International Perspectives on Spinal Cord Injury

World Health Organization

ISCOS
The International Spinal Cord Society

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Preface

The international symbol of disability is the wheelchair and the stereotype of a person with disability is a young man with paraplegia. While these images are very familiar, at the same time we know that this is not an accurate picture of the diversity of global disability. Whereas 15% of the population are affected by disability, less than 0.1% of the population have spinal cord injury.

However, spinal cord injury is particularly devastating, for two reasons. First, it often strikes out of the blue. A driver is tired and inebriated late at night, and veers off the road, resulting in a roll-over crash and consequent tetraplegia. The teenager dives into a pool, only to break her neck. A workman falls from scaffolding, and becomes paraplegic. An earthquake strikes and a person's back is injured by falling masonry. A middle aged woman is paralysed due to pressure from a tumour. In all these examples, someone in the prime of their life becomes disabled in an instant. None of us are immune from this risk.

Second, the consequences of SCI are commonly either premature mortality or at best social exclusion. Trauma care systems are frequently inadequate. For many, access to high quality rehabilitation and assistive devices is unavailable. Ongoing health care is lacking, which means that a person with spinal cord injury is likely to die within a few years from urinary tract infections or pressure sores. Even when individuals are lucky enough to receive the health and rehabilitation care they require, they are likely to be denied access to the education and employment which could enable them to regain their independence and make a contribution to their families and their society.

None of these devastating outcomes is necessary. The message of this report is that spinal cord injury is preventable; that spinal cord injury is survivable; and that spinal cord injury need not prevent good quality of life and full contribution to society. The report contains the best available scientific evidence about strategies to reduce the incidence of spinal cord injury, particularly from traumatic causes. The report also discusses how the health system can respond effectively to people who are injured. Finally, the report discusses how personal adjustment and relationships can be supported, how barriers in the environment can be removed, and how individuals with spinal cord injury can gain access to schools, universities and workplaces.

We can turn spinal cord injury from a threat into an opportunity. This has two dimensions. First, spinal cord injury challenges almost every aspect of the health system. So enabling health systems to react effectively to the challenge of spinal cord injury will mean that they can respond better to many other types of illness and injury. Second, a world which is hospitable to people with spinal cord injury in particular will inevitably be more inclusive

of disability in general. Improved accessibility and greater availability of assistive devices will help millions of the world's disabled and older people. And finally, of course, the word "opportunity" signals the better lives and the productive contribution to which people with spinal cord injury rightly aspire, and which we can help them to attain, if only we have the political will and the organizational commitment. As earlier with the *World report on disability*, so now with *International Perspectives on Spinal Cord Injury*, this report has potential to change lives and open doors. I urge the world's policy-makers to pay attention to its findings.

Dr Margaret Chan
Director-General

Summary

Spinal cord injury (SCI) is a medically complex and life-disrupting condition. SCI refers to damage to the spinal cord arising from trauma – such as car crash – or from non-traumatic disease or degeneration – such as tuberculosis (TB). SCI encompasses the baby born with spina bifida and the construction worker who falls from scaffolding. It includes the victim of conflict or gun violence, and the older person who develops SCI as a result of osteoporosis or a tumour.

SCI has costly consequences, both for individuals and society. People are left dependent, are excluded from school, and are less likely to be employed. Worst of all, they risk premature death. SCI is both a public health and human rights challenge. With the right policy responses, it is possible to live, thrive and contribute with SCI anywhere in the world. People with SCI are people with disabilities, and they are entitled to the same human rights and respect as all other people with disabilities. Once a person with SCI has had their immediate health needs met, social and environmental barriers are the main obstacles to successful functioning and inclusion in society. It is essential to ensure that health services, education, transport and employment are available and accessible to people with SCI, alongside other people with disabilities. SCI will always be life-changing, but it need not be a tragedy and it need not be a burden.

The aims of *International Perspectives on Spinal Cord Injury* are to:

- assemble and summarize information on SCI, in particular the epidemiology, services, interventions and policies that are relevant, together with the lived experience of people with SCI across the life course and throughout the world;
- make recommendations for actions based on this evidence that are consistent with the aspirations for inclusion and participation as expressed in the *Convention on the Rights of Persons with Disabilities*.

Key findings

1. Spinal cord injury is a significant public health issue

- ***The global incidence of SCI, both traumatic and non-traumatic, is likely to be between 40 and 80 cases per million population***. Based on the 2012 world population estimates, this means that every year between 250 000 and 500 000 people suffer a spinal cord injury (*1*). The incidence of traumatic SCI (TSCI) reported in country-level studies ranges from 13 per million to 53 per million. Historically, up to 90% of SCI has been traumatic in origin, but data from the most recent studies indicate a slight trend towards an increase in the share of non-traumatic SCI (NTSCI). Available studies report an incidence of NTSCI of 26 per million.
- ***No global estimates of SCI prevalence are available***. Data on SCI incidence and prevalence are inadequate and inconsistent. Even in developed countries, figures vary due to differences in case ascertainment and modelling methodology, as well as to real differences in epidemiology. TSCI prevalence figures range from 280 per million population in Finland (*2*) to 681 per million in Australia (*3*) to 1298 per million in Canada (*4*). NTSCI prevalence for adults and children in Australia is 367 per million (*5*) and in Canada 1227 per million (*4*). Overall combined TSCI and NTSCI prevalence for Canada in 2010 was 2525 per million population.
- ***Increasing prevalence of SCI in some countries.*** There is a trend towards increasing prevalence of SCI in high-income countries due to increases in survival rates, which have reached approximately 70% of general population life expectancy for tetraplegics and 88% for people with complete paraplegia (*6*). However, survival rates in low- and middle-income countries remain poor – as low as one to two years after injury in some settings – and this contributes to lower prevalence (*7*). Global ageing is likely to increase rates of NTSCI, and there is a slight trend for NTSCI to increase as a proportion of total SCI.
- ***Changing profile of victims.*** The SCI incidence rate peaks in young adulthood and, to a lesser extent, in old age. While young males dominate the statistics, the profile is changing to include more older people and more women. Overall, age at time of injury is increasing.
- ***Road traffic crashes, falls and violence are the main three causes of SCI.*** Road traffic injuries predominate in the African Region, accounting for nearly 70% of cases, and are a prominent underlying cause of SCI in other WHO regions as well, ranging between 40% in the South-East Asia Region and 55% in the Western Pacific Region. Falls, the second leading cause, account for just over 40% of all cases in the South-East Asia and Eastern Mediterranean Regions. The African Region reports the lowest percentage (14%) of falls, with the other WHO regions showing percentages between 27% and 36%. Rates of assault, including violence and self-harm, mostly from firearms, as a cause of SCI vary considerably across regions, the Americas, African and Eastern Mediterranean Regions reporting the highest percentages of 14%, 12% and

11%, respectively. Work-related accidents contribute to at least 15% of all TSCI cases. Across all regions, sport and leisure activities contribute less than 10% of all cases of TSCI. Attempted suicide has been shown to contribute to over 10% of TSCI cases in some countries. Tuberculosis may account for up to 20% of all NTSCI cases in some contexts.

- ***People with SCI die earlier.*** Studies have indicated that people with SCI are 2 to 5 times more likely to die prematurely than people without SCI. People with tetraplegia are at higher risk than people with paraplegia, and people with complete lesions are at higher risk than people with incomplete lesions. Mortality is particularly high in the first year after injury (*8*), and mortality rates are strongly affected by the capacity of the health-care system, especially emergency care. Studies on in-hospital average mortality rates in low-income countries are at least three times as high as those in the high-resource settings.
- ***In low-income countries, preventable secondary conditions remain the main causes of death for people with SCI*** (*9*). In high-income countries, the main causes of death for people with SCI have changed over recent decades (*10*, *11*), with urological complications in decline and the leading cause of death shifting to respiratory problems, pneumonia or influenza in particular. Heart disease, suicide and neurological problems are other associated causes of death.

2. Personal and social impacts of spinal cord injury are considerable

- ***SCI has a debilitating psychological impact***. 20–30% of people with SCI show clinically significant symptoms of depression, which is substantially higher than the general population (*12*), although the majority of people eventually adapt well to SCI.
- ***People with SCI have a narrower margin of health***, due partly to preventable complications such as urinary tract infections and pressure sores.
- ***SCI is associated with family breakdown, but also family resilience.*** Immediately after injury, SCI can have a negative impact on personal relationships and is associated with a higher rate of divorce. However, post-SCI relationships generally do better. Carers of children and young people with spina bifida or traumatic SCI typically experience isolation and stress.
- ***Lower participation in school.*** Children and young people with spina bifida or acquired SCI are less likely to attend school and less likely to participate in tertiary education. They face obstacles in the transition between school and tertiary education, and between education and employment.
- ***SCI is associated with lower rates of economic participation***. Average global employment rates for people with SCI are only 37%, with a high of 51% in Europe (*13*).
- ***Costs of SCI are higher than for comparable conditions*** such as dementia, multiple sclerosis, cerebral palsy and bipolar disorder. In Australia the lifetime costs (including the financial costs and burden-of-disease costs) were

estimated to be AUS$5 million for a person with paraplegia and AUS$9.5 million for a person with tetraplegia (*14*). Indirect costs, such as lost earnings, generally exceed direct costs.

3. Barriers to services and environments restrict participation and undermine quality of life

- ***Inadequate policy and provision***. Often appropriate policies and services are lacking in areas such as inclusive education, accessible environments and rehabilitation. For example in low- and middle- income countries, only 5–15% of people have the assistive devices that they need (*15*). In a Netherlands study, more than half of respondents with SCI were delayed leaving in-patient rehabilitation due to delays in obtaining wheelchairs (*16*).
- ***Lack of funding***. One Nigerian study, for instance, showed that for more than 40% of respondents with SCI, acute treatment costs represented over 50% of their annual income (*17*). Similarly, cost is one of the main barriers when it comes to assistive devices.
- ***Physical access barriers***. Homes, schools, workplaces and even hospitals are often inaccessible to people who use wheelchairs. Inaccessibility of transport is a major obstacle to participating in society, particularly for those who live in rural areas. This prevents people with SCI leaving hospital or nursing home and becoming independent.
- ***Negative attitudes***. It may be falsely perceived, for example, that tetraplegia is a fate worse than death, or that people in wheelchairs cannot work or cannot have intimate relations. Even family members may have negative attitudes and low expectations. Often, prejudice arises from lack of knowledge and lack of contact.
- ***Lack of knowledge***. Rehabilitation providers may lack knowledge and skills relevant to SCI. For example, lack of expertise among service providers can hinder people with SCI receiving appropriate assistive technologies. Primary care staff may not know about preventable complications in SCI, and diagnostic overshadowing can mean that people with SCI do not receive screening or treatment for their general health needs. More evidence is needed on what works, both in prevention and management of SCI.

4. Spinal cord injury is preventable

- ***Death and disability associated with road traffic crashes can be reduced*** through the safe systems approach, which highlights what can be done to improve road environments, vehicle safety and driver behaviour (*18*). For example the world's first compulsory seat-belt laws were introduced in Australia in 1970, and, in conjunction with government efforts to improve road design and regulations on car safety, there was a 4% p.a. drop in the annual incidence of SCI from road traffic crashes (*19*).

- ***Workplace codes on health and safety can reduce injuries*** caused in mining, construction and agriculture.
- ***Limiting access to guns and knives prevents injuries*** and reduces cost to society. Measures for limiting access include bans, licensing schemes, a minimum age for buyers, background checks and safe storage requirements. These measures have been successfully implemented in Austria, Brazil and some states in the USA.
- ***Injuries from sporting and leisure activities can be minimized*** through better design (e.g. of swimming pools, play equipment and ski runs), safety information (e.g. dangers of diving into shallow water, training of rugby coaches) and sports-wide awareness.
- ***Early detection and treatment can reduce the prevalence of spinal TB*** (*20*), as well as spinal tumours arising from cancer.
- ***Improved nutrition reduces the incidence of spina bifida and other neural tube defects*** (*21*). Voluntary periconceptional oral folate supplementation (three months before and after conception) has been shown to reduce the rate of infants being born with neural tube defects, including spina bifida (*22*, *23*). Many countries that have a policy of supplementation of wheat flour with folic acid have also seen a fall in the incidence of spina bifida (*24–27*).

5. Spinal cord injury is survivable

- ***Appropriate pre-hospital care is vital for immediate survival.*** Quick recognition, early evaluation and appropriate management of suspected SCI are required. Pre-hospital management in traumatic SCI requires: a rapid evaluation, including measurement of vital signs and level of consciousness; initiation of injury management, including stabilization of vital functions, immobilization of the spine to preserve neurological function until long-term spinal stability can be established, and control of bleeding, body temperature and pain; and prompt and safe access to the health-care system. People should ideally arrive in an acute care setting within two hours, which relies on adequate emergency and rescue services.
- ***Acute care ensures stabilization.*** Acute care may involve surgical intervention or conservative management, but accurate diagnosis of SCI and co-occurring conditions is the vital first step. Many factors should be taken into consideration to determine the most appropriate management approach, including level of injury, type of fracture, degree of instability, presence of neural compression, impact of other injuries, surgical timing, availability of resources such as expertise and appropriate medical and surgical facilities, and benefits and risks. In all cases, people with SCI and their family members should be given an informed choice between conservative and surgical management.
- ***Ongoing health care maintenance is required for survival and good quality of life.*** The individual can avoid or survive the complications of SCI, such as urinary tract infections and pressure ulcers, remain healthy and enjoy a long and full life with access to ongoing health care. People with SCI often have

a narrower margin of health, for example, a raised risk of chest infections and cardiovascular disease. Without access to basic health care, together with products such as catheters and appropriate cushions followed up by advice on healthy living, a person with SCI is more likely to die prematurely.

6. Spinal cord injury need not prevent good health and social inclusion

A person with SCI who has access to health care, personal assistance if required, and assistive devices should be able to return to study, live independently, make an economic contribution, and participate in family and community life.

- ***Once stabilized, there is a need for access to relevant acute and post-acute medical care and rehabilitation services***, to ensure that functioning is maximized and that the individual can become as independent as possible. There are different models of service delivery, but specialist centres have been shown to reduce costs, result in fewer complications, and result in fewer rehospitalizations, compared to nonspecialized services. People with SCI give high priority to achieving control of bladder and bowel functions. Therapy can enhance function in lower and upper limbs and teach techniques for achieving independence in everyday activities. Mental health services and advice are important: depression is associated with fewer improvements in functioning and increased rate of health complications. Information and support with sexual and reproductive health needs should also be part of rehabilitation.
- ***Appropriate assistive devices are a vital component of rehabilitation.*** For example, more than 90% of people with SCI require some form of wheelchair. These must be appropriate for the individual and for the setting. Other assistive technology needs include modifications in and around the home, environmental control, and sometimes communication systems for people with tetraplegia.
- ***Services should support return to education and employment.*** Self-help groups, accessible buildings and transport, vocational rehabilitation and antidiscrimination measures can ensure that children and adults can return to study, live independently, make an economic contribution and participate in family and community life.

Recommendations

1. Improve health sector response to spinal cord injury

This requires: building capacity of the health and rehabilitation workforce; strengthening prevention and early response services; ensuring that appropriate medical services and rehabilitation services are available and accessible; improving coordination to enhance effectiveness and save costs; extending health insurance coverage so that SCI does not lead to catastrophic health expenditure; and identifying strategies for the supply of appropriate assistive technology and health products.

2. Empower people with spinal cord injury and their families

People with SCI need information so that they can take responsibility for their own health care after discharge. Information should be shared with family members during rehabilitation. Support for family members and other caregivers can prevent stress and burnout.

In high-income countries, an independent living model of personal assistance can be empowering and cost-effective for people with SCI who have high support needs. Community-based rehabilitation (CBR) is important in low-income settings. In all settings, social networks, self-help groups and disabled people's organizations can promote empowerment and participation. Access to physical activities and sport can promote both physiological and psychological well-being.

3. Challenge negative attitudes to people with spinal cord injury

As part of general disability awareness campaigns, this can involve a range of interventions, including undergraduate education for doctors and other health professionals, classroom activities to reduce stigma, and awareness campaigns through media.

4. Ensure that buildings, transport and information are accessible

This requires: enforceable national access standards; teaching architects and designers about universal design; improving access to social housing; promoting "universally designed" bus rapid transport; mandating accessibility for private taxis; and using organizations of persons with disabilities to consult on accessibility and monitor progress.

5. Support employment and self-employment

Vocational training, flexible working, supported employment, and community-based rehabilitation projects with a focus on livelihood are all promising options for people with SCI returning to work. Social protection schemes should be

available, depending on the setting and the economic status of the individual, but should not act as a disincentive to return to work.

6. Promote appropriate research and data collection

There is a pressing need to both increase and improve routine data collection and research on SCI. Disaggregated statistics on SCI, using standardized ICECI terminology, can assist incident trend analysis and help in monitoring of policy responses. SCI registries, which compile data directly from hospitals, together with longitudinal population-based cohort studies covering major life areas, are the best ways of collecting SCI data. At service level, data are required on costs, outcomes and cost/benefits.

7. Implement recommendations

Implementing these recommendations requires the involvement of different ***sectors*** – health, education, social protection, labour, transport and housing – and different ***actors*** – governments, civil society organizations (including organizations of persons with disabilities), professionals, the private sector, and people with SCI and their families. Sectors and actors need to work together because multidisciplinary teamwork will maximize success. It is essential that countries tailor their actions to their specific contexts. Where countries are limited by resource constraints, some of the priority actions, particularly those requiring technical assistance and capacity-building, can be included within the framework of international cooperation.

Conclusion

While the incidence of traumatic and non-traumatic SCI can and should be reduced, there will always be new cases of SCI. SCI will continue to affect mainly individuals in the prime of life. Ensuring an adequate medical and rehabilitation response, followed by supportive services and accessible environments, will help minimize the disruption to people with SCI and their families. These measures will also reduce the overall costs to society, in terms of dependency and lost productivity, and to the individual, in terms of lower self-esteem and impaired quality of life. SCI is preventable, survivable and need not preclude good health and social inclusion. But action by governments and other stakeholders is urgently required. Without effective action, SCI will remain, all too often, a catastrophe.

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"Spinal cord injury need not be a death sentence. But this requires effective emergency response and proper rehabilitation services, which are currently not available to the majority of people in the world. Once we have ensured survival, then the next step is to promote the human rights of people with spinal cord injury, alongside other persons with disabilities. All this is as much about awareness as it is about resources. I welcome this important report, because it will contribute to improved understanding and therefore better practice."

SHUAIB CHALKEN, UN SPECIAL RAPPORTEUR ON DISABILITY

"Spina bifida is no obstacle to a full and useful life. I've been a Paralympic champion, a wife, a mother, a broadcaster and a member of the upper house of the British Parliament. It's taken grit and dedication, but I'm certainly not superhuman. All of this was only made possible because I could rely on good healthcare, inclusive education, appropriate wheelchairs, an accessible environment, and proper welfare benefits. I hope that policy-makers everywhere will read this report, understand how to tackle the challenge of spinal cord injury, and take the necessary actions."

TANNI GREY-THOMPSON, PARALYMPIC MEDALLIST AND MEMBER OF UK HOUSE OF LORDS

"Disability is not incapability, it is part of the marvelous diversity we are surrounded by. We need to understand that persons with disability do not want charity, but opportunities. Charity involves the presence of an inferior and a superior who, 'generously', gives what he does not need, while solidarity is given between equals, in a horizontal way among human beings who are different, but equal in their rights. We need to eliminate the barriers, construct a way to liberty: the liberty of being different. This is true inclusion."

LENÍN MORENO, FORMER VICE-PRESIDENT OF THE REPUBLIC OF ECUADOR

WHO/NMH/VIP/13.03