SPINAL CORD INJURY COMMUNITY SURVEY Participants Report - Traumatic Injuries











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Traumatic Injuries

CAUSED BY AN ACCIDENT

(vehicle, fall, impact by an object, sports, violence) 1,137 people with a traumatic injury participated in the survey, just like you.

Demographics Who you are

22%

Reside in a city with

more than 100,000

inhabitants

56%

Live in an urban setting

22%

Live in a rural setting

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

MALE

71% of respondents

Average age: 49

60 yrs + 7%

21%

50-60 yrs

32%

18-30 yrs

30-40 yrs

16%

40-50 yrs

24%





Most participants are between 39 and 57 years of age.



25%

27%

24%

23%

0%



FEMALE

29% of respondents

Average age: 46

60 yrs+ 18-30 yrs

40-50 yrs

25%

14%

30-40 yrs

20%

17%

50-60 yrs

24%

Post-injury time is on average 18 years and for more than half of you, this period exceeds 16 years. More than 30 yrs 15 to 30 yrs



Traumatic

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 major secondary complications for people with a traumatic spinal cord injury.

- *Sexual dysfunction* is characterised by its high frequency and impact on activities.
- Pressure ulcers (two or + / last 12 months) are not among the most frequent complication (approximately one person in seven or 15%), but significantly limit activities for almost half of the respondents presenting this complication.

According to the type of injury ...

- *Pressure ulcers* are more frequent in people with a **complete spinal cord injury**.
- People with **tetraplegia** have more *spasticity* problems than those with paraplegia.

For some secondary complications (e.g., *sexual dysfunction*), there is **no link** between the type of injury and the frequency, percentages for both groups are similar.

Secondary Complications

Mood disorders and time since injury

Mood disorders (occasionally or frequently) are more commonly reported in the early years postinjury. They tend to diminish with time, suggesting better adjustment to the situation.



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

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

For the secondary complications presented in the graphs below, the percentage of people who are limited in their activities decreases with time.



NEUROPATHIC PAIN: LINK BETWEEN THE NUMBER OF

URINARY TRACT INFECTIONS: LINK BETWEEN THE NUMBER OF YEARS POST-INJURY AND LIMITATION OF ACTIVITIES



URINARY INCONTINENCE: LINK BETWEEN THE NUMBER OF YEARS POST-INJURY AND LIMITATION OF ACTIVITIES



Need for Services

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

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



According to the type of injury ...

- Needs for an *accessible home* and *adapted equipment* are more frequent when the **injury is complete**.
- People with tetraplegia have more need for home care and financial support.
- Short distance and long distance transportation needs tend to be less satisfied for people with **tetraplegia**. However, their needs in terms of home care are more highly satisfied.

Need for Services

Some needs are better satisfied through the years

For example, response to the need for *general healthcare services*, and for *peer support* improve as the number of post-injury years increases. It is the same for *professional training* but, in this case, the situation affects a lower number of people who are able to work.

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

Through the years, more people develop needs for *transportation*, *home accessibility* and *professional training*, whereas the need for *emotional support* decreases.



GENERAL HEALTHCARE NEEDS THROUGH THE YEARS



NEED FOR PEER SUPPORT THROUGH THE YEARS



Mostly satisfied and more.

NEED FOR PROFESSIONAL TRAINING THOUGH THE YEARS



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)

Paying job preparation activities Holiday and travel activities Productive remunerated activities Home-based activities Remaining healthy Taking care of financial obligations Personal hygiene Eating Communicating electronically



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 VARIOUS QUALITY OF LIFE CATEGORIES



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

For most of the measures, satisfaction increases with the years. Here are a few examples:



MY PSYCHOLOGICAL HEALTH IS SATISFYING

MY LIFE IN GENERAL IS SATISFYING OR VERY SATISFYING



According to the type of injury ...

The type of injury is not linked to satisfaction regarding different aspects of life, except for the two following measures:

- Personal hygiene management: For people with paraplegia, twice as many were satisfied by their ability to manage their personal hygiene compared to those with tetraplegia.
- Psychological health: there are slightly more people with tetraplegia and a complete injury who are satisfied with their psychological health than people with another type of injury.

MY PROFESSIONAL SITUATION IS SATISFYING OR VERY SATISFYING



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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 forfamily 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

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