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REVIEW

Global maps of non-traumatic spinal cord injury epidemiology: towards a living data repository

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Study design: Literature review.
Objectives: Globally map non-traumatic spinal cord injury (NTSCI) incidence, prevalence, survival, level of injury and aetiology. Propose a research framework for NTSCI prevention and launch a repository of NTSCI data.
Setting: Initiative of the International Spinal Cord Society Prevention Committee.
Methods: Literature search of Medline and Embase (1959–June 2011). Relevant articles in any language regarding adults with NTSCI were included. Stratification of information about incidence and prevalence into green/yellow/orange/red data quality 'zones' and comparisons between World Health Organisation (WHO) regions and countries.
Results: Three hundred and seventy-seven abstracts reviewed—45 of these from 24 countries in 12 of the 21 WHO global regions had relevant information. Only one publication had survival data. Prevalence data for NTSCI existed for only two countries, India (prevalence of 2 310/million population, Kashmir region) and Canada (prevalence of 1 120/million population). The incidence rates for WHO regions were: Asia Pacific, high income 20/million population/year; Australasia (26/million population/year); Western Europe median of 6/million population/year; North America, high income median 76/million population/year (based on poor-quality studies); and Oceania 9/million population/year. Developed countries tended to have a higher proportion of cases with degenerative conditions and tumours. Developing countries, in comparison, tended to have a higher proportion of infections, particularly tuberculosis and HIV, although a number also reported tumours as a major cause.
Conclusions: Insufficient survival, prevalence and incidence data are a predominant finding of this review. The piecemeal approach to epidemiological reporting of NTSCI, particularly failing to include sound regional population denominators, has exhausted its utility. Minimum data collection standards are required.
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Keywords: non-traumatic spinal cord injury; spinal cord diseases; epidemiology; incidence; prevalence; aetiology

INTRODUCTION

It is well documented that damage to the spinal cord can arise from many causes other than trauma, often referred to as non-traumatic spinal cord injury (NTSCI).[1,2] Compared with traumatic spinal cord injury (TSCI), there are relatively few publications on NTSCI. It is anticipated that with the aging of the global population in coming decades the incidence of NTSCI will increase substantially.[3] Therefore, studies of the incidence, aetiology, prevalence and survival following NTSCI will be vital to assist in health-care service planning and delivery, and will facilitate the development of preventive strategies where these are possible.

The International Spinal Cord Society (ISCoS) Prevention Committee has presented information on TSCI using global maps to provide direction for international collaboration regarding TSCI injury prevention.[4] These enhanced mapping techniques are just as relevant for NTSCI. The project described here is part of a world-wide spinal cord injury (SCI) mapping project that is being undertaken by the Prevention Committee of ISCoS. The NTSCI subsection of the ISCoS Prevention Committee aims to:

1. Disseminate NTSCI data through global maps for Spinal Cord Injury epidemiology (http://iscos.org.uk/page.php?content=67).
2. Create partnerships within ISCoS to facilitate development of strategies for primary and secondary prevention of NTSCI.
3. As with the TSCI maps,[4] establish an electronic data repository accessible through the ISCoS website to enable conversion of key demographic information to an easily interpretable and updatable map of global trends in NTSCI.

It is intended that this work continues as an ongoing project that will be open to contributions of published and unpublished data to assist the ISCoS Prevention Committee and other organisations in the task of NTSCI prevention.

The primary aim of this project was to report the results of a comprehensive literature review and to compile global maps

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summarising the epidemiology of NTSCI, with a focus on the incidence, prevalence, level of injury, aetiology and survival. Secondary aims were: (a) to propose a research framework for health-care management strategies that could potentially prevent some types of NTSCI and improve NTSCI survival, and (b) to make suggestions for improving the epidemiological data collection and reporting of NTSCI studies.

MATERIALS AND METHODS

The literature searches of New and Sundararajan[3] and Wyndaele[5] were repeated without language restriction using search phrases (exploded): 'Epidemiology of spinal cord injury'; 'Prevalence of spinal cord injury'; 'Incidence of spinal cord injury'; 'nontraumatic'; 'non-traumatic'; and 'spinal cord damage' using the Medline and Embase databases as part of the global mapping project first described in Cripps *et al*.[4] In addition, the reference lists from articles identified in the literature search were reviewed to help identify other potentially relevant sources of information. The articles about NTSCI identified in New and Sundararajan[3] were also reviewed. All publications regarding adults from 1959 up to June 2011 were included. The personal libraries of the authors were also reviewed to identify additional potential publications. Publications covering paediatric NTSCI were excluded and will be the subject of a separate project.

The quality of information and level of national representation in the identified publications was appraised using a grading system to guide readers in interpreting the results and conclusions reached. Each paper's quality (Table 1) was graded as high (H), moderate (M) or low (L) using the methodology described by Lee *et al*.[6] in this issue. Where no incidence data were available, the most representative and best-quality studies covering the other epidemiological parameters were included, and the overall quality of the publication and how the information was collected was noted. The initial quality grading was performed by two of the authors independently (RAC and PWN). The results were compared and any conflicting assessments ($n=7$) were then reviewed by the third author (BBL), who made the final determination.

World Health Organisation (WHO) global regions were utilised to allow epidemiologically similar countries to be compared.[7] Maps using SCI incidence and aetiological data were developed for WHO global regions and countries within these regions using mapping and graphical techniques developed by Myriad Editions (http://www.myriadeditions.com/health). Data were divided into four broad zones of information quality (Box 1). The best ranked studies for each WHO region determined the colour coding used in the global map. Where possible, comparisons of incidence, prevalence, level of injury, aetiology and survival were planned between WHO regions and countries.

The classification of NTSCI has not been standardised until recently, when ISCoS and American Spinal Injury Association (ASIA) approved the International Non-traumatic Spinal Cord Injury Data Sets.[8] This present project used the classification of NTSCI from the NTSCI Data Sets at the first two levels, with some categories collapsed or omitted, as recommended, because of the absence or rarity of cases.[8] The use of the classification in these global maps is proof of concept of how aetiology data can be represented using the classification.

RESULTS

The abstracts of 377 publications were reviewed and 45 reports from 24 countries in 12 of the 21 WHO global regions were included with information on the incidence, prevalence, survival, level of injury and aetiology of NTSCI.[3,9–54] The country/region, observation period, data sources, handling of merged data and rating of quality are summarised in Table 1. Publications identified were primarily from peer-reviewed journals and a few governmental reports. Studies were prospective and retrospective and used data from spinal registries, population registries, hospital data (admission and discharge data) and health surveys.

No country had data that were graded green or yellow. Orange Zone data were only available for North America, high income (Canada), Australasia (Australia) and Western Europe (Denmark, Israel, Italy, Netherlands and Spain). Median values of country data were used for mapping WHO global regions and countries where there was more than one result.

Global incidence and aetiology of non-traumatic SCI

There was a paucity of quality population-based incidence data on NTSCI. The incidence, neurological level and aetiology of NTSCI by WHO region and year of publication are shown in Table 2. Global maps of NTSCI epidemiological outcomes (1959–2011) are presented by WHO global regions (Figure 1) and countries (Figure 2).

Asia pacific, high income

This WHO global region's profile is based on an epidemiological survey conducted in the Okayama Prefecture located in the western region of Honshu, Japan.[9] The incident rate of NTSCI was 20 per million population per year. A high rate of degenerative deformity of the spine (59%) was reported and accounted for 76% of the tetraplegic cases. Given the age profile of Japan, this is not unexpected. Tumours were also common in this group (19%).

Asia, south

Only Indian data were available for this WHO global region and was based on three studies, from Bangalore, Karnataka and Kashmir.[10,12,53] High rates of tuberculosis were reported in Bangalore (26%), Karnataka (25%) and Kashmir (38%). Tumours were surprisingly high in Bangalore (29%) and Karnataka (27%).

Australasia

Data for this WHO global region were only available from Australia. The incidence rate is consistent across a range of studies using different methodologies, and estimated to be around 26/million adults/year.[16] The most common causes were tumour, degenerative and vascular conditions.

Europe, western

In this WHO global region, data were available from eight countries (Denmark,[22] France,[23] Germany,[54] Israel,[25] Italy,[28] Netherlands,[31] Scotland[32] and Spain[33]). The median incidence rate of NTSCI for this region was 6 NTSCI per million population per year. High rates of tumours and degenerative conditions were reported (25% and 32% medians, respectively), quite likely influenced by the age profile of the Western European population. Spina bifida was reported as a cause of NTSCI in Spain, Italy (both 5%) and Denmark (2%). Myelitis was lower in Israel (7%) and higher in Denmark (14%) and Italy (23%).

North Africa/Middle East

Very few published articles were found for this WHO global region. Two retrospective studies from Turkey were located, from Ankara and Istanbul.[35,36] Spinal tumours and degenerative causes of NTSCI were the most commonly diagnosed conditions. Tumours and degenerative conditions were slightly higher in Ankara (29% for both causes) than in Istanbul (22% and 25%, respectively). Inflammatory conditions were common in Ankara (23%) and in Istanbul (20%). Six percentage of NTSCI cases reported in Istanbul were spina bifida.

North America, high income

In this WHO global region, an estimated Canadian NTSCI incidence rate of 68 NTSCI per million population per year was reported

Table 1 Summary of reference data sources

Ref. number	*Reference*	*Country/region*	*Observation period*	*Data source*	*Reasons for exclusion and handling of merged data*	*Rating of evidence**
9	Ide M, Ogata H, Tokuhiro A, Takechi H. Spinal Cord Injuries in Okayama Prefecture: An epidemiological Study '88-'89. *J UOEH* 1993; **15**(3): 209-215.	Japan/Okayama	1988–1989	Retrospective review of registration lists of patients contained in the Law for the Welfare of the Physically disabled	Only data available	M
10	Nair K, Taly A, Maheshwarappa B, Kumar J, Murali T, Rao S. Nontraumatic spinal cord lesions: a prospective study of medical complications during in-patient rehabilitation. *Spinal Cord* 2005; **43**(9): 558-564.	India/Bangalore	1995–1999	Prospective descriptive study of consecutive patient admissions to a rehabilitation unit of a Tertiary Care University Hospital for Neurology, Neurosurgery and Psychiatry in South India	Include: large sample, regional	L
11	Agarwal P, Upadhyay P, Raja K. A demographic profile of traumatic and non-traumatic spinal injury cases: a hospital-based study from India. *Spinal Cord* 2007; **45**(9): 597-602.	India/Karnataka	2003–2004	Retrospective descriptive study using data of patients admitted to Tertiary Referral Medical Centre	Exclude: poor aetiology data, few cases	L
12	Gupta A, Taly AB, Srivastava A, Murali T. Non-traumatic spinal cord lesions: epidemiology, complications, neurological and functional outcome of rehabilitation. *Spinal Cord* 2009; **47**(4): 307-311.	India/Karnataka	2005–2008	Prospective cross-sectional study of patients admitted to a Neurological Rehabilitation Unit of a Tertiary Research Hospital	Include: latest data, regional	L
13	Bhaskar P, Arjundas G, Ramamurthi B. Acute non-traumatic paraplegia. *J Ass Physician India* 1972; **20:** 687-691.	India/Madras	1950–1970	Retrospective review of patients admitted to General Hospital, Madras	Include: regional	L
14	Silva JF. Some experiences with non-traumatic paraplegia in Malaysia. *Paraplegia* 1973; **11:** 146-158.	Malaysia	1967–1971	Retrospective study based on admissions to the University Hospital, Kuala Lumpur	Include: Only one ref for Malaysia	L
15	New PW. Non-traumatic spinal cord injury: what is the ideal setting for rehabilitation? *Aust Health Rev* 2006; **30**(3): 353-61.	Australia	2004–2005	Postal and email survey	Exclude: no aetiology data	L
16	New PW, Simmonds F, Stevermuer T. A population-based study comparing traumatic spinal cord injury and non-traumatic spinal cord injury using a national rehabilitation database. Spinal Cord 2011; **49**(3): 397-403.	Australia	2002–2006	Retrospective review of patient admission records in the Australasian Rehabilitation Outcomes Centre's database	Exclude: no aetiology data	H
3	New PW, Sundararajan V. Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review. *Spinal Cord* 2008; **46**(6): 406-411.	Australia/Victoria	2000–2006	Retrospective study of patients admitted to a state-wide, population-based, health-administration database of hospital admissions	Include: incidence data	H
17	New PW, Rawicki HB, Bailey MJ. Nontraumatic spinal cord injury: Demographic characteristics and complications. *Arch Phys Med Rehabil* 2002; **83:** 996-1001.	Australia/Victoria	1995–1997	Retrospective, 3-year, case series of consecutive sample of adult referred inpatients with NTSCI	Include: Regional data	L
18	New P. Functional Outcomes and Disability After Nontraumatic Spinal Cord Injury Rehabilitation: Results From a Retrospective Study. *Arch Phys Med Rehabil* 2005; **86**(Feb): 250-261.	Australia/Victoria	N/R	Retrospective study of patients admitted to a state-wide, population-based, health-administration database of hospital admissions	Include: Regional data	L
19	Burke DC, Burley HT, Ungar GH. Data on spinal injuries - Part 1. Collection and analysis of 352 consecutive admissions. *Aust NZ J Surg* 1985; **55:** 3-12.	Australia/Victoria	1978–1982	Prospective study. Used consecutive admissions	Exclude: old data	L
20	Penington GR. Management of non-traumatic paraplegia. *Medical Journal of Australia* 1986; **144**: 364-365.	Australia/Victoria	N/R	Retrospective study of patients admitted to a state rehabilitation and extended care hospital	Exclude: old data	L
21	Cheshire DJE. *The Complete and Centralized Treatment of Paraplegia: A Report on the Spinal Injuries Centre for Victoria, Australia.* National Institute for Neurological Diseases Workshop: Melbourne, Victoria, 1966.	Australia/Victoria	1959–1966	Retrospective study	Exclude: old data	L
22	Biering-Sorensen F, Pedersen V, Clausen S. Epidemiology of Spinal Cord Lesions in Denmark. *Paraplegia* 1990; **28:** 105-108.	Denmark/Greenland/Faroe Islands	1975–1984	Retrospective study on records of all patients with SCI admitted to rehabilitation hospital in Hornbaek	Include	M

Table 1 (Continued)

Ref. number	*Reference*	*Country/region*	*Observation period*	*Data source*	*Reasons for exclusion and handling of merged data*	*Rating of evidence**
23	Minaire P, Castanier M, Girard R, Berard E, Deidier C, Bourret J. Epidemiology of spinal cord injury in the Rhone-Alpes Region, France, 1970-75. *Paraplegia* 1978-79; **16:** 76-87.	France/Rhone-Alpes region	1970–1975	Retrospective study at Henry Gabrielle Hospital	Exclude: No aetiological data	L
24	Exner G, Meinecke F-W. Trends in the treatment of patients with spinal cord lesions seen within a period of 20 years in German centers. *Spinal Cord* 1997; **35:** 415-419.	Germany	1976–1981	Retrospective study of records from all SCI Centres in Germany	Exclude: Poor aetiological data	M
25	Ronen J, Goldin D, Bluvshtein V, Fishel B, Gelernter I, Catz A. Survival after nontraumatic spinal cord lesions in Israel. *Arch Phys Med Rehabil* 2004; **85**(September): 1499-1502.	Israel	1962–2000	Retrospective cohort study of patients admitted to the Loewenstein Rehabilitation Hospital	Include	M
26	Catz A, Goldin D, Fishel B, Ronen J, Bluvshtein V, Gelernter I. Recovery of neurologic function following nontraumatic spinal cord lesions in Israel. *Spine* 2004; **29**(20): 2278-2282.	Israel	1962–2000	Retrospective cohort study of patients admitted to the Loewenstein Rehabilitation Hospital	Include	M
27	Citterio A, Franceschini M, Spizzichino L, Reggio A, Rossi B, Stampacchia G. Nontraumatic spinal cord injury: An Italian survey 1. *Arch Phys Med Rehabil* 2004; **85**(9): 1483-1487.	Italy	1997–1999	Multicentre prospective study	Include	M
28	Caldana L, Lucca L. Epidemiological remarks on traumatic spinal cord injuries and non-traumatic spinal cord diseases in Veneto 1994–1995. *Eur Med Phys* 1998; **34:** 159-168.	Italy/Veneto	1994–1995	Prospective study	Include	L
29	Celani MG, Spizzichino L, Ricci S, Zampolini M, Franceschini M. Spinal Cord Injury in Italy: A Multicenter Retrospective Study. *Arch Phys Med Rehabil* 2001; **82**(May): 589-596.	Italy/Seven rehabiliation centres	1989–1994	Multicentre retrospective study of SCI patients admitted to rehabilitation centres	Exclude: regional data	M
30	Scivoletto G, Farchi S, Laurenza L, Molinari M. Traumatic and non-traumatic spinal cord lesions: an Italian comparison of neurological and functional outcomes. *Spinal Cord* 2011; **49**(3): 391-396.	Italy	1996–2004	Retrospective study based on SCI admissions to a spinal cord unit in a rehabilitation hospital	Exclude: regional data	L
31	Schonherr MC, Groothoff JW, Mulder GA, Eisma WH. Rehabilitation of patients with spinal cord lesions in the Netherlands: an epidemiological study. *Spinal Cord* 1996; **34:** 679-683.	Netherlands	1982–1993	Retrospective study based on SCI admissions to the rehabilitation centre Beatrixoord	Include	L
32	Buchan AC, Fulford GE, Harris P, Jellinek E, Kerr WG, Kirkland I *et al*. A preliminary survey of the incidence and aetiology of spinal paralysis. *Paraplegia* 1972; **10:** 23-28.	Scotland/SE and W	1968	Prospective study	Exclude: regional data	L
33	Garcia-Reneses J, Herruzo-Cabrera R, Martinez-Moreno M. Epidemiological study of spinal cord injury in Spain 1984-1985. *Paraplegia* 1991; **29:** 180-190.	Spain	1984–1985	Prospective study of admitted SCI patients to specialised centres	Include	M
34	Al-Jadid MS, Asirvatham RA. An analysis of the length of stay in traumatic and non-traumatic spinal cord injured patients. *Saudi Med J* 2010; **31**(5): 555-559.	Saudi Arabia	2005–2008	Retrospective study of all patients who completed the SCI rehabilitation programme at Sultan Bin Abdulaziz Humanitarian City, Riyadh	Exclude: no data	L
35	Ones K, Yilmaz E, Beydogan A, Gultekin O, Caglar N, Ones K *et al*. Comparison of functional results in non-traumatic and traumatic spinal cord injury. *Disabil Rehabil* 2007; **29**(15): 1185-91.	Turkey/Istanbul	2002–2005	Retrospective study of patients admitted to a Physical-Medicine and Rehabilitation Training and Research Centre	Include: Regional data	L
36	Cosar S, Yemisci O, Oztop P, Cetin N, Sarifakioglu B, Yalbuzdag S *et al*. Demographic characteristics after traumatic and non-traumatic spinal cord injury: a retrospective comparison study. *Spinal Cord* 2010; **48**(12): 862-866.	Turkey/Ankara	1996–2008	Retrospective, 12-year case series of patients accepted to an in-patient rehabilitation programme at the rehabilitation unit of a Tertiary Research Hospital	Include: Regional data	L

Table 1 (Continued)

Ref. number	*Reference*	*Country/region*	*Observation period*	*Data source*	*Reasons for exclusion and handling of merged data*	*Rating of evidence**
37	Farry A, Baxter D. *The Incidence and Prevalence of Spinal Cord Injury in Canada: Overview and estimates based on current evidence*. Rick Hansen Institute and Urban Futures Institute, December 2010.	Canada	2010	Rick Hansen Institute estimates based on modelling data from other publications	Include	M
38	Guilcher SJ, Munce SE, Couris CM, Fung K, Craven BC, Verrier M *et al*. Health care utilisation in non-traumatic and traumatic spinal cord injury: a population-based study. *Spinal Cord* 2010; **48**(1): 45-50.	Canada/Ontario	2003–2006	Retrospective cohort design	Exclude: no data	M
39	Loblaw DA, Laperriere NJ, Mackillop WJ. A Population-based Study of Malignant Spinal Cord Compression in Ontario. *Clinical Oncology* 2003; **15:** 211-217.	Canada/Ontario	1990–1995	Population-based cohort study	Exclude: no data	M
40	McKinley WO, Seel R, Hardman J. Non traumatic spinal cord injury: incidence, epidemiology, and functional outcome. *Arch Phys Med Rehabil* 1999; **80:** 619-623.	USA		Five-year prospective study of consecutive patients with SC1 who were admitted over a 5-year period to the rehabilitation medicine unit at a Level I tertiary trauma centre. The centre is a regional participant in the National Spinal Cord Injury Model Systems programme	Include: Aetiological data	L
41	Kurtzke JF. Epidemiology of Spinal Cord Injury. *Experimental Neurology* 1975; **48**(3, Part 2): 163-236.	USA	1971	Health Interview Survey	Exclude: minimal aetiological data	L
42	Murray PK, Kusior MF. Epidemiology of nontraumatic and traumatic spinal cord injury. *Arch Phys Med Rehabil* 1984; **65:** 634.	USA/New York		Retrospective review	Exclude: minimal aetiological data	L
43	Maharaj JC. Epidemiology of spinal cord paralysis in Fiji: 1985-1994. *Spinal Cord* 1996; **34**(9): 549-59.	Fiji	1985–1994	Restrospective study using medical rehabilitation hospital data	Include	L
44	Zenebe G. Myelopathies in Ethiopia. *East African Medical Journal* 1995; **72**(1): 42-45.	Ethiopia	1990–1993	Retrospective study based on admissions to the Tikur Anbessa Teaching Hospital	Include: Aetiological data	L
45	Zenebe G, Oli K, Tekle-Haimanot R. Paraplegia at the Tikur Anbessa Teaching Hospital: a seven year retrospective study of 164 cases. *Ethiop Med J*. 1995; **33**(1): 7-13.	Ethiopia	1990–1993	Retrospective study based on admissions to the Tikur Anbessa Teaching Hospital	Include: Aetiological data	L
46	Ojiambo HP. Neurological disease at Kenyatta National Hospital, Nairobi. *East Afr Med J*. 1966; **43**(9): 366-376.	Kenya	1965	Retrospective study based on a study of neurological disease seen in a unit at Kenyatta National Hospital, Nairobi	Include: Aetiological data	L
47	Brown KGE. Non-traumatic paraplegia in sub-saharan Africa. *East African Medical Journal* 1979; **56**(7): 300-310.	Malawi/Blantyre	1972–1975	Prospective study	Include: Aetiological data	L
48	Parry O, Bhebhe E, Levy LF. Non-traumatic paraplegia in a Zimbabwean population–a retrospective survey. *Cent Afr J Med*. 1999; **45**(5): 114-119.	Zimbabwe	1989–1994	Retrospective survey of NTSCI patients who were rehabilitated at the National Rehabilitation Centre, Ruwa	Include: Aetiological data	L
49	Nyame P. An aetiological survey of paraplegia in Accra. *East Afr Med J*. 1994; **71**(8): 527-530.	Ghana/Accra	1991–1994	Prospective study of all patients admitted to hospitals in Accra	Include: Aetiological data	L
50	Ogunniyi A, Shokunbi M, Oluwole O, Adeyinka A, Malomo A, Adebiyi A. Non-traumatic spinal cord diseases in Ibadan, Nigeria: aetiology and prognostic factors. *Cent Afr J Med*. 1995; **41**(2): 50-54.	Nigeria/Ibadan	1988–1993	Retrospective review of patient records	Include: Aetiological data	L
51	Odeku LE, Adeloye A, Osuntokun BO. Non-tuberculous intraspinal canal masses in Ibadan. *Afr J Med Sci* 1971; **2:** 37-48.	Nigeria/Ibadan	1971	Retrospective review of patient records	Exclude: Poor aetiological data	L
52	Osuntokun BO. The pattern of neurological illness in tropical Africa: Experience at Ibadan, Nigeria. *J neurol Sci* 1970; **12:** 417-442.	Nigeria/Ibadan	1957–1969	Retrospective review of patient records	Include: Aetiological data	L

Abbreviations: H, high; L, low; M, moderate; N/R, not reported; NTSCI, non-traumatic spinal cord injury; SCI, spinal cord injury.
*High: Green/Yellow zone data and nationally representative data; Moderate: Green/Yellow zone data and not nationally representative data or Orange zone data (national data through adjusted regression techniques) or Red zone data and nationally representative data; low: other Red Zone data (See Box 1).

Box 1 Zones of Information*

Green zone: used a prospective spinal cord injury registry (PSCIR) or population health registry (including population registries linked or able to be linked to health and/or mortality data).
Yellow zone: partial coverage of region or country by PSCIR or population health registry.
Orange zone: Extrapolated data (not directly collected through a formal registry but derived from multiple sources with documented assumptions). Dependent on the assumptions and methods used, caution needs to be made in interpreting this data.
Red zone: no PSCIR or population health registry data. Available information is considered to be of insufficient quality to make between global region or country comparisons on the basis of incidence.

*Incidence data are rated on NTSCI map 1 using these colours.

by the Rick Hansen Institute in 2010, with this being calculated by population modelling and extrapolation techniques.[37] No aetiological causes of NTSCI were reported in this publication. For the United States, only two reports on incidence were identified—a health survey conducted by the National Centre for Health Statistics in 1971[41] and an abstract of a study conducted in New York.[42] These rates were 80 and 52 NTSCI per million population per year, respectively. A 5-year prospective study in a Level 1 trauma centre of a Regional SCI Model System[40] indicated that proportionally spinal stenosis and tumours were common (54% and 26%, respectively) and myelitis was low (5%).

Oceania

One Fijian study was available for this WHO global region.[43] The incident rate was 9 NTSCI per million population per year. Tumour-related NTSCI was low (9%) and the most frequent cause was infection and the unknown categories (32% and 52%, respectively).

Sub-Saharan Africa, East

In this WHO global region, published information was available for Ethiopia,[44,45] Kenya[46] and Malawi.[47] Tuberculosis was a major cause of NTSCI in all of these countries. Tuberculosis was highest in Kenya and Malawi (33% in both countries) and lower in Ethiopia (20 and 27%). HIV-related NTSCI was common in Ethiopia (17%). HIV was not reported for Kenya or Malawi as these papers were published before the emergence of HIV. Tumour-related NTSCI cases were highest in Kenya (33%), Malawi (25%) and Ethiopia (22%). Myelitis was low in Ethiopia (4%) and Malawi (7%).

Sub-Saharan Africa, Southern

Zimbabwean data were the only data available for this WHO global region.[48] Tumours and tuberculosis-related NTSCI cases were high (28% and 27%, respectively). Transverse myelopathy accounted for 11% of the NTSCI cases.

Sub-Saharan Africa, West

Ghanan and Nigeria data were available for this WHO global region.[49–52] Tuberculosis-related NTSCI was relatively common in both Ghana and Nigeria (30% and 25%, respectively). The proportion of neoplastic NTSCI and myelitis was similar in both countries (about 15% and 12%, respectively).

Global prevalence of non-traumatic SCI

Prevalence data for NTSCI were located for only two countries, India and Canada. Indian prevalence data of 2 310 NTSCI per million population were from the region of Kashmir,[53] and not national prevalence. The Canadian result of 1 120/million population is Orange Zone quality extrapolated from other studies; however, this was the only available national estimate.[37] The lack of additional studies of NTSCI prevalence limits the usefulness of these statistics for this report. They remain, however, the only currently available estimates (Table 3).

Global survival of NTSCI

Survival data for people with NTSCI are extremely limited, with only one study identified.[25] An Israeli study of 1085 patients with NTSCI admitted between 1962 and 2000 reported a median survival of 24 years. Survival was significantly affected by aetiology of lesion, age, gender, severity of lesion, decade of lesion onset and was generally shorter with higher-level lesions. The cumulative mortality was 0.6% at the first year, 6% at 5 years and 16% after 10 years. The mortality risk for patients with disk protrusion, spinal stenosis and benign tumours (majority of tumours) was lower than for patients with myelitis or multiple sclerosis.[25]

DISCUSSION

There tended to be more reports of better quality from high-income countries compared with medium- and low-income countries. Regarding aetiology, there were clear trends apparent from the available information. Developed countries tended to have a higher proportion of cases with degenerative conditions and tumours causing NTSCI. Developing countries, in comparison, tended to have a higher proportion of infections, particularly tuberculosis and HIV, although it was interesting that a number also reported tumours as a major cause. Irrespective of setting (country or WHO region), NTSCI is much more likely to cause paraplegia. The incidence varied widely across the WHO global regions, and the extremely limited data on prevalence and survival prevented comparisons.

One interesting finding was that given Western Europe has an aged population, the incidence of NTSCI reported was very low compared with other developed regions. We cannot explain this low incidence, and its veracity will be tested by improved regional data reporting standards.

There are poorer-quality epidemiological data on NTSCI than there are for TSCI. One reason for this may be that many spinal registries only include TSCI or have very poor capture of NTSCI. Therefore, data based on these registries underestimate NTSCI. Furthermore, many traditional Spinal Cord Injury Units or Rehabilitation Centres have been established with a TSCI focus and often exclude NTSCI, or subgroups with these disorders. Despite the higher incidence of NTSCI compared with TSCI in some regions,[3,37] there is a reported bias against NTSCI patients being able to access specialist SCI rehabilitation services.[15] We believe that this selection bias increases the likelihood of poor-quality data collection regarding these patients because NTSCI patients managed in non-specialist units are less likely to be reported to SCI registries, and if they are, the staff may not have the necessary skills or expertise (for example, AIS grading) to do this accurately. Most clinicians are probably aware of the need for regional SCI statistics. Given the paucity of quality data on NTSCI, it is very likely that clinicians lack the systems and financial resources to undertake the required data collection. Failure to refer patients with NTSCI to a specialised centre, or lack of resources in the specialised centres to accept referrals, makes this task more difficult unless

Table 2 Incidence, neurological level and aetiology of non-traumatic spinal cord injury by region and author(s) of published data

Region	*Country*	*Author(s) of published data*	*Observation period*	*Incidence per million population per year (n = sample size; males; females)*	*Neurological level of injury*		*Cause of SCI*
					Tetraplegia (%)	*Paraplegia (%)*	
Asia Pacific, high income							
	Japan (Okayama Prefecture)	Ide[9]	1988–1989	20 ($n=37$; males, $n=25$, females, $n=12$)	68	32	Degenerative deformity of spine (59%, $n=22$), tumours (19%, $n=7$) and other non-traumas (22%, $n=8$).
Asia, South							
	India (Karnataka)	Gupta[12]	June 2005–January 2008	N/R ($n=64$; males, $n=28$, females, $n=36$)	33	67	Spinal tumours (27%, $n=17$), Pott's spine (25%, $n=16$), transverse myelitis (22%, $n=14$), ossification posterior longitudinal ligament (11%, $n=7$), demyelination (6%, $n=4$), spinal arachnoiditis (3%, $n=2$), prolapsed intervertebral disc (3%, $n=2$), ischaemic myelopathy (2%, n = 1) and organophosphorus poisoning-induced myelopathy (2%, $n=1$).
	India (Karnataka)	Agarwal[11]	2003–2004	N/R ($n=26$; males, $n=11$, females, $n=15$)	55	45	Cranio-vertebral anomalies, rheumatoid arthritis and systemic diseases
	India (Bangalore)	Nair[10]	1995–1999	N/R ($n=297$; males, $n=154$, females, $n=143$)	22	78	Tuberculosis of spine (15%, $n=44$), tuberculosis with spinal arachnoiditis (11%, $n=33$), tumours (29%, $n=85$), acute transverse myelitis (34%, $n=101$), degenerative diseases of spine (6%, $n=17$), multiple sclerosis (5%, $n=14$) and spinal cord infarction (1%, $n=3$).
	India (Madras)	Bhaskar[13]	1950–1970	N/R ($n=97$; males, $n=71$, females, $n=26$)		100	Tuberculosis (22%, $n=21$), transverse myelitis (12%, $n=12$), spinal tumour (25%, $n=24$), Guillain–Barre syndrome (10%, $n=10$), spinal syphilis (9%, $n=9$), spinal abscess (3%, $n=3$) and other causes (19%, $n=18$).
Asia, South East							
	Malaysia	Silva[14]	1967–1971	N/R ($n=141$; males, $n=89$, females, $n=52$)			Hansen's disease (30%, $n=42$), poliomyelitis (26%, $n=37$), Pott's paraplegia (16%, $n=22$), cerebral palsy (14%, $n=20$), spinal tumour (9%, $n=13$) and spina bifida (5%, $n=7$).
Australasia							
	Australia	New[15]	2004–2005	26 ($n=414$)	N/R	N/R	N/R
	Australia	New[16]	2002–2006	N/R ($n=2,246$; males, $n=1176$, females, $n=976$)	31	69	N/R
	Australia (Victoria)	New[3]	1 July 2000–30 June 2006	26 (Based on ages $\geqslant 15$ years; $n=631$; males, $n=356$, females, $n=275$)	N/R	N/R	N/R
	Australia (Victoria)	New[17]	1995–1997	N/R ($n=134$; males, $n=56$, females, $n=78$)	33	67	Tumour (20%, $n=27$), degenerative (18%, $n=24$), vascular (12%, $n=16$), transverse myelitis (8%, $n=11$), spina bifida (5%, $n=6$), infection (3%, $n=4$), multiple sclerosis (19%, $n=26$) and other causes (15%, $n=20$).
	Australia (Victoria)	New[18]	1995–1997 (inclusive)	N/R ($n=70$; males, $n=32$, females, $n=38$)	33	67	Tumour (33%, $n=23$), degenerative (26%, $n=18$), vascular (14%, $n=10$), transverse myelitis (10%, $n=7$), infection (4%, $n=3$), multiple sclerosis (3%, $n=2$) and other causes (10%, $n=7$).
	Australia (Victoria)	Burke[19]	1978–1982	N/R ($n=27$)	N/R	N/R	Vascular lesions, infection and post-surgical complications
	Australia (Victoria)	Penington[20]	N/R. 5 years	N/R ($n=109$)	N/R	N/R	Tumour (37%, $n=40$), vascular (19%, $n=21$), transverse myelitis (8%, $n=9$), multiple sclerosis (10%, $n=11$), Guillain–Barre disease (2%, $n=2$) and other causes (24%, $n=26$).
	Australia (Victoria)	Cheshire[21]	1959–1966	N/R ($n=88$)	N/R	N/R	N/R
Europe, Western							
	Denmark	Biering-Sorensen[22]	1975–1984	2 ($n=92$; males, $n=57$, females, $n=35$)	41	59	Disc degeneration/prolapse (29%, $n=27$), neoplasm (24%, $n=22$), transverse myelitis (12%, $n=11$), vascular (12%, $n=11$), osteomyelitis (3%, $n=3$), abscess (3%, $n=3$), arachnoiditis (2%, $n=2$), spina bifida (2%, $n=2$), syringomyelia (2%, $n=2$) and other causes(11%, $n=17$).
	France (Rhone-Alpes Region)	Minaire[23]	1970–1975	7 ($n=189$)	N/R	N/R	N/R
	Germany	Exner[54]	1976–1996	4 (Based on 1985 population of 77,685,000; $n=5653$ over reporting period)	40	60	Disease (97%, $n=5457$) and malformation (3%, $n=196$).

Table 2 (Continued)

Region	Country	Author(s) of published data	Observation period	Incidence per million population per year (*n* = sample size; males; females)	Neurological level of injury		Cause of SCI
					Tetraplegia (%)	Paraplegia (%)	
	Israel	Ronen[25]	1962–2000	7 Mean rate over reporting periods (*n* = 1085; males, *n* = 599, females, *n* = 486)	32	68	Spinal stenosis (24%, *n* = 261), disk protrusion (15%, *n* = 158), multiple sclerosis (22%, *n* = 237), tumours (20%, *n* = 220), myelitis (7%, *n* = 71), infection (5%, *n* = 51) and other causes (7%, *n* = 76).
	Israel	Catz[26]	1962–1992	N/R (*n* = 1085; males, *n* = 592, females, *n* = 493)	32	68	Spinal stenosis (24%, *n* = 260), disc protrusion (15%, *n* = 158), multiple sclerosis (22%, *n* = 237), tumours (20%, *n* = 220), myelitis (7%, *n* = 71), infection (mainly tuberculosis and *Staphylococcus aureus*) 5%, *n* = 51), C1–C2 instability (3%, *n* = 29), vascular malformation (2%, *n* = 24), spinal cord ischaemia (2%, *n* = 17) and spina bifida (1%, *n* = 8).
	Italy	Citerrio[27]	1 February 1997–31 January 1999	6 (Based on 330 patients using 2000 pop; *n* = 330; males, *n* = 209, females, *n* = 121)[a]	22.3	77.7	Inflammatory (20%, *n* = 63), vascular (25%, *n* = 81), neoplastic (25%, *n* = 81), degenerative (19%, *n* = 60) and other causes (12%, *n* = 38).
	Italy	Caldana[28]	1994–1995	11 (n = 450)	30	70	Tumours (34%, *n* = 153), vascular myelopathies (7%, *n* = 33), myelopathy due to herniated disk (2%, *n* = 11), stenosis of vertebral canal (33%, *n* = 149), multiple sclerosis (11%, *n* = 51), spina bifida and the Arnold–Chiari syndrome (5%, *n* = 21) and other causes (8%, *n* = 36).
	Italy (seven rehabilitation centres)	Celani[29]	1989–1994	1 (Based on 1990 population; *n* = 217; males, *n* = 121, females, *n* = 96)	22.6	77.4	Neoplasia (36%, *n* = 79), vascular (25%, *n* = 55), infective (14%, *n* = 30) and other causes (24%, *n* = 53).
	Italy (Rome)	Scivoletto[30]	1996–2004	N/R (*n* = 236; males, *n* = 128, females, *n* = 108)	20	80	Degenerative disease of spine (32%, *n* = 76), vascular (24%, *n* = 57), inflammatory (23%, *n* = 54) and neoplastic diseases (21%, *n* = 49).
	Netherlands	Schonherr[31]	1982–1993	8 (*n* = 151; males, *n* = 93, females, *n* = 58)	36	64	Tumours (32%, *n* = 49), vascular causes (24%, *n* = 36), spinal degenerative causes (29%, *n* = 44) and other causes (15%, *n* = 22).
	Scotland (SE and W regions)	Buchan[32]	1968	N/R (*n* = 245; males, *n* = 137, females, *n* = 108)	N/R	N/R	Spina bifida (56%, *n* = 138), disc disease (16%, *n* = 39), neoplasm (11%, *n* = 28), myelitis (11%, *n* = 27) and other causes (6%, *n* = 13).
	Spain	Garcia-Reneses[33]	1984–1985	5 (*n* = 394)	38	62	Tumours (44%, *n* = 173), vascular (16%, *n* = 63), infection (19%, *n* = 75), spina bifida (5%, *n* = 20) and other causes (16%, *n* = 63).
North Africa/ Middle East							
	Saudi Arabia	Al-Jadid[34]	2005–2008	N/R (*n* = 126; males, *n* = 81, females, *n* = 45)	N/R	N/R	N/R
	Turkey (Istanbul)	Ones[34]	January 2002–June 2005	N/R (*n* = 63; males, *n* = 30, females, *n* = 33)	17	83	Spinal degeneration (25%, *n* = 16), tumours (22%, *n* = 14), infection (18%, *n* = 11), myelitis (14%, *n* = 9), vascular (8%, *n* = 5), spina bifida (6%, *n* = 4) and syringomyelitis (6%, *n* = 4).
	Turkey (Ankara)	Cosar[36]	1996–2008	N/R (*n* = 38; males, *n* = 21, females, *n* = 17)	74	26	Spinal tumours (29%, *n* = 11), spinal stenosis (29%, *n* = 11), vascular origin (16%, *n* = 6), transverse myelitis (18%, *n* = 7), spinal arachnoiditis (5%, *n* = 2) and syringomyelia (3%, *n* = 1).
North America, high income							
	Canada	Farry[37]	2010	73 (estimate based on 2010 population of 34,111,316; *n* = 2474; males, *n* = 1415, females, *n* = 1059)	N/R	N/R	N/R
	Canada (Ontario)	Guilcher[37]	April 2003–June 2005	N/R (*n* = 1002; males, *n* = 523, females, *n* = 479)	19	81	N/R
	Canada (Ontario)	Loblaw[39]	1990–1995	Estimated lifetime incidence of MSCC from all sites 2.5%	N/R	N/R	Malignant spinal cord compression (MSCC).
	USA	McKinley[40]	5-year prospective study	N/R (*n* = 86; males, *n* = 43, females, *n* = 43)	27	73	Spinal stenosis (54%, *n* = 46), tumour (26%, *n* = 22), ischaemia (8%, *n* = 7), infection (7%, *n* = 6) and myelitis (5%, *n* = 4).
	USA	Kurtzke[41]	1971	80 (Estimate)	N/R	N/R	Poliomyelitis, cerebro-vascular disease, congenital or birth injuries

Table 2 (Continued)

Region	Country	Author(s) of published data	Observation period	Incidence per million population per year (n = sample size; males; females)	Neurological level of injury		Cause of SCI
					Tetraplegia (%)	Paraplegia (%)	
	USA (New York)	Murray[42]	1980–1983	52 (n = 109)	N/R	N/R	Cancer, benign tumours (46%, n = 50), intraspinal abcess, vascular injury, epidural haematoma and transverse myelitis
Oceania							
	Fiji	Maharaj[43]	1985–1994	9 (n = 65; males, n = 47, females, n = 18)	5	95	Neoplasm (9%, n = 6), infections (32%, n = 21), unknown and other causes (58%, n = 38).
Sub-Saharan Africa, East							
	Ethiopia	Zenebe[44]	1990–1994	N/R (n = 130; males, n = 84, females, n = 46)	23	77	Tuberculous spondylitis (27%, n = 35), HIV-1-associated myelopathy (17%, n = 22), metastatic cord compression (15%, n = 20), tropical spastic paraparesis (14%, n = 18), cervical spondylosis (9%, n = 11), primary cord tumour (8%, n = 11), transverse myelitis (4%, n = 7) and other causes (4%, n = 5).
	Ethiopia	Zenebe[45]	1981–1988	N/R (n = 223; males, n = 140, females, n = 83)			Tuberculosis (20%, n = 45), tumours (20%, n = 45), disc prolapse, transverse myelitis, spinal artery stroke
	Kenya	Ojiambo[46]	April 1965–October 1965	N/R (n = 6; males, n = 4, females, n = 2)	N/R	N/R	Tuberculosis (33%, n = 2), tumours (33%, n = 2), cervical spondylosis (17%, n = 1) and brucellosis (17%, n = 1).
	Malawi, Blantyre	Brown[47]	October 1972–January 1975	77 (n = 102; males, n = 70, females, n = 32)	N/R	N/R	Tuberculosis (33%, n = 33), tumours (25%, n = 25), transverse myelitis (7%, n = 7), syphilis (6%, n = 6), invertebral disc disease (5%, n = 5), poliomyelitis (5%, n = 5), motor neurone disease (5%, n = 5), arachnoiditis (3%, n = 3), unknown spastic (3%, n = 3), Guillain–Barre (2%, n = 2), nutritional (2%, n = 2), epidural abscess (1%, n = 1) and miscellaneous (5%, n = 5).
Sub-Saharan Africa, Southern							
	Zimbabwe	Parry[48]	1989–1994	N/R (n = 159; males, n = 88, females, n = 71)	16	84	Neoplasms (28%, n = 44), tuberculosis (27%, n = 43), transverse myelopathy (11%, n = 17), Guillain–Barre syndrome (7%, n = 10), degenerative bone and joint conditions, degenerative cord disorders and infections (21%, n = 33) and unknown causes (6%, n = 12).
Sub-Saharan Africa, West							
	Ghana (Accra)	Nyame[49]	March 1991–February 1994	N/R (n = 64; males, n = 38, females, n = 26)			Tuberculosis (30%, n = 19), transverse myelitis (11%, n = 7), Guillain–Barre syndrome (11%, n = 7), neoplastic conditions (14%, n = 9), cervical spondylosis with myelopathy (13%, n = 8) and motor neurone disease (6%, n = 4).
	Nigeria (Ibadan)	Ogunniyi[50]	1988–1993	N/R (n = 104; males, n = 80, females, n = 24)			Spondylotic myelopathy (30%, n = 31), tuberculosis of the spine (25%, n = 26), neoplastic (15%, n = 16), myelitis (12%, n = 12) and other causes (13%, n = 13).
	Nigeria (Ibadan)	Odeku[51]	1962–1969	N/R (n = 53; males, n = 39, females, n = 14)	8	92	Neoplasms (91%, n = 48) and other causes (9%, n = 5).
	Nigeria (Ibadan)	Osuntokun[52]	1957–1965	N/R (n = 1327)	N/R	N/R	Tuberculosis (31%, n = 406), transverse myelitis (2%, n = 22), neoplasms (4%, n = 54), spina bifida (15%, n = 201), Arnold–Chiari malformation (0.4%, n = 6), multiple sclerosis (0.1%, n = 2), arachnoiditis (0.4, n = 6) and other causes (47%, n = 630).

Abbreviations: N/R, not reported; SCI, spinal cord injury; SE, South East; W, West.
[a]Source: Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat, /World Population Prospects: The 2008 Revision/, http://esa.un.org/unpp.

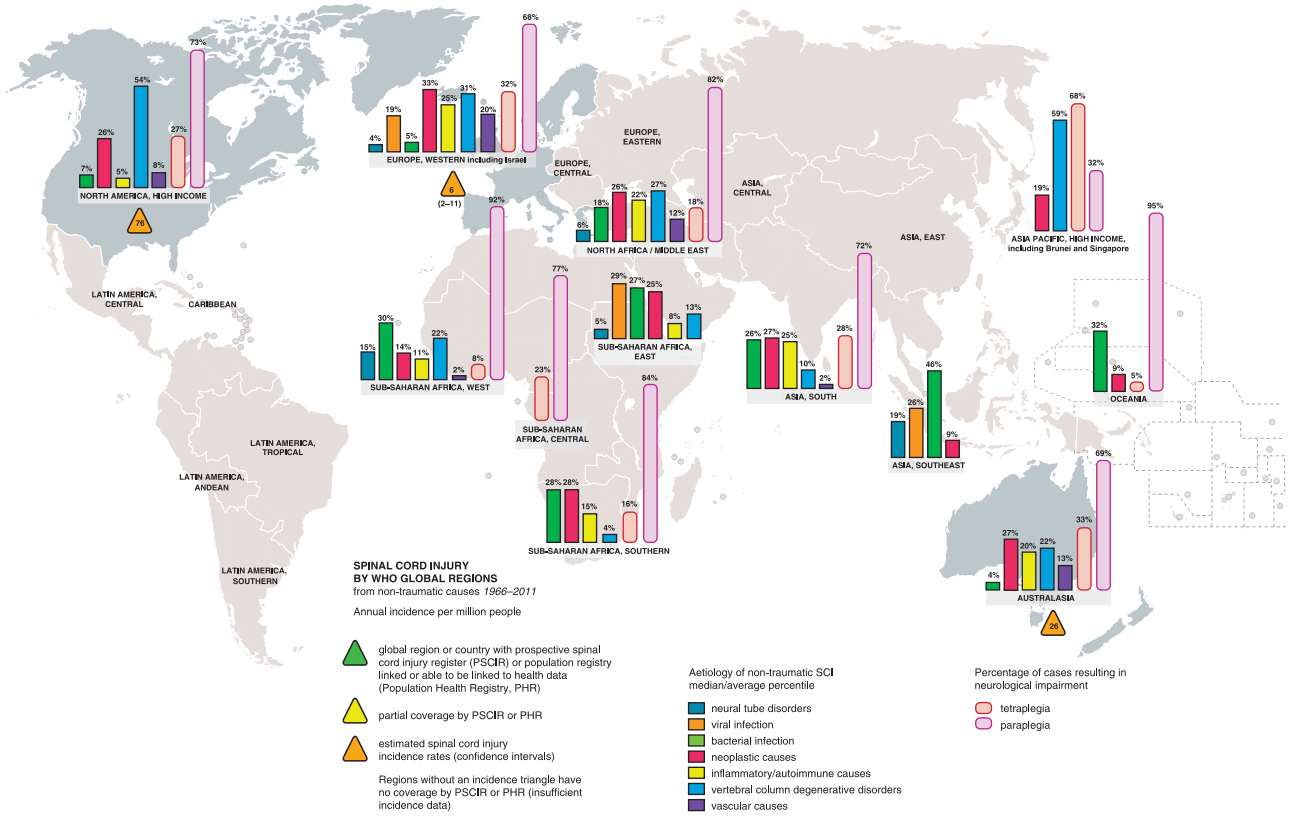

Figure 1 Global maps of NTSCI epidemiological outcomes (1959–2011) by WHO global regions.

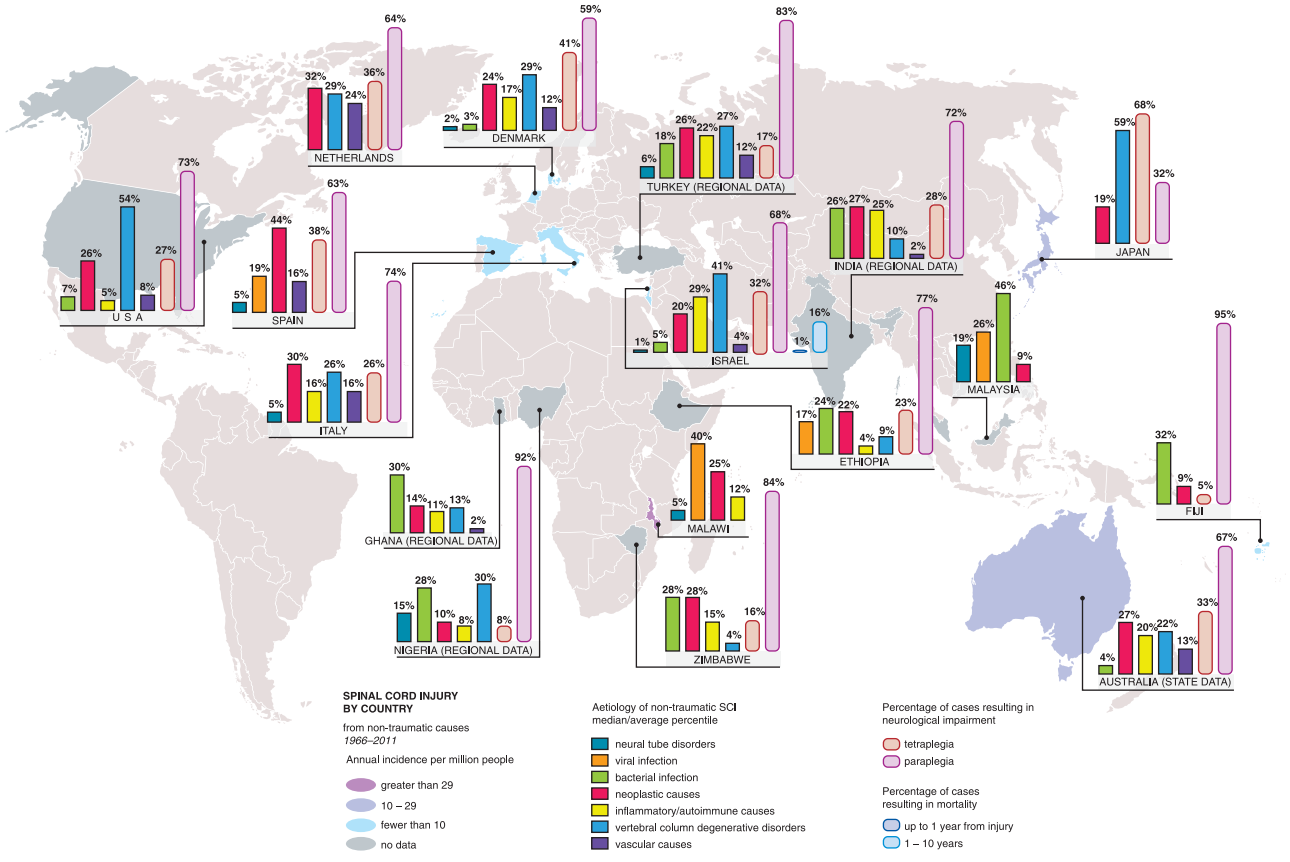

Figure 2 Global maps of NTSCI epidemiological outcomes (1959–2011) by country.

Table 3 Prevalence of non-traumatic spinal cord injury by region and author(s) of published data

Region	*Country*	*Author(s) of published data*	*Observation period*	*Prevalence per million population*
Asia, South				
	India (Kashmir)	Razdan[53]	1986	2310 (poliomyelitis 2180/million and Potts's paraplegia, hereditary spastic paraplegia and 'others' 126/million) prevalence rate based on 1986 population of 63 645; $n=147$)
North America, high income				
	Canada	Rick Hansen SCI Register[37]	2010	1120 (extrapolated from Australian data).[16]

national or regional reporting is routinely occurring using internationally accepted data standards through an adequately resourced registry. The absence of national reporting, illustrated by the 'Red Zone' areas in the global maps, makes it difficult to determine valid population denominators.

Using the methods outlined by Fitzharris *et al.*,[55] it could be possible to extrapolate data to appropriate regions and to adjust for variables, such as socio-economic development, which influence NTSCI. NTSCI data are currently inadequate for this approach. This emphasises the need, in planning future studies, for quality national or regional data that may be used to contribute to global estimates of NTSCI incidence and prevalence.

In any epidemiological study of NTSCI, incidence or prevalence will be influenced by many factors. These factors have not been well studied to date. It is suggested that these include the following: underlying population characteristics (age distribution and genetic factors); regional disease patterns (especially infectious diseases and cancer); socio-economic and geographic factors; health systems resources and models of care (for example, medical diagnostics and management, and availability of acute hospital, rehabilitation and long-term follow-up); the range of readily accessible disability services within each region; and local referral patterns.

Proposed research framework for the prevention of NTSCI and improving survival

There are a range of health-care management strategies that could potentially reduce the incidence of and improve the survival following NTSCI. Given the relevance of prevention to incidence and survival, we propose the following approaches for preliminary consideration:

- Care for patients with degenerative conditions of the spinal column causing myelopathy ideally includes access to appropriate radiology and surgery for treatment where there is canal compromise causing significant symptomatic cord compression. Better-quality studies are required comparing conservative management with surgery in order to optimise management decision making.[56,57]
- For patients with suspected spinal tumours, ideal clinical care requires prompt access to magnetic resonance imaging and other diagnostic investigations. Secondary malignant tumours require surgery and radiotherapy to reduce the progression from bony lesions to symptomatic NTSCI and to limit the severity of the neurological impairment, especially within the first 48 h.[58] Chemotherapy is also sometimes indicated to improve the survival and cure prospects, especially for primary tumours, but also some secondary malignancies.
- Infections causing NTSCI require prompt access to radiological imaging, neurosurgery in some cases, and appropriate antibiotic, antiviral or antiparasitic treatments, as indicated.[59,60]
- NTSCI due to spinal vascular conditions require emergency access to radiological imaging and neurosurgery or specialist interventional radiology to optimise outcomes.[60] In cases of NTSCI due to infarction, there is often little that can be done. Improved vascular surgery techniques, such as endo-luminal stenting of abdominal aortic aneurysms instead of open repair, may reduce the occurrence of cord infarction; however, evidence is currently inconclusive.[61]
- Folic acid prevents neural tube defects, including spina bifida,[62] but is probably suboptimally utilised in many countries, especially developing countries.

A few aspects of the models of care for NTSCI management can potentially influence NTSCI survival, and therefore prevalence. Following the acute phase after onset of NTSCI in many settings, patients have suboptimal access to specialist SCI rehabilitation, despite experts in rehabilitation recommending such access[15] and evidence of suboptimal outcomes when people with NTSCI are not able to access this expertise.[63,64] Better follow-up after discharge from hospital following acute care or rehabilitation is needed for NTSCI patients. This should include life-long monitoring, prevention and treatment of complications related to NTSCI and risk reduction strategies for potential medical conditions or existing comorbid diseases that increase the risk or mortality in NTSCI patients (for example, cardiovascular diseases and obesity).

There is a paucity of publication on the prevention of NTSCI and improving survival. The suggestions proposed here are a starting framework for research and possible application.

Limitations

A limitation of this project is that there is a scarcity of quality research in the field of NTSCI epidemiology—highlighted by the absence of Green and Yellow information zones (Map 1). The scope and depth of information in most studies is scant. Furthermore, most studies are single-centre, with the potential for selection bias to influence the results. This applies especially to the aetiology of NTSCI and emphasises the need for state, or national population-based studies of incidence and outcome. Furthermore, there was no internationally accepted classification of NTSCI available at the time that the studies included in this review were carried out. This limited the ability to report and compare the aetiology of NTSCI across many countries and WHO regions.

There are major problems with some studies regarding the classification of the causes of NTSCI. These include in incidence studies the mixing of chronic NTSCI with new onset NTSCI patients when describing the study sample. For example, congenital and genetic cases are included with acute/subacute onset NTSCI patients. Furthermore, including multiple sclerosis in studies of NTSCI incidence or prevalence is problematic because lesions can occur in

the brain or spinal cord. A case could be made for considering it a 'special case' of NTSCI, and reporting data separately. Some studies included conditions that do not actually constitute NTSCI. These include Guillain–Barré Syndrome (a lower motor neurone condition) and 'hysteria' (conversion disorders).

Future directions

More robust studies of the incidence, prevalence and survival of NTSCI are required. We have a number of recommendations for improving the quality of epidemiological studies of NTSCI that would result in more accurate, relevant and usable information for informing health planning and prevention strategies. We propose that the following standards be followed to improve the quality of research data in future studies of the incidence, prevalence and survival of NTSCI:

1. Authors should provide a clear description of their study sample(s). It is essential that a distinction be made between recent onset NTSCI cases that are newly diagnosed from those that are chronic.
2. Population-based study designs should be used where incidence and prevalence studies are carried out, especially in well-resourced countries.
3. Data should be reported using International Standards for reporting results of studies and data analysis.[65]
4. NTSCI aetiology should be described using the International NTSCI Data Sets, which includes a standardised classification system.[8]
5. Survival studies of NTSCI patients would help estimate prevalence and help plan for future health-care needs.
6. Ideally, annual reports of national statistics should be published on the internet in a searchable manner.
7. ISCoS and other relevant organisations should explore options for a centralised data repository and/or related links to national registries that together would function as a centralised data repository in order to facilitate NTSCI prevention efforts. The tabulations and a summary form for data submissions are available on the ISCoS website as part of the Global Mapping project (http://iscos.org.uk/page.php?content=67). We welcome submissions of unpublished or published data from the ISCoS readership and aim to produce regular updates for the ISCoS Prevention Committee and community.

CONCLUSIONS

Mapping techniques can allow complex data to be interpreted quickly and intuitively by clinicians and policy makers. Incorporation of epidemiological data regarding NTSCI into a central data repository, assessing the quality and determination of a course of action aimed at reducing NTSCI incidence or improve survival can benefit from mapping techniques. Future efforts of NTSCI researchers should address deficiencies identified here in order to improve the quality, quantity and comparability of available information. It is hoped that eventually research could extend to comparison of prevention methodology and allow more rapid global learning about what works and why, as well as provide policy support for advocates of NTSCI prevention.

CONFLICT OF INTEREST

The authors declare no conflict interest.

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