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ORIGINAL ARTICLE

Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review

PW New[1,2,3] and V Sundararajan[4]

[1]Spinal Rehabilitation Unit, Caulfield General Medical Centre, Caulfield, Victoria, Australia; [2]Department of Medicine, Monash University, Melbourne, Victoria, Australia; [3]Department of Epidemiology and Preventive Medicine, Monash University, Melbourne, Victoria, Australia and [4]Victorian Department of Human Services, Melbourne, Victoria, Australia

Study design: Data extraction from a state-wide, population-based, health-administration database of hospital admissions.
Objective: To determine the incidence of non-traumatic spinal cord injury (NTSCI).
Setting: Victoria, Australia.
Methods: All patients admitted to hospital with a new onset of NTSCI, or who developed NTSCI after hospitalization, between 1 July 2000 and 30 June 2006, were identified using a population-based database. Age and gender of NTSCI patients were recorded.
Results: The number of adults aged 15 years and older with NTSCI in each of the 12-month periods was 82, 111, 96, 108, 133 and 101. The average age-adjusted incidence rate of NTSCI in adults was 26.3 cases per million per year. There was no statistically significant increase in the age-adjusted incidence of NTSCI over the study period (Spearman's $\rho = 0.35$, $P = 0.5$). The incidence of NTSCI was significantly greater than the reported incidence for traumatic spinal cord injury ($\chi^2_1 = 19.5$, $P < 0.0000$). There was a very strong correlation between age and the incidence of NTSCI, for both men (Spearman's $\rho = 1$, $P < 0.0000$) and women (Spearman's $\rho = 0.98$, $P = 0.0000$). Men had a statistically significantly ($\chi^2_1 = 13.1$, $P = 0.000$) higher incidence of NTSCI (30.5 million adults per year) compared to women (22.9 million adults per year). The average incidence of NTSCI in children <15 years was 0.7 cases per million per year.
Conclusion: NTSCI is strongly correlated with age and is more common than traumatic spinal cord injury. The method used in this study to calculate the incidence of NTSCI can be used to monitor the anticipated increase in the incidence of NTSCI in the years ahead, and can be used to in comparative studies.
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Keywords: spinal cord diseases; spinal cord injury; spinal cord lesion; incidence; epidemiology

Introduction

Spinal cord injury (SCI) or damage is one of the most devastating medical conditions possible. It causes life-changing consequences in all facets of human functioning and existence. Overseas studies of traumatic spinal cord injury (TSCI) have reported a wide variation in the incidence. A recent review reported that the incidence of TSCI worldwide varied between 10·4 and 83 per million per year.[1] In Australia, the age-adjusted incidence rate of TSCI in adults aged 15 years and older surviving to reach hospital has remained at about 15–17 cases per million per year over the past decade. The incidence in Victoria is currently 11·9 cases per million adults per year.[2]

Correspondence: Dr PW New, Spinal Rehabilitation Unit, Caulfield General Medical Centre, 260 Kooyong Road, Caulfield, Victoria 3162, Australia.
E-mail: p.new@cgmc.org.au
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In comparison to TSCI, there is relatively little research regarding non-traumatic spinal cord injury (NTSCI). There are many different aetiologies of NTSCI.[3] The most common causes of NTSCI described in case series in Western countries are degenerative disc disease and spinal canal stenosis, tumours, vascular diseases and inflammatory conditions.[4–6] Factors influencing the aetiology of NTSCI have not been studied in detail, but have been noted to be associated with age-related conditions.[6]

Australia is one of the few countries with a national SCI register, however, it has poor coverage of patients with NTSCI.[7] Studies of the incidence of NTSCI face greater problems compared to those of TSCI. The acute management and rehabilitation of NTSCI patients is conducted in a variety of different settings, and their overall care tends to be poorly integrated and coordinated. For example, NTSCI patients often do not receive specialized SCI rehabilitation

services.[8–9] A specific NTSCI registry or population census would be expensive, time consuming and impractical because of the multiple care settings where NTSCI patients are managed, and the rarity of this condition.

Patients with NTSCI are often very disabled. There is a high burden of care following the onset of NTSCI, and in numerous cases this persists after discharge from inpatient rehabilitation.[10] There is an enormous socio-economic impact in caring for these patients. An estimate of the incidence of NTSCI is important for health care planning.

The aims of this study were (1) to use a population-based health-administration database to identify episodes of acute NTSCI, and to use this information to calculate the incidence and (2) to review the literature on the incidence of NTSCI. The study hypothesis was that the incidence of NTSCI is greater than that reported for TSCI.

Methods

Setting

The Victorian Department of Human Services (DHS) is the data custodian for the state's hospital discharge database, the Victorian Admitted Episodes Dataset (VAED), which includes all public and private hospital admissions.[11] Through a process of statistical record linkage, the data are transformed into an anonymous case-based dataset that allows tracking of patient care through differing service providers and settings. There are over 1 500 000 admissions per year.

Information recorded in the discharge data includes medical diagnoses. These are coded using the *International Classification of Diseases and Related Health Problems*, 10th edn, Australian modification (ICD-10-AM).[12] Presenting medical diagnoses, comorbid problems and complications are included, with up to 25–40 conditions recordable in each category, depending on year. Victorian coding guidelines require a prefix to the ICD-10-AM diagnoses. These prefixes are used to indicate the primary reasons for admission for conditions that were present on admission to hospital and underwent evaluation and treatment (P), or occurred during the course of hospitalization (C). The codes have a classification specifically for NTSCI. Coding guidelines require that relevant codes be entered for both the aetiology of the NTSCI (for example, cord compression from tumour, transverse myelitis and so on) and the neurological consequence (acute paraplegia, acute tetraplegia or cauda equina syndrome).

Case definition

Data were extracted from the VAED on all patients with a new diagnosis of NTSCI admitted into hospital in Victoria, Australia, between 1 July 2000 and 30 June 2006. We included patients with an NTSCI that either was a reason for hospital admission or occurred as a complication during inpatient stay. Patients were considered to have a new-onset NTSCI if they had a diagnosis of acute paraplegia (ICD-10-AM codes G8201, G8203, G8205, G8211, G8213, G8215, G8221, G8223, G8225), acute tetraplegia (ICD-10-AM codes G8231, G8233, G8235, G8241, G8243, G8245, G8251, G8253, G8255) or a cauda equina syndrome (ICD-10-AM code G834).

All patients with a cauda equina diagnosis and the C prefix were included. If the P prefix was used, only those patients with the cauda equina SCI listed as the first of the presenting diagnoses were included in our results. This approach was adopted because the P prefix applies to both new injuries and pre-existing conditions that are active during hospitalization. It was believed that by limiting the inclusion to cases with the P-G834 code in the first diagnostic position it would increase the likelihood of including only those patients who had a new-onset NTSCI and excluding those who had a pre-existing cauda equina NTSCI. It is important to mention that patients with a pre-existing cauda equina NTSCI who were admitted for a late onset complication, such as a pressure ulcer or urinary tract infection, would, by convention, have these complications listed in the first position, and the cauda equina in a subsequent position. For illustrative purposes, the total number of patients for the period 2000–2006 identified in the VAED with the P-G834 diagnosis in the first position was 220, second position 178, third position 128 and 60 in the fourth position. An audit of medical files of patients with the P-G834 code discharged between 1 January 2000 and 30 June 2007 from a major acute hospital (Alfred Hospital, Prahran, Victoria) was conducted by the first author to access the accuracy of the assumptions in our methodology for coding acute-onset cauda equina syndrome, and to determine the influence of the P-G834 code in the second or third position. The percentage of patients with the P-G834 code and a new-onset cauda equina syndrome causing NTSCI was noted as follows: 96% (23 of 24) with the P-G834 code in the first position; 70% (7 of 10) in the second position and 56% (9 of 16) in the third position. It was felt that these results validated our approach.

For identified cases we searched the data for a previous admission that included an SCI, and if one was found, these cases were excluded from the study sample (ICD-10-AM exclude codes 2000–2006: T91; 1998–2000: G82, G83, S140, S141, S240, S241, S340, S341 and S343; ICD-9-AM exclude codes 1996–1998: 336, 340, 341, 344, 440, 441, 806, 952, 953, 013·4, 013·5, 192·2, 192·3, 198·3, 198·4, 225·3, 225·4, 324·1, 721·1, 721·4, 722·7, 907·2, 907·3 and 721·91). Patients with congenital conditions causing NTSCI were excluded because they are recorded in a paediatric birth defect register. Patients with motor neurone disease and multiple sclerosis were also excluded from the study sample. This was because the ICD-10-AM coding for these conditions does not necessitate coding for NTSCI. Furthermore, with multiple sclerosis, there is no way to determine from the coding whether the spinal cord was affected. Non-Victorian residents and immigrants and residents moving from other states of Australia or overseas after their NTSCI were excluded.

The incidence in patients aged less than 15 years was reported separately from older patients. This was because SCI is believed to be very rare in this age group and to facilitate comparison with the reported incidence of TSCI in Australian, which excludes patients under 15 years.[2]

Data validation

Because of concern about possible bias or inaccuracies in ICD-10-AM coding and the need to validate our methodology an assessment was made of the accuracy of the coding method used in this study for defining an acute NTSCI. We did this by comparing the cases identified in the VAED discharge data as having an NTSCI with a database of new-onset NTSCI cases admitted to either of the two designated SCI rehabilitation hospitals in Melbourne (Royal Talbot Rehabilitation Centre and Caulfield General Medical Centre) between 1 July 2000 and 30 June 2004. This comparison database of rehabilitation admissions was established only for the purposes of determining the validity of the methodology used in this manuscript. The decision was made to only include these two units for practical reasons because they manage the greatest number of rehabilitation patients with NTSCI in the state. We found that 77% of patients with NTSCI admitted to the rehabilitation hospitals ($n=373$) were also matched to the VAED sample. It was not possible to discern any systematic errors in the sample that did not match.

Literature search

An electronic literature search for articles published on the incidence of NTSCI was carried out using the Medline (1966–2007) and Embase (1980–2007) databases with the Ovid search engine. The search was limited to articles or abstracts published in English. Search terms used were 'incidence', 'nontraumatic', 'non-traumatic', 'spinal cord injury' and 'spinal cord damage'. The identified publications were screened for relevance to this review and the included articles had their methodology appraised. The reference section of all relevant articles identified and pertinent textbooks were also screened for any other useful articles.

Statistical methods

The extracted data from the VAED (gender and age) had any identifying information removed before being transferred into a database and analysed using Stata, intercooled version 6.0 for Windows (Stata Corp., College Station, TX, USA).

The population at risk was all residents of Victoria aged 15 years or older, as determined by the Australian Bureau of Statistics estimates (30 June 2003, 3 959 000).[13] For each study period examined, the population was calculated using the average mid-point population. The annual incidence rates were adjusted to overcome the effect of differences in the proportions of people at different ages, and different risks of NTSCI. Age adjustment was also performed to allow comparison with the reported incidence of TSCI, which also uses this approach. Direct standardization was employed, taking the Australian population at 30 June 2001 as the standard. Spearman's correlation was used to analyse for the presence of a significant change in the incidence over the study period, and for a trend in the age-specific rates for men and women. The 95% confidence intervals (CI) for the annual age-adjusted rates were performed using the standard error for proportions. The comparisons of the incidence of NTSCI in men with women, and of the incidence in Victorian of NTSCI with TSCI, were calculated using the χ^2-test. *P*-values less than 0.05 were deemed to be statistically significant.

We certify that institutional and governmental regulations concerning the ethical use of patient information were followed during the course of this research.

Results

Incidence of NTSCI

The number of adults aged 15 years or older with NTSCI in each of the 12-month periods between 1 July 2000 and 30 June 2006 was 82, 111, 96, 108, 133 and 101. By comparison, the number of patients with TSCI from Victoria registered with the national SCI database over the corresponding period was 58, 57, 48, 47, 44 and 46 (personal communication Dr Raymond A Cripps, Australian Spinal Cord Injury Register, Flinders University, Research Centre for Injury Studies). Four cases were identified with NTSCI who were less than 15 years old. A total of 59 cases were excluded because coding indicated another previous admission for SCI before the study period.

The average age-adjusted incidence rate of NTSCI in adults over the study period was 26.3 cases per million per year. There was no increase in incidence over the study period (Spearman's $\rho=0.35$, $P=0.5$; Figure 1). The incidence of NTSCI over the study period was much greater than the incidence of TSCI ($\chi^2_1=19.5$, $P<0.0000$).

The age-specific incidence rates are shown in Table 1. There was a very strong correlation between age and the incidence of NTSCI, for both men (Spearman's $\rho=1$, $P<0.0000$) and women (Spearman's $\rho=0.98$, $P=0.0000$). Men had a significantly ($\chi^2_1=13.1$, $P=0.000$) higher incidence of NTSCI (30 · 5 million adults per year) compared to women (22.9 million adults per year). The average incidence rate of NTSCI in the population aged less that 15 years was 0.7 cases per million children per year.

Review of NTSCI

The literature search identified two unpublished and nine published studies that reported the incidence of NTSCI.[4,9,14–20]

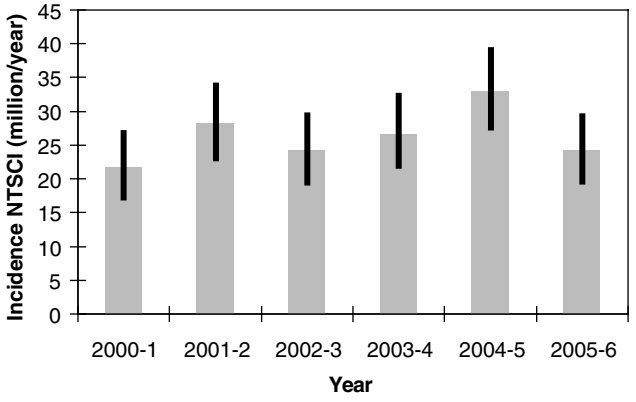

Figure 1 Annual incidence non-traumatic spinal cord injury (NTSCI; cases per million adults ⩾15 years). Vertical lines represent 95% CIs.

Table 1 Incidence of non-traumatic SCI (cases per million adults per year) by age groups and gender

Age group[a]	*Men*	*Women*	*Total*	*Rate ratio*[b]
15–24	8.2	4.0	6.1	1
25–34	9.7	8.1	8.9	1.5
35–44	19.5	13.3	16.4	2.7
45–54	28.6	16.4	22.4	3.7
55–64	44.5	31.7	38.1	6.2
65–74	74.1	53.4	63.4	10.4
75–84	101.9	77.9	88.0	14.4
85+	127.4	71.5	89.1	14.6

[a]Adults aged $\geqslant$15 years at June 2003 taken as the population at risk.
[b]Adults aged 15–24 taken as 1 to facilitate comparison with the incidence of TSCI, because this is the age group with the highest incidence.

The incidence of NTSCI varied between 5.1 and 80 cases per million population per year. No separate reporting of the incidence of NTSCI in children was located. A summary of the studies and methodological issues is shown in Table 2.

Discussion

Incidence NTSCI

The incidence of NTSCI reported here is the most accurate estimate available for anywhere in Australia and is consistent with the recently published rough estimate of the incidence of new-onset NTSCI cases admitted for rehabilitation[9] and with the two unpublished studies (Table 2). No significant increase in the incidence of NTSCI was demonstrated over the study period. There was a significant increase in rate with advancing age and NTSCI is much more common in men. NTSCI is extremely rare in children. The authors have no reason to believe that the results could not be generalized to other states in Australia. Our findings could not, however, be generalized to other countries. This is because the prevalence of diseases that cause NTSCI, and their management, may differ from that in Australia. This could influence the incidence of NTSCI in an unpredictable manner.

The incidence of NTSCI in this study is more than twice that currently reported for TSCI in Victoria over the corresponding period.[2] Although there was not a significant increase in the incidence of NTSCI during the study period, there appeared to be an upward trend. It is predicted that the Australian population aged over 65 years will double over the next 40–50 years,[21] and this is a worldwide trend.[22] Therefore, it is anticipated that the incidence and prevalence of NTSCI will also dramatically increase in the years ahead. The projected increase in NTSCI has major implications worldwide regarding the organization and delivery of care for these patients. This applies especially to the areas of acute medical care, specialist inpatient rehabilitation, sub-acute ambulatory care, community services, carer supports and residential care.

Previous NTSCI studies

No review of the incidence of NTSCI was located in the literature search. The incidence of NTSCI in the present study is compatible with that of previous studies, and falls in the middle of the range of earlier results. The previous reports of the incidence of NTSCI have important methodological problems that raise serious concerns about their accuracy. All studies reviewed have limitations due to incomplete case ascertainment, and many have issues with reporting or calculating the population at risk. The methodological differences also make accurate comparisons between the reviewed studies challenging. This applies particularly to the differing inclusion and exclusion criteria for NTSCI cases.

Study limitations

Concern has been raised about the accuracy of recorded diagnoses[23] and possible bias in discharge data from administrative databases.[24] These concerns, however, are mainly in the context of using administrative databases for assessment of the quality of care. In Victoria, it is standard practice for hospital coders to use the *Australian Coding Standards* (vol. 5) of the ICD-10-AM to improve accuracy and reliability.[12] A recent audit comparing over 14 000 case files to the IDC-10-AM coding demonstrated a high level of reliability and adherence to coding standards.[25] Although the audit compared data between 1998–1999 and 2000–2001, and this present study only has a small overlap with this audit period, the authors do not believe that an audit performed during the present study inclusion time would find a significantly different result.

The approach used in this study to identify patients with NTSCI is not totally accurate. This applies especially to cases with a cauda equina syndrome. The inclusion method used for this subgroup was based on a conservative approach. It is likely that some patients with the P-G834 code in the first diagnostic position had a pre-existing cauda equina NTSCI, and were included. Based on the audit described above it is likely that the numbers incorrectly included were very small. It is quite likely, on the other hand, that patients with a new-onset cauda equina NTSCI and the P-G834 code in the second or subsequent position were incorrectly excluded. The results of the comparison of NTSCI cases identified through the VAED with those identified from admissions to the two SCI rehabilitation hospitals in the state suggest that the accuracy of the coding method used to identify acute-onset NTSCI cases in this study was acceptable. Although the validation of the coding for acute-onset NTSCI used in this study produced reasonable results, it may not be generalized to other settings, especially in other countries, where coding guidelines differ.

It is important to mention that in Victoria there are no other viable alternative health care providers to public or private hospitals that could manage patients with new onset of NTSCI. It is possible, however, that some patients with a very mild NTSCI could be investigated and managed in the community without any inpatient admission, but this would be extremely uncommon.

Despite the above, there are advantages of using a health-administration database for this research. The whole of the population at risk can be included in a convenient approach.

Table 2 Studies of the incidence of NTSCI

Author	*Year published*	*Country*	*Observation period*	*Incidence (cases per million per year)*	*Methodology issues with case ascertainment and population at risk*
Kurtzke[14]	1975	USA	1969–1972	80	Cases: self-responded health survey. Limited description of methodology. Acknowledged as inaccurate. Paediatric cases included. Population: NS.
Minaire[15]	1978	France	1970–1975	6.6	Cases: only patients admitted to SCI unit. Population: census data 1975 not mid-point of study period.
Murray[16]	1984 (abstract)	USA	NS (3 years)	51.9	Cases: NS Population: NS
Biering-Sørensen[17]	1990	Denmark	1975–1984	8.3	Cases: severe SCI needing specialized treatment in rehabilitation hospital. Paediatric cases included. Excluded progressive conditions, multiple sclerosis and some cancers. Population: source NS. Data from 1985 not mid-point of study period.
Garcia-Reneses[18]	1991	Spain	1984–1985	5.1	Cases: questionnaire to 13 specialist hospitals surveying cases admitted. Spina bifida and paediatric cases included. Population: source NS
Schönherr[4]	1996	Netherlands	1982–1993	8.3	Cases: admitted rehabilitation hospital. Included patients <21 years, but NS if paediatric cases included. Excluded systemic diseases, demyelination, degenerative nervous system and congenital diagnoses. Population: source given. Data from 1991 not mid-point of study period
Maharaj[19]	1996	Fiji	1985–1994	8.7	Cases: admitted rehabilitation hospital. Paediatric cases included. Excluded Spina bifida Population: source NS
Caldana[20]	1998	Italy	1994–1995	42.7	Cases: Diagnostic codes from hospital databases from major hospitals (not all) in region. Crosschecked with records but no reporting of missing files or error rate. Incomplete cases ascertainment acknowledged. Paediatric cases NS. Population: source NS. Used data for mid-point of study period.
New[9]	2006	Australia	2005	26	Cases: survey of neurorehabilitation consultants or SCI unit doctors for an estimate of number of new cases in adults treated per year. Population: ABS. Adults 15 years and older
New	Unpublished	Australia (Victoria)	1995–1997	17	Cases: admitted to 2 specialist SCI rehabilitation hospitals in Melbourne (Drs Peter New and Doug Brown, personal communication). Excluded congenital, multiple sclerosis and cases <18 years. Population: ABS. Adults 18 years and older
New	Unpublished	Australia	2005	19	Cases: admitted to adult inpatient rehabilitation hospitals in Australia and reported to the Australasian Rehabilitation Outcomes Centre, University of Wollongong (http://www.uow.edu.au/commerce/aroc/documents/05_06/sci_rehab_tsci.pdf) Exclusions NS. Population: ABS. Adults 15 years and older

Abbreviations: ABS, Australian Bureau of Statistics; NS, not specified; SCI, spinal cord injury.

Given the practicalities of studying this rare condition, the use of the VAED and the coding method employed offers an opportunity to determine an estimate of this important and devastation condition that is not available by any other means.

There are currently no internationally accepted criteria for what aetiologies of SCI constitute NTSCI. There has been little discussion of this in the literature, although a recent conference presentation has discussed this issue.[26] To facilitate comparative studies, internationally agreed criteria for NTSCI should be established.

Study implications

There is a need to replicate, validate and possibly refine the methodology used to calculate the incidence of NTSCI.

Improving coding practices and changes to the ICD-10 coding of NTSCI may both be helpful in this regard. This applies particularly to the coding for cauda equina syndrome. Changes should be made to the coding convention for equina syndrome to code separately for acute and chronic injury. In the interim, as part of a planned national study of the incidence of NTSCI in Australia, it is envisaged that a larger audit will be conducted to determine the accuracy of the approach to the P-G834 coding.

Follow-up studies should be conducted to monitor the incidence of NTSCI. It is anticipated that future studies will demonstrate the anticipated significant increase in the incidence of NTSCI in coming decades. This information will facilitate health care planning. It would be prudent, however, for government departments and health care organizations that care for these patients to start planning now how they will adequately meet the anticipated increased demand for the specialist services that care for NTSCI patients.

The methods used here could also be implemented in other settings to determine comparative estimates of NTSCI.

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