# Non-traumatic spinal cord injury: what is the ideal setting for rehabilitation?

#### Peter W New

#### **Abstract**

**Objective:** To survey rehabilitation physicians about management of patients with non-traumatic spinal cord injury (NTSCI).

**Methods:** Postal and email survey of Australian physicians treating adult inpatients in neurological rehabilitation or Spinal Injury Units (SIUs). 59/69 returned surveys met inclusion criteria. 75% (44) of respondents were from neurological rehabilitation units (response rate 72%) and 25% (15) were from SIUs (response rate 94%). Outcomes were: incidence of NTSCI, opinion regarding ideal setting for NTSCI inpatient rehabilitation, and availability of key services for NTSCI patients in neurological rehabilitation units.

Results: Estimated incidence of NTSCI was 26/million adults/year. 60% of NTSCI patients were managed in general neurological rehabilitation units. The majority of respondents (85% (50/59); 95% CI, 73%—92%) believed that the most appropriate setting for NTSCI rehabilitation was either an SIU or a neurological team that specialises in NTSCI patients. Neurological rehabilitation units offered NTSCI patients the following services: education regarding coping with NTSCI and preventing complications (55% [18/33]); specialised wheelchair and seating prescription (85% [28/33]); Environmental Control Unit training (36% [12/33]); and bladder training (97% [32/33]).

**Conclusions:** The most appropriate setting for rehabilitation of NTSCI patients is either a dedicated SIU or a neurological rehabilitation team that specialises in NTSCI. The organisation of inpatient rehabilitation services for NTSCI patients in Australia should be improved.

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**SPINAL CORD INJURY** (SCI) or damage from any cause is one of the most devastating medical conditions possible. It affects the ability to

#### What is known about the topic?

There are no estimates of the incidence of non-traumatic spinal cord injury (NTSCI) in Australia. In comparison to patients with traumatic spinal cord injury (TSCI), NTSCI patients tend to receive care that is fragmented and less coordinated. There has been little discussion in Australia regarding the setting of management for patients with NTSCI.

#### What does this paper add?

Australian physicians caring for NTSCI patients believe that they should receive rehabilitation in a dedicated Spinal Injuries Unit or with a specialised neurological rehabilitation team. Those not cared for in specialised units may have worse outcomes, such as longer stays in inpatient care, higher rates of discharge to nursing homes, and more preventable complications.

#### What are the implications?

There is a need to improve access and referral pathways for patients with NTSCI to specialised care and rehabilitation. A centralised register and referral system in each state for all SCI patients may help.◆

move, feel sensations, control bladder and bowel functioning, engage in sexual activity, and a range of autonomic functions.

The most common causes of non-traumatic spinal cord injury (NTSCI) are arthritic degeneration, tumours, vascular disorders and inflammation. The demographic and clinical characteristics of NTSCI are different from traumatic SCI (TSCI). NTSCI tends to affect older adults, with an even gender distribution, and

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results in SCI that is more likely to be incomplete and paraplegic.<sup>2-4</sup> There are no published estimates of the incidence of NTSCI in Australia. Overseas estimates vary between 5–80/million population/year.<sup>5-10</sup> There are, however, methodological problems with all these estimates, and the results are not generalisable to Australia.

The major disabilities necessitating inpatient rehabilitation after NTSCI are the same as those that occur after TSCI. Despite their demographic and clinical differences, patients with NTSCI and TSCI appear to have comparable outcomes regarding their initial rehabilitation length of stay (LOS) following the onset of SCI, disability at discharge, 11,12 and recovery when they are managed in spinal units or neurological rehabilitation teams that specialise in NTSCI

Because of the poorer results obtained when SCI patients were managed sporadically in small numbers in non-specialised departments<sup>14</sup> it is currently standard practice to manage acute TSCI patients in specialist Spinal Injury Units (SIUs). 15,16 Patients with SCI have improved outcomes with a specialised and systematic approach to the management of their multiple problems. 15,16 Studies have reported that a coordinated and integrated system of care for TSCI patients reduces their complications, 17,18 time from injury to rehabilitation, <sup>19</sup> LOS<sup>20</sup> and treatment costs, 17,21 and improves the efficiency of restoring functional ability<sup>19</sup> when compared with alternative models of care. In contrast, the management of NTSCI patients tends to be fragmented and less coordinated.

A recent UK survey of patients with SCI reported that fewer patients with NTSCI attended a specialist SIU, compared with TSCI patients. <sup>22</sup> The non-specialist group had statistically significant worse outcomes regarding health, self-care, and social activity. The non-specialist managed group consisted mostly of patients with NTSCI.

There has been little discussion in Australia regarding the setting of management for patients with NTSCI. Twenty years ago it was suggested that if TSCI and NTSCI patients are managed in

separate units, then a close liaison should be established between these units to help ensure optimum training of staff and patient management. Fifteen years ago, an Australian Health Ministers' report on SCI services recommended that all patients who sustained an acute SCI, including NTSCI (italic added for emphasis), should be admitted to a dedicated acute SIU. Has was acknowledged that specialist units in NTSCI might complement dedicated SIUs in providing this service. Unfortunately, since this report there has been little or no change regarding the organisation of rehabilitation services for NTSCI patients in Australia.

The primary aims of this study were to survey physicians working with adult inpatients in SIUs or neurological rehabilitation units in Australia regarding the following:

- An estimate of the average number of adult inpatients with new onset of NTSCI seen each year. Based on this, it was planned to calculate a rough estimate of the incidence of NTSCI.
- The setting in which NTSCI patients should ideally be managed. It was hypothesised that there would be no influence on this opinion by the number of years post specialist qualification, or whether respondents worked in an SIU or a neurological rehabilitation unit.
- The key SCI services NTSCI patients are offered in neurological rehabilitation units.

A secondary aim of this study was to compare the survey results with data from the Australasian Rehabilitation Outcomes Centre (AROC).

AROC is an initiative of providers, funders, regulators and consumers in the Australian rehabilitation sector (http://www.uow.edu.au/commerce/aroc/). AROC maintains a database of inpatient rehabilitation outcomes from public and private hospitals that differentiates between NTSCI and TSCI.

#### **Methods**

#### Survey development and distribution

Two related surveys were developed by the author. One version was for rehabilitation physi-

cians in adult neurological rehabilitation units and the other was for physicians in designated SIUs (copies of surveys available on request).

Questions were asked about respondents' practice location, public or private/compensation funding sources, specialist training, and practices involving the management of adult inpatients with TSCI and NTSCI. The survey asked for a reason if the unit where the respondent worked did not manage NTSCI patients, and if the SIU had any selection bias for admission of TSCI over NTSCI patients. The survey asked about the estimated average number of inpatients with new onset of NTSCI each year that were managed by the respondent. An opinion was sought from respondents regarding where NTSCI patients should ideally be managed. It was planned to compare the practices and opinion of physicians in dedicated SIUs with those working in neurological rehabilitation. Neurological rehabilitation unit respondents were also asked about the provision of the following key specialist services to NTSCI patients: education for patients about coping with their SCI and the prevention of complications; specialised wheelchair and seating prescription; Environmental Control Unit training; and bladder training. No assessment was made regarding the quality or comprehensiveness of these various specialised services. Designated SIUs were not asked about these because they are standard practice in all Australian SIUs.

The neurological rehabilitation survey was distributed to all Australian consultant physicians who are Fellows of the Australasian Faculty of Rehabilitation Medicine (AFRM) in the June 2004 edition of the Faculty newsletter. Relevant copies of each survey were also emailed to members of the AFRM neurological rehabilitation and SCI Special Interest Groups, and members of the Australian and New Zealand Spinal Cord Society in April, June and October 2004.

The AFRM has advised that there were about 200 rehabilitation medicine consultant physicians in clinical practice at the time of conducting this survey. No information, however, is

available regarding the exact number of Fellows working in neurological rehabilitation, but 61 Fellows were registered with the neurological rehabilitation Special Interest Group (personal communication, Sybil Cumming, Executive Officer, AFRM). This number was used for calculating the response rate for this sub-group. Membership of the Special Interest Groups is free and open to any member of the Faculty.

The Heads of the six SIUs in Australia were contacted. They were asked to provide information regarding the numbers of doctors clinically involved with the rehabilitation of adult SCI inpatients in their units, and to distribute the survey to these staff, if they had not already received a copy. There were 16 rehabilitation doctors working in SIUs at the time of the survey.

Medical practitioners were included in the survey only if they were in clinical practice in adult rehabilitation medicine in Australia involving inpatients with SCI or neurological disorders at the time the survey was conducted. It was believed appropriate to restrict inclusion to this group of medical practitioners because it was considered an important requisite for this survey to involve only those with relevant clinical experience in the field. This way, an opinion from a relevant group of experts in the field could be obtained. Based on current guidelines, ethics committee approval was not obtained for this project.<sup>25</sup>

#### AROC data

Data were supplied by AROC with no identifying patient information, based on the pooled information from all separations for the year 2004–05.

### Data analysis

Survey results were entered into an Excel 97 spreadsheet (Microsoft Corp, Redmond, Wash, USA) and then imported into STATA, intercooled version 6.0 for Windows (Stata Corp, College Station, Tex, USA) for statistical analysis. The Wilcoxon rank-sum (Mann–Whitney) test was used to assess for a difference in the median

	% (no.)
tate of practice	
New South Wales	46% (27)
/ictoria	25% (15)
Queensland	8% (5)
South Australia	5% (3)
Australian Capital Territory	3% (2)
Tasmania	3% (2)
Northern Territory	2% (1)
Western Australia	2% (1)
SA and NT	2% (1)
Unknown	3% (2)
Payment source	
Public hospital	48% (28)
Private/compensation	14% (8)
Both public and private	36% (21)
Unknown	3% (2)

number of patients managed by SIU doctors and neurological rehabilitation doctors. The  $\chi^2$  test was used to assess any difference in the opinion between SIU doctors and those in neurological rehabilitation regarding the ideal setting for the rehabilitation of patients with NTSCI. The Kruskal–Wallis method of one-way ANOVA was used to assess the influence of the number of years post-specialist qualifications on practitioners' beliefs about the ideal setting of rehabilitation. P values of 0.05 or less were deemed statistically significant.

Totals not 100% because of rounding.

#### Results

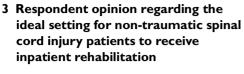
Sixty-nine surveys were returned by November 2004, and 59 met the inclusion criteria. Ten surveys were excluded because clinicians were not clinically involved in neurological rehabilitation (n = 5), they worked in paediatric neurological rehabilitation (n = 4) and because another survey was completed jointly with a colleague

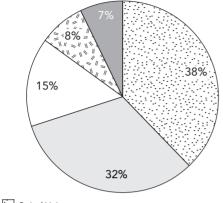
(*n* = 1). Respondent doctors held a median of 11 years (interquartile range [IQR], 5.5–19; range, 0.5–32) post-specialist qualifications. The state of origin of respondents matched the known distribution of rehabilitation physicians (personal communication Sybil Cumming, Executive Officer, AFRM), and most worked at public hospitals (Box 1). Thirty-seven respondents (63%) worked in a state capital, 18 (31%) in a regional city and 2 (3%) in a remote area. This information was missing from two returns (3%).

A summary of survey responses is shown in Box 2. Respondents estimated that a total of 414 patients with new onset of NTSCI were seen each year. Based on Australian Bureau of Statistics population data for Australians 15 years and older, the estimated incidence of NTSCI was 26/million adults/year. Fewer NTSCI patients were managed in dedicated SIUs compared with neurological rehabilitation units. However, doctors working in SIUs each managed a statistically significant (Mann–Whitney test, z = -2.9, P = 0.004) greater number of patients (median, 10; IQR, 6–20) than those working in neurological rehabilitation units (median, 5; IQR, 3–10).

Almost all SIU physicians reported that they also managed patients with NTSCI, however 67% (10/15) reported preferential admission for

	Neurological Rehabilitation Unit (75%; <i>n</i> =44)	Spinal Injury Unit (25%; <i>n</i> =15)
Estimated response rate from potential respondents	72% (44/61)	94% (15/16)
Estimated total number of NTSCI patients seen/year (%)	250 (60%)	164 (40%)
Manage TSCI patients	37% (15/44)	100% (15/15)
Manage NTSCI patients	81% (36/44)	93% (14/15)





- Spinal Unit
- Specialist neurological rehabilitation team
- Spinal Unit or specialist neurological rehabilitation team
- Any neurological rehabilitation unit
- Other

patients with TSCI. The reasons given for this bias were: excluding patients with metastatic cancer (n = 4); NTSCI considered less urgent (n = 4); and excluding older patients (n = 2).

Although most neurological rehabilitation physicians managed patients with NTSCI, 18% (8/44) did not. The reasons given for this included the lack of necessary expertise (n = 5), NTSCI patients being managed by a specialist SIU on site (n = 2), and not being referred NTSCI patients (n = 1).

#### Physicians' opinion on the ideal setting

The opinion of respondents regarding the ideal setting for NTSCI patients to receive inpatient rehabilitation is shown in Box 3. Most respondents (85%; 95% CI, 73%–92%) indicated that either a dedicated SIU or a neurological rehabilitation team that specialises in NTSCI patients was the ideal. The four respondents (7%; 95% CI, 2%–16%) who gave "other" as the best setting all reported that they believed that there

was not a straight forward answer to this question. They indicated that it depended on numerous factors, such as age, or level and completeness of SCI. Another four respondents added similar sentiments to their initial answer. Only five respondents (8%; 95% CI, 3%–18%) nominated "any neurological rehabilitation unit" as the ideal setting.

There was no statistically significant relationship between the opinion of doctors regarding the ideal setting for rehabilitation of NTSCI patients and whether the doctor practised in an SIU or neurological rehabilitation unit ( $\chi^2_2 = 3.2$ ; P = 0.5). There was no relationship between the opinion of doctors regarding the ideal setting for rehabilitation and number of years post-specialist qualifications (ANOVA F = 0.3; P = 0.7).

# 4 AROC 2004-05 inpatient rehabilitation LOS in different impairment groups

Impairment groups	% (no.)	Median LOS (days)	Interquartile
Traumatic SCI	1.1 (454)	18	10–41
Non-traumatic SCI	0.6 (275)	36	15–88
Other SCI*	0.2 (81)	45	31–66
Stroke	11.0 (4747)	21	13–35
Brain dysfunction	3.6 (1539)	21	13–37
Neurological	4.7 (2035)	16	11–26
Amputation – lower limb	2.1 (900)	28	14–45
Orthopaedic	43.0 (18 494)	14	10–21
Arthritis	1.5 (630)	12	9–16
Debility	10.9 (4706)	14	10–21
Cardiac	5.1 (2192)	12	8–17
Pulmonary	2.8 (1225)	14	10–19
Other <sup>†</sup>	13.2 (5692)	14	10–23

<sup>\*</sup>Other SCI are episodes that are not identified as traumatic or non-traumatic (invalid spinal cord code used). †Other episodes comprised of: amputation (upper limb, other), pain, burns, congenital deformity, other disabling impairment, major multiple trauma, developmental disabilities. SCI = spinal cord injury. LOS = length of stay.

# Specialist services in neurological rehabilitation units

Neurological rehabilitation units offered NTSCI patients the following specialist services: education about learning to cope with SCI and prevent complications (55% [18/33]); specialised wheelchair, cushion and mattress prescription (85% [28/33]); Environmental Control Unit training for tetraplegic patients (36% [12/33]); and bladder training (including teaching intermittent catheterisation) (97% [32/33]).

#### **AROC** results

In the financial year 2004-05 there were 43 038 inpatient admissions recorded in the AROC database. The inpatient rehabilitation LOSs for NTSCI patients and other impairment groups are shown in Box 4. There were data contributions from five of the six SIUs in Australia and 104 of the 124 non-SIU rehabilitation units. AROC data on the management of NTSCI patients showed that 61% (168) were managed in one of the five dedicated SIUs and 39% (107) were managed in 46 other rehabilitation hospitals. The number of NTSCI patients managed in each SIU (median 35; IQR, 15-49) was significantly greater than the number of patients managed in each non-SIU rehabilitation hospital (median 1.5; IQR, 1-3) (Mann-Whitney test z =-8.6; P < 0.0001).

#### **Discussion**

### Incidence of NTSCI

The estimated incidence of NTSCI in Australia is consistent with overseas estimates, and is almost double the current reported incidence of TSCI in Australia, of 15.3/million adults/year.<sup>27</sup>

The LOS for NTSCI patients tends to be relatively lengthy in both acute hospital (geometric mean 31 days) and inpatient rehabilitation (geometric mean 56 days)<sup>12</sup> compared with other impairment groups (Box 4). The indirect costs and financial burden of caring for these patients are enormous. Age-related factors are estimated to be responsible for half the causes of

NTSCI.<sup>4</sup> It is estimated that the population aged over 65 years will double over the next 40–50 years.<sup>28</sup> Therefore, it is anticipated that the incidence of NTSCI will also dramatically increase over the coming decades, with major implications regarding the organisation and delivery of rehabilitation, support services, and ongoing care for NTSCI patients.

# Specialist services and rehabilitation setting

The assertion that specialist teams should manage NTSCI patients, based on the results of this present study and the patient survey,<sup>22</sup> corresponds with level IV evidence using National Health and Medical Research Council guidelines.<sup>29</sup> This is an appropriate level of evidence to guide clinical practice on this issue given the challenges of conducting more rigorous studies. A recent editorial in the journal *Spinal Cord* argued strongly that NTSCI patients should receive equal access to care in SIUs, and asserted that a matched case—control study would not be ethical or practical.<sup>30</sup>

Excluding the compensation system entitlement of patients to private hospital treatment, in no other area of rehabilitation in Australia are patients given preferential access to specialist services on the basis of the aetiology of their impairment. Patients with limb amputation, for example, are not segregated into different units on the basis of whether their amputation was due to trauma or vascular disease.

The rehabilitation team members who care for SCI patients have specialised skills and areas of expertise, acquired through years of training, clinical practice, and treatment of a critical mass of SCI patients. These are essential to achieving optimal patient outcomes, and preventing or treating SCI complications, and are not generic to all rehabilitation unit teams.

The survey results and AROC data show that a considerable proportion of patients with NTSCI do not have access to rehabilitation in an SIU. Medical practitioners in SIUs tend to manage significantly more NTSCI patients than their colleagues in general neurological rehabilitation

units. They would be expected to have more clinical experience and expertise with managing the complex problems encountered in these patients. Many NTSCI patients managed in neurological rehabilitation units do not have access to important SCI specialist services. This applies especially to education about their condition, and to a lesser extent, appropriate wheelchair and seating prescription. This suggests that general neurological rehabilitation units may have inadequate resources to provide NTSCI patients with the advice, therapy and equipment they require.

#### Outcomes and resource utilisation

Although NTSCI patients are not a large group, their management is an important public health issue because of the burden of disability and the cost of their subacute and ongoing community care

A previous survey has concluded that NTSCI patients managed in non-specialist settings have worse outcomes.<sup>22</sup> The results presented here reinforce the possibility that NTSCI patients managed in general neurological rehabilitation units may have worse outcomes (eg, longer rehabilitation LOS and higher discharge to nursing homes) and more preventable complications (eg, pressure ulcers, and readmissions into hospital post-discharge).

# Suggestions to improve the management of patients with NTSCI

A more integrated and coordinated system for the management of NTSCI patients should be developed. This process should involve the following groups: State Departments of Health, Australasian Faculty of Rehabilitation Medicine, Australian and New Zealand Spinal Cord Society, regional health networks, all SIUs, key neurological rehabilitation centres, and community support agencies.

Where needed, specialist neurological rehabilitation teams that manage NTSCI patients should be established within the network of existing inpatient rehabilitation facilities. This applies especially where existing SIUs do not

admit these patients. This is essential to improving the care and long-term management of NTSCI patients.

It is suggested that a centralised referral and register system be developed in each state to facilitate the triage and transfer into rehabilitation of all TSCI and NTSCI patients, as has been implemented elsewhere. As occurs with TSCI, immediate referral by acute hospitals of NTSCI patients should also be encouraged to facilitate the involvement of a consultant with expertise in SCI medicine. This would be to provide advice regarding the management of the consequences of SCI during the acute medical phase, and to help prevent secondary complications, such as pressure ulcers and contractures.

There should be a close and formalised relationship between the various centres within each state that manage patients with TSCI and NTSCI. The access to care provided by palliative care, renal dialysis and tertiary pain management centres are ideal models of care for this type of service. Ideally, there should be sharing and pooling of resources between different centres to improve efficiency and patient treatment options. This applies particularly to sexual counselling, gait laboratory services, seating clinics and Environmental Control Unit assessment and training.

#### Limitations

There was difficulty in ascertaining the exact number of specialists working in the clinical management of adult inpatients in neurological rehabilitation units in Australia. As a result, it is not possible to know the exact response rate for this sub-group of the study sample. This is particularly relevant for the question regarding the ideal setting for the rehabilitation of NTSCI patients. If the opinion of non-responders was significantly different from responders, this could affect the generalisability of the results. The response rate from SIUs, however, was excellent, and the opinion was strongly in favour of either a designated SIU or a dedicated neurological rehabilitation team.

A limitation of the AROC data was that there was not complete capture of admissions from all rehabilitation hospitals in Australia in 2004–05. Importantly, only one public rehabilitation hospital in Victoria, that included the dedicated spinal unit, contributed data to AROC in 2004–05, meaning that there would be many NTSCI patients from Victoria not included. Overall, there were 20 rehabilitation units Australia-wide in 2004–05 that did not contribute data to AROC. For this reason, the AROC information was not used for the estimate of the incidence of NTSCI

The estimate of the incidence of NTSCI is the most accurate available at present for Australia. It is consistent with overseas estimates of NTSCI. It is, however, only a rough estimate. The estimated incidence would be reduced by non-responders, and patients not referred to rehabilitation but managed elsewhere, such as a hospice. The estimate could be increased by the possibility of double-counting patients initially managed in one setting and later transferred to another. Although this occurs, it is probably quite uncommon overall. A population-based study is planned that will provide a more reliable estimate of the incidence of NTSCI

#### **Conclusions**

Further studies are required to determine a more accurate estimate of the incidence of new NTSCI in Australia.

There is a discrepancy between the ideal setting of rehabilitation for NTSCI patients and where they actually receive their rehabilitation.

## **Implications**

The most appropriate setting for the rehabilitation of NTSCI patients is in either a dedicated SIU, or a neurological rehabilitation team that specialises in NTSCI patients. The organisation of rehabilitation services for patients with NTSCI in Australia should be improved.

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## **Competing interests**

The author declares that he has no competing interests.

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