

ORIGINAL REPORT

RESULTS FROM THE INTERNATIONAL SPINAL CORD INJURY COMMUNITY SURVEY: THE LIVED EXPERIENCE OF PEOPLE WITH SPINAL CORD INJURY IN SOUTH-EASTERN BRAZIL

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Objective: The incidence of spinal cord injury in Brazil is increasing. It is important to understand more about how individuals are living with spinal cord injury.

Design: Cross-sectional, observational study of individuals with spinal cord injury in south-eastern Brazil.

Subjects: A questionnaire with 125 questions was applied to individuals diagnosed with spinal cord injury. Participants were recruited by survey team from 2 rehabilitation centres (both in south-eastern Brazil) that treat persons diagnosed with SCI. Personal characteristics, associated health conditions, quality of life, work status, environmental factors, and other functioning-related aspects were evaluated.

Results: A total of 201 individuals participated in the survey. Of these, 79% were male, mean age 44 years, 60% were considered paraplegic, and the major causes of impairment were firearm injuries and road traffic accidents. Spasticity was the most frequently reported health condition, followed by neuropathic pain. 50% of subjects did not report any difficulty with participation in activities of daily living. However, only approximately 10% of subjects returned to work after spinal trauma. Their quality of life is reported 44% as good.

Conclusion: Most people with spinal cord injury in south-eastern Brazil are male and paraplegic, health problems and spasticity is considered their most problematic health condition. Although they report having a good quality of life, they still encounter disabling environmental barriers that make their life more difficult, such as poor accessibility of public spaces, and only a small proportion (10%) returned to work after their injury. This study provides an initial overview of the lived experience of people with spinal cord injury in south-eastern Brazil and should serve as a starting point for future research on this population.

Key words: spinal cord injury; spinal cord injury characteristics; work; functioning; health conditions.

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LAY ABSTRACT

The number of cases of spinal cord injury in Brazil is increasing. It is important to know more about how individuals are living with this condition. A questionnaire with 125 questions was applied to individuals diagnosed with spinal cord injury. Participants were recruited by survey team from 2 rehabilitation centres (both in south-eastern Brazil) that treat persons diagnosed with SCI. Personal characteristics, associated health conditions, quality of life, work status, environmental factors, and other functioning-related aspects were evaluated. A total of 201 individuals participated in the survey. Of these, 79% were male, and the major causes of impairment were firearm injuries and road traffic accidents. Fifty percent of individuals did not report any difficulty performing activities of daily living. Although people with spinal cord injury reported having a good quality of life, they still encounter disabling environmental barriers that make their life more difficult. This study provides an initial overview of the lived experience of people with spinal cord injury in south-eastern Brazil and should serve as a starting point for future research on this population.

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Spinal cord injury (SCI) is one of the most serious and devastating disabling events. SCI can result in severe motor, urinary, intestinal, and sexual dysfunction, among others, altering individuals' autonomy, quality of life, overall satisfaction and lifestyle, in addition to affecting their participation in society (1, 2).

Despite inconsistencies in data on the incidence and prevalence of SCI, some recent estimates indicate that 250,000–500,000 people are affected by SCI yearly (1–4).

According to Singh et al. (2), the country with the highest prevalence of persons with SCI is the USA (906 people per million), with SCI affecting mostly males,

and was due by injuries (road traffic accidents), followed by falls in the elderly population. This number has increased in recent years; in 1975 the prevalence of SCI was approximately 30 people per million in the USA (5). Better understanding of the prevalence of SCI enables healthcare systems to implement preventive strategies and allocate appropriate resources to manage the consequences of this condition.

According to Botelho et al. (6), the incidence of SCI in Brazil is 40 new cases per year per million inhabitants; approximately 6,000–8,000 new cases each year. Of these individuals, 80% are male, and 60% are in the age range 10–30 years (1, 7, 8).

In 2013, the International Perspectives on Spinal Cord Injury (IPSCI) report (3) summarized a large amount of evidence and indicated that persons with SCI had a higher risk of mortality and were at greater risk of developing physical and mental health conditions. In addition to the risk of premature mortality and morbidity, SCI has been associated with reduced participation in social and economic activities, resulting in higher social exclusion and unemployment rates compared with in the worldwide population.

The environmental barriers that hinder persons with SCI from participating fully in society and from maintaining an optimal standard of health contribute to this situation. Inadequate policy and service delivery, a lack of assistive products, inaccessible environments, negative attitudes towards people with disabilities and a lack of knowledge and skills among health professionals are examples of barriers that influence people's daily lives and, ultimately, their health and quality of life (3, 4, 9, 10).

Health status and functioning play an important role in allowing persons with SCI to participate in daily life and social activities in general. Recent studies of persons with SCI, such as the International Spinal Cord Injury (InSCI) Community Survey (9) and the Swiss Spinal Cord Injury Cohort (SwiSCI) (10), use the components of the International Classification of Functioning, Disability and Health and Disability (ICF) (11) as a reference to collect data on this condition and identify the most appropriate approaches to manage impairments in body structures and functions and limitations in activities and social participation, as well as the personal and environmental factors surrounding persons living with SCI for longer (12) or shorter periods (13).

The InSCI survey was developed to describe the lived experience of persons with SCI in the participating countries and, in particular, to collect data on the functioning, health and well-being of these individuals.

The incidence of SCI in Brazil is increasing and there is a need to understand more about how individuals are living with this condition. Although there are studies providing epidemiological data (6, 7) and on some functioning aspects (11–13), no study has observed the

issues reported by persons with SCI in relation to their lived experience after the injury in relation to health, accessibility barriers, quality of life, and work status. Therefore, the current study addresses issues that may contribute to setting new policies and practices, as well as providing evidence input for rehabilitation professionals treating persons with SCI. As such, the aim of this study is to provide data on persons with SCI, in south-eastern Brazil their personal characteristics, environmental factors, associated health conditions, quality of life, work status and other functioning-related aspects.

METHODS

This cross-sectional, observational study was approved by the Institutional Review Board of the University of Sao Paulo Medical School General Hospital, Sao Paulo, Brazil (registration number CAAE 97049118.8.0000.0068) in order to comply with the requirements of the Institutional Review Board, verbal consent was obtained from participants because there was the approval of the Institutional Review Board (IRB).

Participants were recruited from 2 rehabilitation centres that treat persons diagnosed with SCI; the Physical and Rehabilitation Medicine Institute (IMREA) of the University of Sao Paulo Medical School General Hospital and the Rio de Janeiro Rehabilitation Association (Portuguese acronym: AFR) in 2 neighbouring south-eastern states in Brazil: São Paulo and Rio de Janeiro, respectively.

At the Physical and Rehabilitation Medicine Institute (IMREA) of the University of Sao Paulo Medical School General Hospital, the survey team contacted every patient with SCI who had received care at any time during the 2 years (2017–2019) prior to the study. The sample of patients with SCI at the AFR was obtained for convenience. These subjects were those who were on treatment during the study period. All individuals were invited to take part and be interviewed to confirm if they met the eligibility criteria described below. All participants were able to be interviewed by phone or video call or to reach the evaluation site independently, and gave either written or verbal consent to participate in the study. The study team used a mixed approach towards questionnaire administration. When self-administration was not feasible, questionnaires were administered by an experienced member of the team via phone or video calls.

Survey participants

Study participants were of both sexes, aged 18 years and older, with a diagnosis of SCI and at least 3 months since injury onset, according to information published elsewhere (14). Persons with SCI resulting from congenital causes, spina bifida, neurodegenerative diseases

(such as multiple sclerosis and amyotrophic lateral sclerosis), peripheral nerve injuries, first-time rehabilitation inpatients and individuals in acute care were excluded.

Survey questionnaire

The questionnaire (International Spinal Cord Injury Survey) was prepared by the InSCI survey team (3) and translated (by 2 independent translators) into Portuguese from English, incorporating necessary cross-cultural adaptations the questionnaire was tested questionnaire with 10 participants prior to starting the study (14). (The questionnaire is available from: <https://www.revistas.usp.br/actafisiatrica/article/view/172051/162697>). The questionnaire comprises 125 questions and takes 25–40 min to complete. It aims to explore the lived experience of persons with SCI, based on 47 ICF components covering health conditions, psychosocial factors, injury characteristics (e.g. self-reported severity, cause and date of onset), quality of life, health and physical well-being. The InSCI questionnaire included questions from a range of measures, as described below.

Regarding quality of life and mental health, the questionnaire builds on the Short Form (SF)-36 survey (15) and the Spinal Cord Injury Secondary Conditions Scale (16). Activity and participation were assessed mainly by questions from the World Health Organization (WHO) Model Disability Survey (MDS) (17), the Spinal Cord Independence Measure (18) and the Spinal Cord Injury Functional Index (19).

The assessment of integration and health at work involves questions regarding the work environment and accessibility. Environmental factors were evaluated mainly with the Nottwil Environmental Factors Inventory Short Form (20).

Relevant personal factors were measured using the General Self-Efficacy Scale (21), the Moorong Self-Efficacy Scale (22), the General Belongingness Scale (23) and the MDS (17). In addition, the survey collected participants' basic sociodemographic data and socioeconomic characteristics.

Statistical analysis

This study uses descriptive analysis of the evaluated data, presenting its results using absolute values, percentages, means and standard deviations. Excel 2013 for Windows (Microsoft Corporation, Redmond, Washington) was used to organize data and generate analyses.

RESULTS

An initial total of 452 persons were recruited. Of these, 213 were excluded, because they did not meet the inclusion criteria listed above ($n=124$), they were

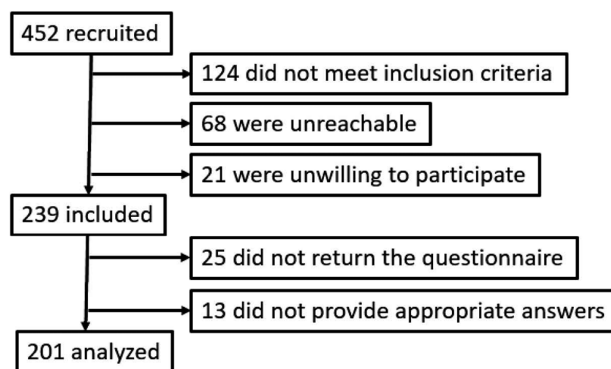


Fig. 1. Study flow.

not contactable ($n=68$), or they declined to participate ($n=21$). A total of 201 participants responded to the questionnaire and were included in the analyses. The remainder of study participants either ($n=38$) did not return the questionnaire ($n=25$) or did not provide appropriate answers ($n=13$) and were therefore excluded from the analysis.

Of the 201 participants included in the analyses, 79% were male, they had an mean age 44 ± 17 years, age range 18–63 years, and 87% were living with other persons (all adults between 18 and 63 years old) (Figure 1).

Regarding education, 39% of participants completed secondary education only, followed by 24% who had a higher education degree largest subgroup. With reference to household income, 29% of the sample was within the range of 3 to 5 minimum wages. Minimum wage is the minimum wage a worker should receive from his employer.

Regarding the characteristics of the injury, 80% of the sample had an incomplete SCI and 60% had an injury at the thoracolumbar level (paraplegia). There was wide variation in the time since injury (3 ± 143 months) and in the causes of injury (Fig. 2). Traumatic aetiologies, such as interpersonal violence (including gunshot wounds) and road traffic accidents, were the main group of causes (19%), followed by degenerative spinal conditions (35%).

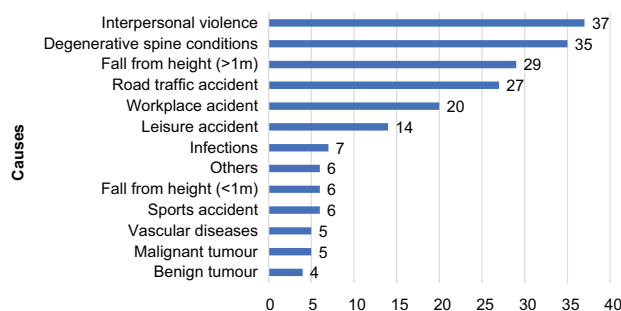


Fig. 2. Number of cause of injury ($n = 201$). The data is collected from International Spinal Cord Injury Survey.

Table I. Participants' perception of health conditions. The data is collected from International Spinal Cord Injury Survey

	1 n (%)	2 n (%)	3 n (%)	4 n (%)	5 n (%)
Sleep problems	125 (63)	12 (6)	33 (17)	15 (8)	14 (7)
Bowel dysfunction	105 (53)	15 (8)	33 (17)	21 (11)	24 (13)
Urinary tract infections	129 (65)	19 (10)	24 (12)	14 (7)	12 (6)
Bladder dysfunctional	145 (73)	16 (8)	15 (8)	8 (4)	13 (7)
Sexual dysfunction	110 (55)	8 (4)	30 (15)	19 (10)	32 (16)
Contractures	105 (53)	13 (7)	41 (21)	21 (11)	17 (9)
Muscular spasms (spasticity)	66 (33)	19 (10)	30 (15)	43 (22)	40 (20)
Pressure sores	170 (85)	9 (5)	12 (6)	5 (3)	2 (1)
Respiratory problems	185 (93)	3 (2)	7 (4)	3 (2)	1 (1)
Injury caused by loss of sensation	178 (89)	6 (3)	8 (4)	3 (2)	4 (2)
Circulatory problems	170 (85)	6 (4)	15 (7)	5 (2)	2 (3)
Autonomic dysreflexia	167 (86)	11 (3)	17 (8)	1 (3)	3 (1)
Postural hypotension	167 (84)	11 (6)	17 (9)	1 (1)	3 (2)
Pain	66 (33)	19 (10)	48 (24)	36 (18)	30 (15)

1. No problem; 5. Extreme problem.

Health conditions

Study participants considered spasticity their most problematic health condition (33%), followed by neuropathic pain (13%) (Table I). Participants' perception of health was good in 47% of the study population, reasonable in 26%, very good in 15%, very bad in 6% and excellent in 6%.

Activity and participation

Data on activities and participation in society are related to individuals' perception of social participation based on their personal choices and preferences. Approximately 50% of the study population reported not having any problem coping with activities of daily living and social roles, such as taking care of their health and interacting with others. However, 47% reported that it was very problematic to participate in many such activities (e.g. using public transport, helping others, and having sex).

Work

Seventy-seven percent of study participants reported being employed before injury onset. Only 16% of participants received vocational rehabilitation after the injury, while 84% did not receive any guidance or training to return to work. After rehabilitation, although 90% reported having never returned to

Table II. Participants' satisfaction with different aspects of quality of life. The data is collected from International Spinal Cord Injury Survey

	1 n (%)	2 n (%)	3 n (%)	4 n (%)	5 n (%)
Health	11 (5)	33 (16)	50 (25)	89 (45)	16 (9)
Ability to perform activities of daily living	15 (7)	43 (22)	36 (18)	94 (47)	11 (6)
Oneself	11 (5)	28 (14)	49 (25)	93 (47)	19 (9)
Personal relationships	5 (2)	11 (5)	36 (18)	122 (61)	25 (14)

1. Very dissatisfied; 2. Dissatisfied; 3. Neither satisfied nor dissatisfied; 4. Satisfied; 5. Very satisfied.

work after the SCI and 20% were unemployed before the SCI.

Quality of life and general health

Forty-four percent of study participants reported having a good quality of life, while it was neither good nor poor for 33%, very good for 11%, very poor for 6%, and poor for 5%. Table II shows the results regarding participants' satisfaction with several aspects of quality of life.

Environmental factors

The most relevant barriers that make the lives of people with SCI at least a little more difficult are the poor accessibility of public spaces and of means transportation for long distances, followed closely by the disabling barriers to accessing the homes of their friends and relatives and the lack of state services (Table III).

DISCUSSION

This study provides an evidence base regarding the lived experience of persons with SCI in south-eastern Brazil. By bringing together participants from 2 south-eastern states of Brazil, the study offers an overview of their living conditions, quality of life, and need for social support and healthcare services. A full understanding of the situation can only be obtained through participants' reports of the issues that are significant to them. Currently, ongoing InSCI surveys are collecting data in 28 countries worldwide (4).

The results suggest that there is a need for interventions and public policies designed to improve overall accessibility and social participation. More specifically, many participants reported difficulty finding appropriate healthcare services that could address their health conditions.

In the current study is not a surprise (6, 7), Canada (9), Finland (24) and Switzerland (25) the large predominance of male participants (close to 80%) in the current study is not a surprise. This situation is quite similar for the distribution of participants across age groups, showing a relatively young adult population.

The study population is also comparable to that of other communities surveyed Australia in terms of severity levels of injuries, with quadriplegic persons accounting for approximately 40% of the SCI population, as per incidence levels generated from hospital records (26).

Previous studies have covered different aspects of the community life of persons with SCI by focusing on a combination of services (27, 28). Such studies have identified unmet needs for both healthcare and social participation, including work and employment, sexual activity and pain management, which are also reported in the current study.

Table III. Environmental factors

	Made life a little harder, %	Made life a lot harder, %	Made life at least a little harder, %
Missing or insufficient accessibility of public places	40	21	61
Lack of or inadequate adapted means of transportation for long distances	33	25	58
Missing or insufficient accessibility to the homes of friends and relatives	39	17	56
Lack of or insufficient state services	27	29	56
Lack of or insufficient adapted assistive technology for moving around over short distances	35	18	53
Unfavourable climatic conditions	33	18	51
Lack of or insufficient medication and medical aids and supplies	26	24	50
Lack of or insufficient nursing care and support services	25	18	43
Lack of or insufficient communication devices	22	21	43

In Canada, according to Hansen (29), accessible transportation and infrastructure are priority needs for people with SCI living in the community. Similarly, in the current study persons living with SCI in south-eastern Brazil identify physical barriers as major disabling environmental factors.

SCI-related health issues might impact quality of life (30) and increase chances to develop long-term secondary health conditions (31), increasing the need for appropriate healthcare services. As such, pain is a relevant condition reported in the current study, as in previous studies (32–34).

The current results suggest that persons with SCI report good performance in carrying out activities of daily living. However, they also report difficulties due to the lack of support and lack of accessible or assistive technologies. Hammel et al. (35) suggest that people with physical disability wish to define their own performance parameters instead of fulfilling various social norms.

Returning to work, for example, is often difficult. This study shows that only 10% of participants returned to work, reinforcing the results of a review that found low employment rates among persons with SCI (36).

On the other hand, quality of life is measured in terms of satisfaction with social participation and general health (37). The current study indicates good levels of satisfaction among subjects with SCI, regarding health, activities of daily living and with themselves, which might be related to the rehabilitation outcomes of the study population. Hill et al. (38) reported that high levels of quality of life are synonymous with positive results of rehabilitation treatment.

Study limitations

This study is the first of its kind in a Brazilian context to analyse several aspects of the lived experience of persons with SCI. The study has a number of limitations.

First, the study population is restricted to participants from 2 well-resourced settings in south-eastern Brazil, which are not representative of the whole population. Secondly, some participants found it difficult to assess and express their perceptions of health, quality of life and disability, and to respond to survey questions. However, the study offers a wide evidence base on diverse topics. Finally, there are no questions specific to rehabilitation treatment of survey participants, which plays a decisive role in the health and participation in society of persons with SCI. However, this omission does not hinder the potential of the study to deliver on its objective.

CONCLUSION

This study was effective in creating a sound evidence base about the lived experience of persons with SCI in south-eastern Brazil. This is the first study to present detailed data regarding personal characteristics, associated health conditions, quality of life, work status, environmental factors, and other functioning-related aspects in this population. The data show that most of the survey respondents with SCI in south-eastern Brazil are male (79%) and paraplegic (60%), and they consider spasticity their most problematic health conditions (33%). Although the study subjects report having a good quality of life (44%), they still encounter disabling environmental barriers that make their life more difficult, such as poor accessibility of public spaces (61%) and means of transportation (58%), and only a small proportion (10%) return to work. This study provides an initial overview of the lived experience of people with SCI in south-eastern Brazil, based on self-reports of their health and socioeconomic conditions and functioning status. The results will serve as a starting point for future research on this population.

The authors have no conflicts of interest to declare.

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