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ORIGINAL ARTICLE

# Prevalence of non-traumatic spinal cord injury in Victoria, Australia

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**Study design:** Forecasting using population modelling.
**Objectives:** To determine the prevalence of non-traumatic spinal cord injury (NTSCI) on 30 June 2010.
**Setting:** Victoria, Australia.
**Methods:** Modelling used the following data: incidence of NTSCI based on state-wide, population-based, health-administration database of hospital admissions; state and national population profiles and life tables; levels of NTSCI based on national rehabilitation outcomes data; and life expectancy for persons with SCI.
**Results:** The total population prevalence rate was 367.2 per million, whereas the prevalence in adults aged 16 years and older was estimated to be 2027, equivalent to a population prevalence rate of 455 per million persons. There were more males (1097) with NTSCI (prevalence rate males 197.8 per million population; females 169.1 per million population) and the prevalence was much higher among those with paraplegia (prevalence rate 269.3 per million compared to 97.8 per million with tetraplegia) and incomplete NTSCI. Ventilator dependency (prevalence rate 1.6 per million population) and paediatric NTSCI (prevalence rate 6 per million population $\leqslant$15 years old) were extremely rare.
**Conclusion:** We have reported a method for calculating an estimate of the prevalence of NTSCI that provides information that will be vital to optimise health care planning for this group of highly disabled members of society. It is suggested that refinements to the modelling methods are required to enhance its reliability. Future projects should be directed at refining the mortality ratios and performing cohort survival studies.
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**Keywords:** spinal cord diseases; non-traumatic spinal cord injury; prevalence; epidemiology; population modelling; forecasting

## INTRODUCTION

Spinal cord injury (SCI) or damage is one of the most devastating conditions possible. It can cause a wide range of impairments, activity limitations and participation restrictions,[1,2] and has an adverse impact on the social network and wider society in which the person lives. Irrespective of the cause, persons with spinal cord damage have complex acute, rehabilitation and long-term care needs that require specialist multidisciplinary expertise in order to optimise outcomes.[3] There is, however, very little literature on the prevalence of SCI.[4] A recent review has reported a wide range in the prevalence across different regions of the world, but with a great variation in the quality of research.[5]

Spinal cord damage can result from traumatic or non-traumatic causes. Although it is reported that the incidence of non-traumatic SCI (NTSCI) in some developed countries is greater than that of traumatic SCI (TSCI),[6,7] much more research has been conducted involving TSCI. As the incidence rates of NTSCI are highest in older age groups,[6] it is anticipated that both the incidence and prevalence of NTSCI will increase in many countries as a result of the projected aging of their populations.

As NTSCI tends to occur in persons of older age, it is associated with more comorbidities than TSCI.[8] These comorbidities, the physiological changes arising from the NTSCI and the associated disease processes that cause the NTSCI can all affect the survival of persons with NTSCI. At a population level, these factors influence the prevalence of NTSCI. Knowledge about the prevalence of NTSCI is important in order to optimise health care planning, especially regarding specialist spinal cord rehabilitation inpatient and ambulatory care programs, community services, carer supports and residential care. Only two publications have been located in the literature that report on the prevalence of NTSCI.[7,9] The objective of this project was to calculate an estimate of the prevalence of NTSCI for the State of Victoria, Australia on 30 June 2010.

## METHODS

### Estimating annual NTSCI incidence

Annual incidence of NTSCI was estimated by applying age- and gender-specific incidence rates to the population by age and gender group. The incidence rates were taken from the study by New *et al.*[6] that reported NTSCI incidence rates for the State of Victoria, Australia. This study included 631 persons identified using ICD-10 codes who were admitted to acute hospitals during the period 2000–2006 with a NTSCI. As it was reported that incidence rates did not change significantly over the study period, in the absence of published historical incidence rates, it was not possible to model temporal

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changes. For purposes of estimating prevalence of NTSCI, it was necessary to assume that incidence rates have remained constant.

The age- and gender-specific incidence rates of NTSCI from New *et al.*[6] were applied to the estimated population of Victoria by age and gender for each year from 1921 to 2010 to estimate the annual incidence of NTSCI. As there is no consistent annual published estimate of the Victorian population by age and gender for this period, it was necessary to develop such a series. This was done by using the total estimated mid-year population of Victoria for the period 1921–2010[10] as the control total. This total was distributed to single years of age and gender using, for the period 1971–2010, the estimated population by single years of age and gender[11], and for earlier years, the periodic census data for the state (1921, 1933, 1947, 1954, 1961, 1966, 1971)[12] combined with inter-censual cohort-specific interpolation and annual birth data.[13]

The resultant estimate of annual incidence of NTSCI by age and gender was then allocated to injury class. The first step in this process was to use data based on patients admitted into all rehabilitation units in Australia[14] to separate incidence into those with paraplegic injuries (69.2%) and tetraplegic injuries (30.8%). These two major injury groups were further disaggregated using data for Australia[15] and the USA National Spinal Cord Injury Statistical Center (NSCISC).[16] The Australian data did not include persons who are ventilator dependant. As clinicians report cases of persons with NTSCI who are ventilator dependent, in the absence of any alternatives, the data from the USA NSCISC was used to estimate the number of people with NTSCI who were ventilator dependent by the level of injury (paraplegia and tetraplegia).[16] Data from Australia[15] was then used to estimate the relative shares of the non-ventilator-dependant groups into four separate categories of injury by level and severity (cervical lesions Frankel A and Frankel D; thoracic/lumbar lesions Frankel A and Frankel D). A summary of the distribution of the types of NTSCI by level and severity is shown in Table 1.

It is relevant to note that the grade of injury is presented here using the Frankel scale[17–18] because that was how patients were classified in the survival studies used in our model.[15–16] The main difference between the Frankel and the American Spinal Injury Association (ASIA) Impairment Scale (AIS)[19] is that the former considers incomplete injury from the perspective of functional muscles, particularly for walking,[20] whereas the latter considers incomplete injury from the perspective of sacral sparing.

### Estimating the 2010 prevalence of NTSCI

Prevalence at a point in time is estimated as the cumulative survivorship of all previous year's incidence. NTSCI prevalence for Victoria in 2010 was calculated by adding each past year's estimated NTSCI incidence population by age, gender and injury group to the survivors of the prevalence population from the previous year, assuming zero prevalence in 1921. The year 1921 was selected as a starting point because there is little likelihood that someone living with SCI in 1921 would be alive in 2010.

Calculation of the number of survivors from the previous year's prevalence population requires the use of group-specific mortality rates. Age- and gender-specific mortality rates for persons living with TSCI are higher than those of their peers in the general population, and are specific to the type and severity of injury.[15,16] No studies of mortality or life expectancy for NTSCI with age- or gender-specific mortality rates were located in a literature search. Therefore, we used studies of TSCI assuming that for any given age, level and severity of SCI, the risk of dying would be similar for both TSCI and NTSCI.

Mortality rates for persons living with SCI injury for each age, gender and injury class were estimated as standard mortality ratios, that is, the rates for these groups relative to the rates that prevailed in the general population. For the non-ventilator-dependant groups, these rates were derived from the standard mortality ratios for people living with SCI by type and severity of injury published in Australia.[15] The standard mortality ratios for the ventilator-dependent groups were derived from USA NSCISC data that present the life expectancy of persons in the two ventilator-dependant groups relative to the general population.[16]

Mortality rates for the general population for Victoria were obtained using life table data published by the Australian Bureau of Statistics. Age- and gender-specific mortality rates for Victoria are available from life tables for the period 2002–2008.[21] For the preceding years, it was assumed that the pattern of change back from 2002 observed in the Australian life tables[22] prevailed in Victoria. Annual tables for Australia were used for the period 1994–2008. Before 1994, it was necessary to estimate annual rates for Australia based on national life tables that were published infrequently during the 1921–1994 period and then apply national trends to the Victorian-base year. For 2009 and 2010, it was assumed that changes in mortality rates in Victoria followed the pattern observed in the 2002–2008 data. The resultant annual estimated age- and gender-specific mortality rates for the population of Victoria provided a reference measure to estimate mortality rates for persons living with NTSCI.

Applying the estimated standard mortality ratios for persons with NTSCI to the annual estimated mortality rates for the general population generated the estimated mortality rates for persons living with NTSCI. These age, gender and class of injury rates were applied each year to the prevailing prevalence population to estimate the number of survivors into the next year. The cumulative result of this process is the estimated 2010 prevalence of NTSCI in Victoria. As mortality rates for the general population have decreased over the 1921–2010 period, the use of standard mortality ratios implies declining mortality rates for persons living with NTSCI over the same time period.

**Table 1 Estimated distribution of non-traumatic spinal cord injury based on level and grade of injury**

| | % |
|---|---|
| *Thoracic/lumbar lesions (paraplegia)* | |
| Frankel D | 20.15 |
| Frankel A | 48.94 |
| Ventilator | 0.16 |
| *Cervical lesions (tetraplegia)* | |
| Frankel D | 11.34 |
| C5–C8 Frankel A | 12.75 |
| C1–C4 Frankel A | 5.54 |
| Ventilator | 1.12 |

## RESULTS

The estimated prevalence of NTSCI in Victoria, Australia on 30 June 2010 was 2034. This is equivalent to a population prevalence rate of 367.2 per million persons. There were more males with NTSCI and the prevalence was much higher among those with paraplegia and incomplete NTSCI. Ventilator dependency was extremely rare. Table 2 provides the breakdown by level and grade of injury severity and gender, giving both absolute numbers and prevalence rates per million total population. The prevalence was very strongly associated with increasing age, as is shown in the age-specific prevalence rates in Table 3. The prevalence in adults aged 16 years and older was 2027, and the prevalence rate for adults was 455 per million.

If the same age- and gender-specific prevalence rates were applied at the national level, it is estimated that there were 8133 people in Australia living with NTSCI on 30 June 2010. This translates to a population prevalence rate of 364 persons per million total population.

## DISCUSSION

We have calculated an estimate of the prevalence of NTSCI in Victoria, Australia on 30 June 2010. This estimate was based on the incidence of NTSCI for the State, the population profile and life expectancy based on Australian Bureau of Statistics data, and life expectancy for Australian persons with TSCI of the same severity of injury, by grade, level and ventilator status.

Our findings are the first estimate of the prevalence of NTSCI for Australia. A prevalence study that involved a house-to-house screening to identify people with possible neurological disorders and

**Table 2 Estimated prevalence of non-traumatic spinal cord injury for Victoria, Australia in 2010**

| | *Prevalence, n* | *Prevalence rate per million total population* |
|---|---|---|
| Male | 1097 | 197.8 |
| Female | 937 | 169.1 |
| Frankel D | 709 | 128.0 |
| Frankel A | 1316 | 237.5 |
| Ventilator | 9 | 1.6 |
| *Thoracic/lumbar lesions (paraplegia)* | 1492 | 269.3 |
| Frankel D | 463 | 83.6 |
| Frankel A | 1028 | 185.6 |
| Ventilator | 1 | 0.2 |
| *Cervical lesions (tetraplegia)* | 542 | 97.8 |
| Frankel D | 246 | 44.2 |
| C5–C8 Frankel A | 215 | 38.8 |
| C1–C4 Frankel A | 73 | 13.2 |
| Ventilator | 8 | 1.4 |
| Total | 2034 | 367.2 |

**Table 3 Prevalence of non-traumatic spinal cord injury (Victoria, Australia, 2010) by different age groups**

| *Age (range)* | *Prevalence number* | *Prevalence rate per million population*[a] |
|---|---|---|
| 0–15 | 7 | 6 |
| 16–30 | 76 | 62 |
| 31–45 | 249 | 210 |
| 46–60 | 531 | 503 |
| 61–75 | 671 | 1007 |
| 76+ | 500 | 1522 |

[a]Prevalence rates calculated using population for each age cohort.

subsequent examination by a neurology team was conducted in the Kashmir region of India in 1986.[9] The study reported a number of conditions that can cause NTSCI. The impairment-specific prevalence rates given were: poliomyelitis 2180 per million and Potts's paraplegia, hereditary spastic paraplegia and 'others' 126 per million. A recent report used the incidence rates of NTSCI previously reported for Victoria[6] and a similar population modelling approach used in this present project to calculate an estimate of the prevalence of NTSCI for Canada in 2010 of 1219 per million total population.[7]

The prevalence of NTSCI in this present study is at the lower end of the range reported for TSCI.[5] For Australia, the prevalence of TSCI reported was considerably greater, with a range of 370–681 per million.[5] It was not possible to report the prevalence by Frankel grades B and C as they were excluded from calculations in the reference paper because of insufficient numbers for credible data analysis as separate groups.[15] The only other publication from Australia that reports on survival of persons with SCI[23] was not able to be used for this project because it records only survivorship at age of injury. Prevalence estimates based on cumulative survivorship require (effectively) estimates of survivorship at each age rather than at age of injury.

There are a number of possible explanations for the difference in prevalence between Victoria and Canada. It is unlikely that the population profiles would account for the large discrepancy and both studies used cohort survival models to produce a cumulative survivor estimate of prevalence. It is more likely that the difference is due to (a) the much higher NTSCI incidence rate used in the Canadian study (67 per million compared with the 22 per per million for the Victoria study), with the Canadian incidence being determined by applying the ratio of NTSCI to TSCI from two studies to the estimated level of TSCI in Canada[8] and (b) the use of USA life expectancy[16] for the Canadian results, while this present paper used Australian standard mortality ratios.[15] The methods of the Australian and USA publications have been compared and we have not been able to identify an explanation to account for the difference. It is important to highlight that the large difference between the prevalence rates for Canada and Australia does not mean that one is right or the other is wrong but highlights both the consequences of using different data sets and the need for more direct research on NTSCI epidemiology.

Further work is planned to refine the estimates presented here and in the related Canadian study.[7] These refinements will focus primarily on the data inputs, as the cohort-survival methodology is the most suitable indirect way to estimate prevalence. With respect to this present study, there are number of topics that future research can address. This includes the age-specific incidence rates used to generate annual incidence populations. With the appropriate measures of incidence, the estimates could be refined if finer age gradations were available, particularly in the older population. The standard mortality ratios determine year-to-year survivorship, and hence are the foundation of the cumulative survivorship definition of prevalence. The most important subsequent step in refinement of the estimate of prevalence, therefore, would be to validate the age and level of injury standard mortality ratios, and to obtain them for finer age gradations, particularly in the older age groups. It is relevant to discuss the dimensions of measurement of survivorship that make it of primary importance in future research.

As there have been no studies of the survivorship (life expectancy or standard mortality ratios) of persons living with NTSCI, it was necessary for this study to consult the literature on survivorship of persons living with TSCI.[15,16] This involved the assumption that the survivorship at each age (by type and level of injury) of a person who suffers NTSCI is the same as one who suffers TSCI. There are two concerns that this assumption gives rise to, one of which is technical and one of which is functional, and both of which derive from the different pattern of age at incidence for the two causes of SCI. That is, the incidence of TSCI is highly skewed to the young adult stage of the life cycle, whereas that for NTSCI is skewed towards the older population.

The technical concern is that in the data used to estimate TSCI survivorship, the majority of the data are for young adults, with relatively few observations for the older population. This leads to the use of curve-fitting techniques to estimate mortality in the older age groups as both an input to life expectancy calculations and standard mortality ratios. The small sample sizes for the older population may explain the significant differences in life expectancy for people living with TSCI between Australia[15] and the USA.[16] This means that the survivorship rates are farthest removed from data and most reliant on curve fitting in the older population where NTSCI incidence rates are highest.

The functional concern lies with survivorship at the age of incidence. From an estimation perspective, the question that must be addressed is whether the life expectancy of an incidence occurrence of NTSCI at a specific age is (a) the same as an incidence occurrence of TSCI at the same age, (b) the same as the life expectancy of a person of that age who suffered a TSCI at an earlier age and (c) the same as the life expectancy of a person of that age who suffered a NTSCI at an earlier age. There are no data that can be used to address

this question, yet it is fundamental to understanding the relative magnitude of survivorship for those suffering TSCI and NTSCI, and to the estimate of the prevalence of persons living with NTSCI.

From this emerges the research imperative—there must be research done into the survivorship of persons living with NTSCI. Without such evidence it will not be possible to develop more accurate estimates of the prevalence of NTSCI. Supplemental research could address the reasons for the large difference between the TSCI life expectancy calculations for Australia[15] and the USA NSCISC,[16] and the relationships between life expectancy by age and age at occurrence. This research would significantly improve our understanding of the prevalence of both TSCI and NTSCI. Ideally, a population-based survey of prevalence should be performed in order to assess the accuracy of the methodology reported here, but this would be extremely expensive to conduct. The International NTSCI Data Set provides a classification scheme for NTSCI that may help to facilitate the accuracy of incidence studies of NTSCI, and thereby improve the accuracy of future prevalence modelling projects.[24]

The foregoing discussion indicates a number of limitations to this study. The incidence rate is based on data that is over 5 years old. Unfortunately it was not possible to obtain more recent data for the present project. It is anticipated that due to the aging population, the current incidence would be higher, but the age-specific rates would most likely be similar. Other limitations are the assumptions made in calculating the prevalence using the methods described and the use of data from other geographical areas. In particular, that the survival of persons with NTSCI is similar to those with TSCI, as outlined. The main concern is regarding patients with tumour causing NTSCI, who make up approximately 33% of patients referred for spinal cord rehabilitation,[25] and who tend to have a relatively poor survival rate compared with other types of NTSCI.[26]

Despite the limitations, we feel that this project has produced the most accurate estimate possible within the constraints of the resources available. Our work, although specific to Victoria, Australia, is important because it can be generalised to other regions or countries where the necessary information is available to perform the modelling that we have described.

## CONCLUSIONS

In conclusion, we have reported a method for calculating an estimate of the prevalence of NTSCI that provides information that will be vital for optimising health care planning for this group of highly disabled members of society who typically require significant and extensive care. It is suggested that refinements to the modelling methods are required to enhance its reliability, as described above.

## DATA ARCHIVING

There were no data to deposit.

## CONFLICT OF INTEREST

The authors declare no conflict of interest.

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