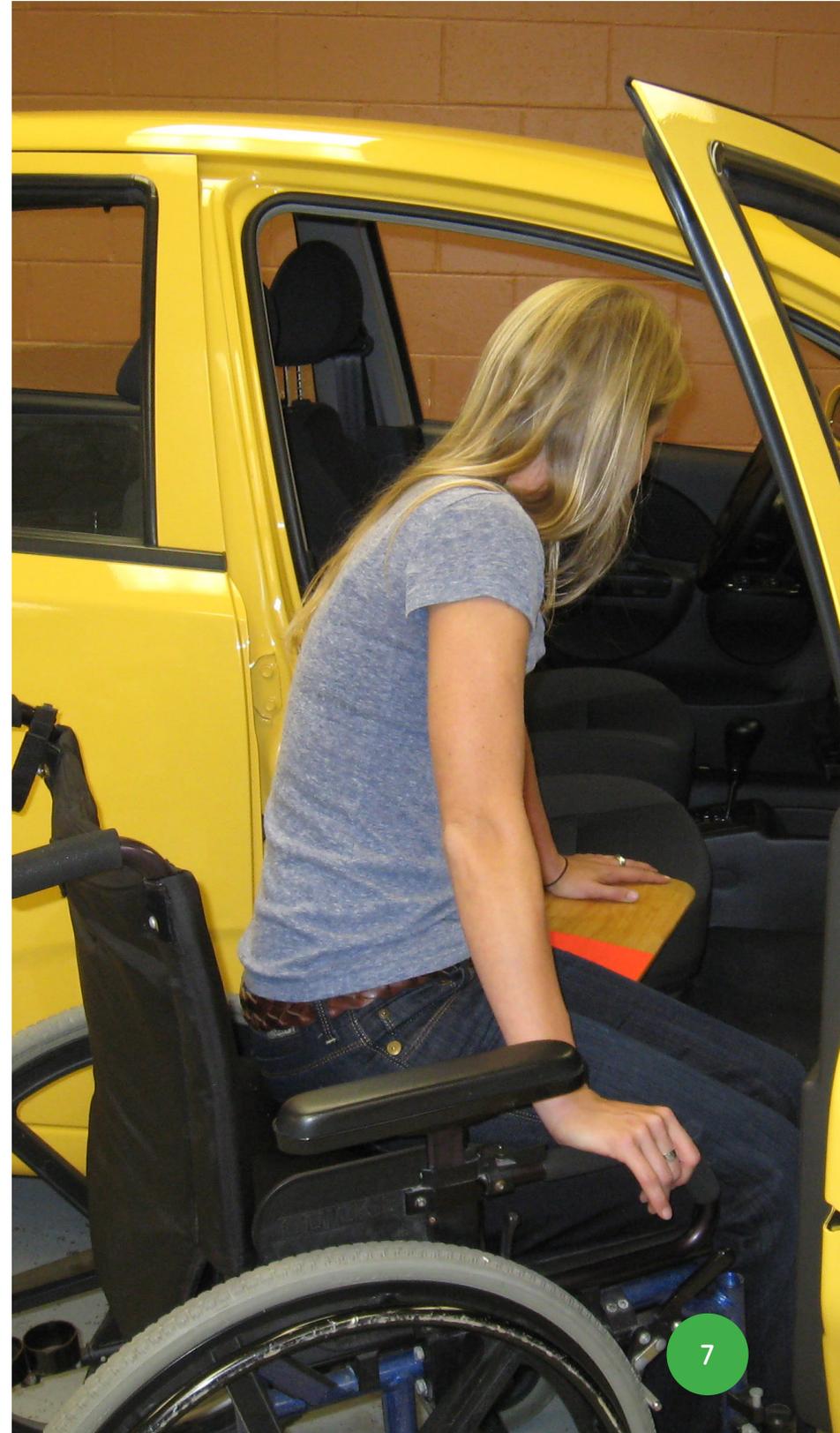
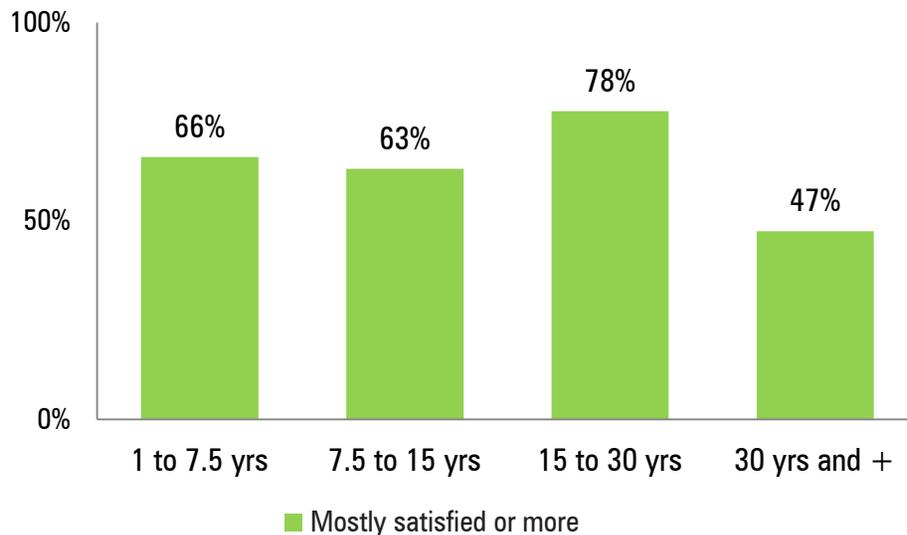
- Many needs are more satisfied for people with **tetraplegia** and a complete injury, except for the five following needs: *specialized healthcare services for spinal cord injuries, short distance transportation, financial support and specialized equipment.*
- For **complete** injuries, *financial support* is the least satisfied need.

Need for Services

According to the number of years post-injury ...

There is only one need (*specialized healthcare services*) for which the percentage of the response “*Mostly satisfied or more*” increases with years, up to 30 years post-injury. However, we notice that the percentage drops beyond 30 years (47%), which may mean that the need for *specialized healthcare services* increases but that it is more difficult to fulfill.

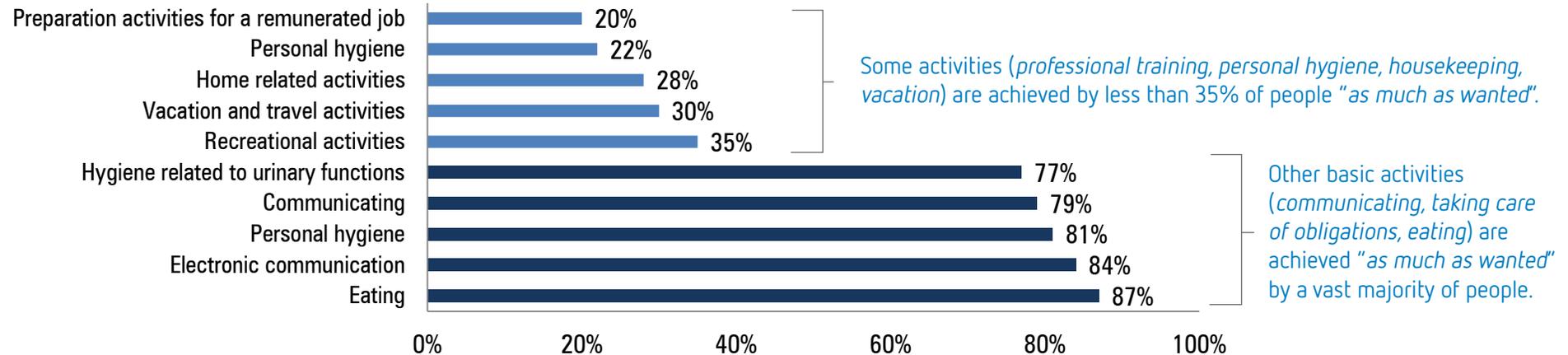
SPECIALIZED HEALTHCARE SERVICES



Social Participation

Social participation refers to activities that you would like to take part in on a daily basis. The study aimed to determine if participation in these activities (n = 26) was “as much as wanted” or if different constraints limit participation.

ACTIVITIES FOR WHICH THE PERCENTAGE OF PEOPLE WHO PARTICIPATE “AS MUCH AS WANTED” IS LOWEST (N= 5) AND HIGHEST (N= 5)



According to the type of injury ...

- People with **tetraplegia** and a **complete injury** experience less “as much as wanted” participation in activities involving personal hygiene.
- However, this same group has the highest “as much as wanted” participation for the following activities: *maintaining psychological health, achieving activities related to home, communicating with others electronically, maintaining relationships with others and achieving non-remunerated activities.*

According to a non-achieved (but desired) participation ...

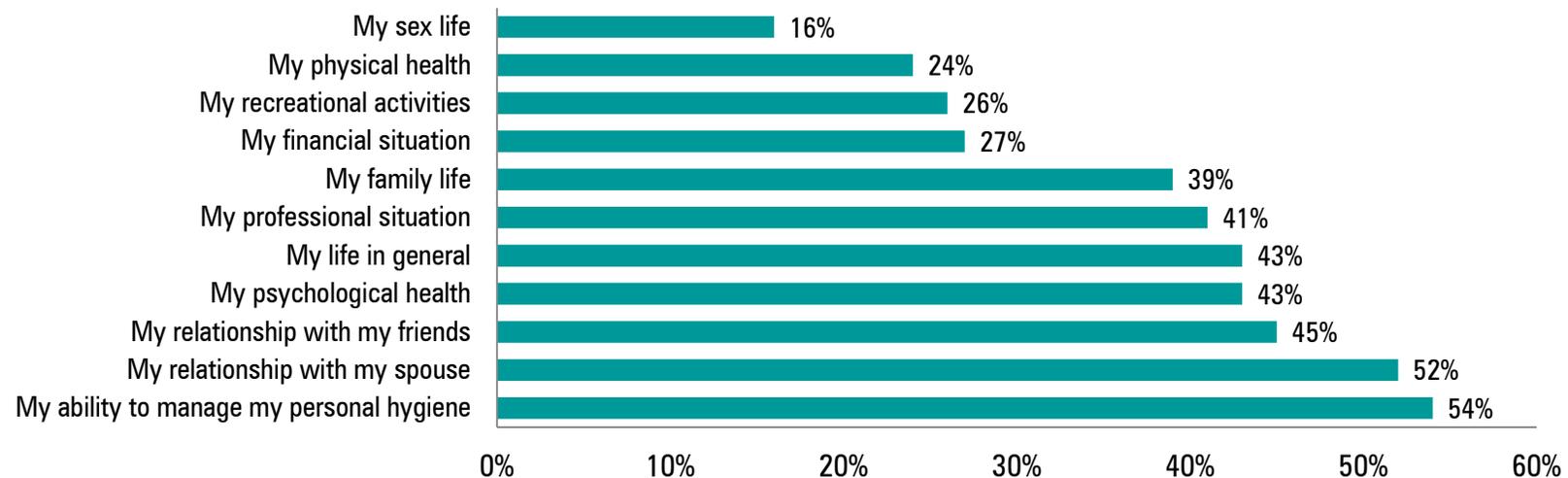
The following activities show the highest percentage of people who do not participate but want to, for all types of injury:

- *Participating in vacation and travel activities (27%)*
- *Achieving productive remunerated activities (25%) and non remunerated activities (18%)*
- *Maintaining a relationship with their spouse (21%)*
- *Preparing for a productive remunerated activity (19%)*

Quality of Life

Quality of life is determined by a series of statements about the satisfaction that you feel regarding different aspects of your life. The study measured your level of satisfaction (over the last 12 months) in relation to 11 categories.

PERCENTAGE OF RESPONDENTS REPORTING "SATISFIED" OR "VERY SATISFIED" IN RELATION TO 11 QUALITY OF LIFE CATEGORIES



According to the type of injury ...

- People with **paraplegia** and a **complete spinal cord injury** experience more satisfaction than people with other types of injuries regarding the following aspects: their *professional situation* and their *physical health*.
- People with **tetraplegia** and a **complete spinal cord injury** are more satisfied with their *psychological health*.

According to the number of years post-injury ...

- There is an improvement in time for satisfaction in relation to *sex life* for people with a non-traumatic spinal cord injury. Beyond 30 years, percentage of dissatisfied people goes from 53% to 34% and percentage of satisfied people goes from 13% to 21%.
- Finally, there is a gradual increase of satisfaction for life in general that seems to develop over time. Beyond 30 years, the percentage of dissatisfied people drops from 16% to 3% and the percentage of satisfied people increases from 37% to 50%.

Glossary

Accessible home/residence: A home/residence that has been adapted to improve access. Adaptations can include the widening of doorways, installation of ramps or transfer bars in the bathroom, etc.

Active life and recreational activities: Participating in programs that increases the quality of life of an individual. (e.g., physical fitness programs, nutrition workshops, yoga classes, participating in or attending leisure activities such as cooking or painting classes, music festivals or other cultural events, etc.).

Care/hygiene linked to intestinal elimination: Adjusting clothing before and after care, using the appropriate materials, maintaining personal hygiene.

Complete spinal cord injury: Absence of motor functions, no ability to move in the areas affected by the spinal cord injury. There may be some sensation in areas affected by the spinal cord injury.

Dressing: The act of putting on or adjusting all clothing or articles.

General healthcare services: Services that are not linked to the spinal cord injury and that require the help of a healthcare professional such as a general practitioner, a specialized community service nurse, etc.

Home care: Help in the home to perform daily activities such as personal hygiene, dressing, personal care, meal preparation, etc.

Incomplete spinal cord injury: Partial motricity and presence of limited movement in the areas affected by the spinal cord injury.

Joint contracture: Limitation of joint movement caused by the atrophy of the soft tissue surrounding the joint, such as the elbow or hip area. This happens when it is no longer possible to achieve complete movement. There is often presence of pain with this problem.

Long distance transportation: Traveling over long distances outside the community (to visit friends or family, for business trips, vacation) by using transportation methods such as the bus, planes, ferries, trains, ships, etc.

Maintaining physical fitness: Exercising (or taking part in similar activities) on a regular basis in order to maintain good health.

Meal preparation: Planning, assembling ingredients, cooking and placing utensils and food.

Neuropathic pain: Pain that is often permanent and intense, caused by affected nerves, occurs spontaneously or triggered by touch, and is characterized by a burning or tingling sensation.

Paraplegia: The injury affects your torso and legs.

Glossary

Peer support: Support offered by a person with a spinal cord injury who has received professional training to help others adapt to life with a disability.

Pressure ulcers: Skin lesions caused by constant pressure on the skin surface, reducing blood flow to this zone and causing tissue necrosis. Lesions appear as skin eruptions or redness and can become infected (also known as bedsores or decubitus acutus).

Productive, non-remunerated activities: Unpaid activities such as volunteer work.

Professional training: Training to prepare for a return to work. This can include a professional assessment, professional career counselling, training, job search, regular professional supervision, etc.

Recreational and social activities: Includes activities such as art, music, outings, informal or competitive sports.

Sexual dysfunction: Includes satisfaction with sexual function. Dissatisfaction can be due to reduced sensitivity, modified body image, difficulty with movement and intestinal and bladder problems, such as infections.

Shoulder problems: Includes joint and/or muscle pain in the shoulder area. People who over-use the shoulder muscle group, or who put too much pressure on their joints are prone to this type of pain.

Spasticity: Involuntary spontaneous and twitchy muscle movements such as muscle contractions or spasms. Spasticity often increases after an infection or due to restrictions such as a tight fitting shoe or belt.

Specialized equipment: Includes adapted equipment, medical supplies, communication systems and technical aides (e.g., wheelchairs, seats for the bathtub, environmental control systems, telephone number composition systems, voice-recognition software, recording or dictation devices for school or work, catheters and other similar supplies).

Taking care of family obligations: Includes activities such as parenting, educating children, caring for family members.

Taking care of financial obligations: Includes activities such as paying bills, expense budgeting, or using an automatic banking machine.

Tetraplegia: The injury affects your arms, hands, torso and legs.

Urinary incontinence: Uncontrollable urine loss.

Urinary tract infections: Includes infections such as cystitis and infections due to pseudomonas bacteria. Symptoms include painful urination, a burning sensation in the entire body, blood in the urine and cloudy urine.

Spinal Cord Injury Community Survey

c/o Rick Hansen Institute
Blusson Spinal Cord Centre
6400 - 818 West 10th Avenue
Vancouver BC V5Z 1M9 CANADA

t: 1 604 707 2100

f: 1 604 707 2121

e: studies@rickhanseninstitute.org

www.rickhanseninstitute.org

