

ORIGINAL ARTICLE

International comparison of the organisation of rehabilitation services and systems of care for patients with spinal cord injury

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Study design: Survey.

Objectives: Describe and compare the organisation and delivery of rehabilitation services and systems of care for patients with spinal cord injury (SCI).

Setting: International. Nine spinal rehabilitation units that manage traumatic SCI and non-traumatic SCI (NTSCI) patients.

Methods: Survey based on clinical expertise and literature review. Completed between November 2010 and April 2011.

Results: All units reported public/government funding. Additional funding sources included compensation schemes, private insurance and self funding. Six units had formal attachment to an acute SCI unit. Five units (Italy, Ireland, India, Pakistan and Switzerland) provided a national service; two units (the Netherlands and USA) provided regional and two units (Australia and Canada) provided state/provincial services. The median number of SCI rehabilitation beds was 23 (interquartile range = 16–30). All units admitted both traumatic SCI and NTSCI patients. The median proportion of patients admitted who had traumatic SCI was 45% (IQR 20–48%) and 40% (IQR 30–42%) had NTSCI. The rehabilitation team in all centres determined patient readiness for discharge. There was great variability between units in the availability of SCI speciality services, ancillary services and staff/patient ratios.

Conclusion: There was a wide range of differences in the organisation, systems of care and services available for patients with SCI in rehabilitation units in different countries. Understanding these differences is important when comparing patient outcomes from different settings. A standardised collection of these system variables should be considered as part of future studies and could be included in the ISCoS data set project.

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Keywords: Spinal cord diseases; rehabilitation; health care surveys, delivery of health care; outcome assessment (health care); multi-center study

INTRODUCTION

Non-traumatic spinal cord injury (NTSCI) is an important cause of spinal cord damage. Despite research suggesting that NTSCI may be more common than traumatic SCI (SCI),¹ there is a relative paucity of literature regarding the epidemiology and rehabilitation outcomes of patients with NTSCI. Most reports about NTSCI patients are typically from single centres and involve relatively small numbers of patients,^{2–5} although some multi-centre studies have been published.^{6,7}

Rehabilitation outcomes following traumatic SCI are influenced by a variety of clinical factors, including injury severity, disability at admission and age.^{8–10} These factors have also been identified as important in patients with NTSCI.^{3,11}

In addition to clinical factors, it is suggested that the hospital processes and systems of care influence outcomes for rehabilitation

patients, including those with spinal cord disease or damage from any cause. These non-clinical factors include the following: referral patterns; selection criteria for admission into rehabilitation;¹² the range of available therapy options and services; the intensity of therapy;¹³ and post inpatient therapy and follow-up review, including programs for health maintenance and prevention. For this reason descriptions of the health care setting are an important component of research reports. The Strengthening the Reporting of Observational Studies in Epidemiology statement guidelines¹⁴ recommend describing the following: the settings and locations; relevant dates (including periods of recruitment, exposure, follow-up and data collection); participant details, including the eligibility criteria, and the sources and methods of selection of participants. In most research reports, publication word limits restrict the amount of detail provided about the above descriptors. Comparing rehabilitation outcomes

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between studies conducted in different settings without describing the setting in adequate detail, including the non-clinical factors listed above, limits the ability to interpret findings, particularly for units from different regions or countries. There are very few international comparative reports of the services and types of programs offered to patients in spinal rehabilitation units (SRU).¹⁵

Our group, the International Non-traumatic SCI Study Group, recognised the need for large, international, collaborative multi-centre research on NTSCI. Preliminary discussions between the principal investigator (PWN) and a number of co-authors (AT, GS, MWMP, ES and RR) were held at the 2009 International Spinal Cord Society Meeting in Florence, Italy. Over the following year email discussions progressed planning for research activities and efforts were made to recruit additional units (see below). In response to the relative paucity of literature regarding NTSCI the group's overall objective is to compare and contrast the rehabilitation outcomes for NTSCI patients in different countries.

The aim of this project was to survey the units involved in the Study Group in order to describe and compare the organisation and delivery of inpatient rehabilitation services and systems of care for patients in participating SRU. The rationale for this was to: (a) benchmark between the units, (b) highlight opportunities to improve systems of care and service delivery and (c) provide an understanding of the context of the SRU and the similarities and differences between them as this will be important for interpreting the results from subsequent phases of this project when patient outcomes are reported.

METHODS

A survey was developed by the principal investigator (PWN) based on clinical expertise and a literature review relevant to the survey focus. Feedback was obtained from an international colleague with expertise in SCI research and modifications subsequently made before the survey was finalised. Most survey questions were about SCI patients in general (that is, did not distinguish between traumatic SCI and NTSCI), except for four questions regarding admission criteria for patients with malignancy and spina bifida.

The participating units were selected by the principal investigator on the basis that they comprised a broad international representation of inpatient SRUs, including a mix of developed and developing countries. It was initially intended to include at least one unit from each continent. Despite our best efforts, and some preliminary interest from a number of centres, no SRU from South America or Africa was identified that met the inclusion criteria. The inclusion criteria were that units treated an estimated minimum of 50 adult patients over a 3-year period with recent onset of NTSCI and were willing to participate in the project. Exclusion criterion was the participation of another unit from the same country.

The survey was completed electronically by a representative from each of the participating units between November 2010 and April 2011. Some clarification of responses occurred up till September 2011. Descriptive analysis was performed with the median and interquartile range (IQR) reported for numerical data not normally distributed. Approval for the project was obtained from the Alfred Health Human Research and Ethics Committee.

RESULTS

Nine units agreed to participate in this project and completed the survey. The names of participating SRU, their location and country, funding sources, relationship with acute hospitals, catchment and referral process are shown in Table 1.

Details about the number of rehabilitation beds and patient case-mix in the units, including age restriction, differences in selection priorities and determination of readiness to discharge are shown in Table 2. All units reported that patients had equal access to rehabilitation beds irrespective of aetiology of their spinal damage—

that is, they did not have a bias against patients with either traumatic SCI or NTSCI—and that the typical location of patients before admission into the SRU was an acute hospital. The approach regarding admission of certain aetiologies of NTSCI that can be contentious (spina bifida and malignancies) was similar along the different units.

There was a notable variation in the staffing ratios of the rehabilitation units, most prominently for nursing staff, as well as a major variation in the intensity of therapy provided to patients Table 3. All units had as the clinical head a physician trained in rehabilitation medicine (physiatry). As noted in Table 2, some units manage patients with neurological impairments other than spinal cord damage. For these units (Australia, Ireland, India and USA), the staffing ratios provided do not pertain just to SCI patients, but apply to all impairment groups cared for in these units. The secondary, or non-core therapists, ancillary services and relevant support programs available to in patients are detailed in Table 4.

A number of units offered a range of group programs for patients in addition to individual therapy sessions. The groups offered by units included the following: wheelchair skills ($n=4$), fitness ($n=4$), hand function/upper limb ($n=4$), health education ($n=4$), breakfast/lunch ($n=3$), community outing ($n=3$), woodwork ($n=3$), balance ($n=2$), gardening ($n=2$), relaxation ($n=2$), hydrotherapy ($n=1$), running ($n=1$), transfer skills ($n=1$) and vocational retraining ($n=1$).

DISCUSSION

This survey is the first published comprehensive comparison of the organisation of services and systems of care for patients in SRU. We have shown that there is a wide range in these parameters between countries. It is likely, for the reasons given above, that these differences influence patient outcomes from rehabilitation, both in the short and longer terms.

The need for multi-centre studies of NTSCI has been highlighted¹⁶ and our Study Group is planning on conducting these in the future. Understanding the similarities and differences between different rehabilitation units is vital for interpreting patient outcomes when multi-centre studies are undertaken. The results reported here will be essential to fully appreciate the findings of our outcome studies. Our results also now allow benchmarking between units and highlight opportunities to improve systems of care and service delivery by identifying services and systems of care that can be implemented where they are not currently available.

It is not surprising, given the aim of the project, that NTSCI patients represented a noteworthy proportion (40–80%) of patients admitted to participating SRU. This is in agreement with previous studies¹ and underlines the need for more comprehensive epidemiological studies on these patients. It has been reported that in Australia NTSCI patients tend to receive care that is fragmented and less coordinated but that most rehabilitation physicians believe that they should receive rehabilitation in a dedicated SRU.¹⁷ Patients not cared for in specialised units may have worse outcomes, such as greater disability at discharge,¹⁸ longer hospital admission, higher rates of discharge to nursing homes and more preventable complications.

The staffing ratios reported for the units that also treated non-SCI patients make comparisons more difficult. These units indicated that patients with SCI typically required a much greater amount of care than patients with other impairments. It was not possible, however, to specify exactly how much extra care this entailed.

It is interesting to note that most units have similar approaches regarding the admission of patients with malignancy and spina bifida.

Table 1 Hospital setting, interaction with acute hospitals and referral processes

	Australia	Canada	Italy	Ireland	India	Netherlands	Pakistan	Switzerland	USA
City Hospital	Meilbourne Spinal Rehabilitation Unit, Caulfield Hospital	Vancouver GF Strong Rehabilitation Centre	Rome IRCCS Fondazione S Lucia	Dublin National Rehabilitation Hospital	Bangalore National Institute of Mental Health and Neuro Sciences	Utrecht De Hoogstraat	Rawalpindi Armed Forces Institute of Rehabilitation Medicine	Nottwil Swiss Paraplegic Center	Rochester Minnesota Saint Marys Hospital
Funding sources	Government Compensation	Government Compensation	Government	Government	Government Private Insurance Compensation	Private Insurance	Government Private Insurance Self Funding	Government private Insurance Compensation Swiss Paraplegic Foundation	Government Private Insurance Compensation Self Fund
Direct links between SRU and acute SCI unit	No	Yes	No	Yes	No	Yes	Yes	Yes	Yes
Relationship between SRU and referring hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Informal link with many acute hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Formal link with many acute hospitals Informal link with many acute hospitals	Formal link to one acute hospital Informal link with many acute hospitals	Formal link to many acute hospitals
Catchment	State-wide	State-wide	Whole country	Whole country	Whole country	Regional	Whole country	Whole country (3 other SCI centres)	Regional National and International Referral Centre
Overlap with other SRU	Yes	No	Yes	No	Yes	No	No	Yes	Yes
Estimated population adults over 18 years in catchment	4 400 000	3 500 000	Unable specify	3 100 000	Unable specify	2 000 000	1 770 000	6 000 000	3 000 000 (primary catchment area)
Formal written criteria for patient admission	No	Yes	No	Ventilator dependent patients excluded	No	No	No patients with MRSA or similar infections excluded	No	Yes
Typical process in SRU for referral and screening for potential patients for admission with recent onset of acute SCI of any cause?	Acute hospitals contact unit directly or a central hospital-wide 'access unit' with referral details. Patient accessed by consultant or trainee in rehabilitation medicine in the acute hospital for eligibility, advice. If ready put on waiting list. If not ready, then phone/face-face reviews until ready.	Consultation/screening if in a hospital with a rehabilitation physician. If not then screening form is completed to identify medical issues and rehab goals and a liaison therapist screens the referral/gathers more information to bring to the medical director for the unit.	Admission proposal sent from acute hospital with essential clinical information. Sometimes phone call made to obtain more information.	In the acute spinal unit, patients are assessed by Rehab physician. If in acute hospitals, patients might be assessed by the SCI liaison nurse or might be admitted based on information provided by the referring team and direct communication between nursing staff.	Primarily referrals from Institute's Department of Neurology and Neurosurgery. Other patients screened by our outpatient service.	In main acute hospital; referral by the SCI physiatrist who also works in the rehab centre. Other hospitals: referral by local physiatrist after deliberation with SCI physiatrist.	Unit is in a military hospital primarily for military personals and their dependant. Majority of referral are from other military hospitals. Rehabilitation physicians in these units makes the referral which is triaged.	Patients are admitted in acute phase directly to our hospital or after stabilisation in other hospitals. Some patients are referred from other SCI centres or neurological rehabilitation centres. A minority of patients come from overseas (Arabic countries, Germany, France and Italy mostly). For patients admission has to be discussed with a senior physician. Planning and coordination by patient administration.	Most patients are seen in acute care by rehabilitation physicians and therapists. Records are reviewed and summarised by admissions coordinators for referrals from outside our acute care system. Payment approval is arranged before admission.

Abbreviations: SCI, spinal cord injury; SRU, Spinal Rehabilitation Unit.

Table 2 Rehabilitation beds and patient case-mix

	Australia	Canada	Italy	Ireland	India	Netherlands	Pakistan	Switzerland	USA	Median, IQR
Number of beds	10	24	23	35	15	30	20	132	16	23
Fixed or variable number of beds	Variable	Fixed	Fixed	Variable	Variable	Variable	Fixed	(includes acute) ^a Fixed		16-30
Estimated annual admissions of patients with any neurological impairment (acute or chronic)	50	110	50	130	150	87	282	150	800	130
Approximate proportion of patients over the past 12 months with:										
Traumatic SCI	18%	60%	45%	44.5%	20%	45%	48%	55%	5%	45%, (20-48)
NTSCI	80%	40%	42%	32.8%	30%	45%	6%	40%	20%	40%, (30-42)
Other neurological conditions	2%	0%	2%	22.7%	50%	10%	46%	5%	75%	10%, (2-46)
Age restriction on admission	Yes	Yes	Yes	Yes	No - any age	Yes	Yes	Yes	No - any age	
Determination of discharge readiness	over 16 years	Over 12 years	Over 14 years	Over 18 years	Rehab team	Over 18 years	Over 14 years	Over 14 years	Rehab team	
Routinely admit patients with benign tumour causing their NTSCI	Rehab team	Rehab team	Rehab team	Rehab team	Rehab team	Rehab team	Rehab team + funding limits	Rehab team	Rehab team	
Routinely admit patients with malignant tumour causing their NTSCI	Yes	Sometimes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	
Processes or systems used to screen patients with malignant tumours	Prognosis > 3 months, preferable longer. Strong family supports and no major environmental barriers are also important factors. Chemotherapy and radiotherapy during course of rehabilitation not absolute contraindication to admission.	Depends on neurologic impairment, other treatments (e.g. radiation or chemo and ability to participate in rehab).	Must be physically able to tolerate intensive rehabilitation. Prognosis > 6 months. Not needing additional treatment (radio or chemotherapy) not available at our centre.	Primary or secondary disease with prognosis > 1 year.	All patients who can be helped in improving their ADL admitted irrespective of prognosis.	Prognosis > 1 year. Duration of stay is limited to 6 weeks and the programme is focussed on adaptations and assistive devices.	Rarely referred.	Dependent on life expectancy. Life expectancy however is a subjective 'Rule'. There are no exact guidelines for this, this also depends on the goals for rehab.	The screening is the same for all patients. (1) can they participate and however is a benefit from intense rehabilitation? (2) Are they medically stable enough to participate?	
Routinely admit adult patients with spina bifida	Sometimes	No	Sometimes	Occasionally	Sometimes	Yes	Yes	Yes	Rarely	
Clarification	Need to prioritise for patients with recent onset SCI. These patients typically are admitted to other-rehabilitation units.	They are rarely admitted. Only admit 'new' injuries and rarely admit patients with chronic conditions. These patients typically are admitted to other-rehabilitation units.	Due to the paucity of dedicated beds for SCI patients, we usually only admit patients with new onset SCI. These patients typically are admitted to other-rehabilitation units.	These patients typically are admitted to other-rehabilitation units.	These patients typically are admitted to other-rehabilitation units.	These patients typically are admitted to other-rehabilitation units.	These patients typically are admitted to other-rehabilitation units.	If an acute condition leads to a significant functional deterioration an adult with spina bifida would be considered for admission just like any other chronic neurological condition.		

Abbreviations: ADL, activity of daily living; NTSCI, non-traumatic SCI; SCI, spinal cord injury.
^aIncludes acute and rehabilitation beds. Rehabilitation starts in acute phase and there is a blurring of boundaries between when acute care finishes.

Table 3 Spinal rehabilitation unit staffing and therapy intensity

	Australia	Canada	Italy	Ireland	India	Netherlands	Pakistan	Switzerland	USA	Median, IQR
<i>Unit staff EFT/10 beds</i>										
Rehab physician	0.4	0.35	1.3	0.25	1.0	0.6	0.5	0.8	0.5	0.5 (0.4–0.8)
Other physicians	Nil	0.4	0.2	Nil	Nil	Nil	Nil	1.0	Nil	
Junior medical staff	1.0	0.2	Nil	0.9	2.0	0.5	1.0	1.4	2.0	1 (0.7–1.7)
Nursing staff	2.4	4.1 day 3.3 evening 1.2 nights	3.0 morning, 2.0 afternoon 0.9 night	Morning shift: 2.3 nurse, 2.1 HCA evening shift: 1.5 nurse, 1.4 HCA night: 1.1 nurse, 1.3 HCA	3	9.6 (5.6 Skilled nursing and 4.0 other nursing) 3.3 morning, 1.3 evening 0.7 night	1.0	1.5	3.0	2.0 (1.5–2.9)
Physiotherapy	1.7	2.0 + Physio assistant 0.4	2.6	2.3 + 0.6 Physio assistants/sports therapist	2	1.6	0.5	2	2.5	2 (1.7–2.5)
Occupational therapy	2.0	1.7 + assistant 0.4	0.3	1.6 + 0.4 OT assistant, woodwork instructor, recreational therapy	1	1.6	Nil	1.7	2.5	1.9 (1.3–2.1)
Social work	0.7	0.8 + 0.1 assistant	0.1	0.9	1	0.6	0.5	0.4	0.7	7 (0.54 – 0.9)
Clinical psychology	0.2	On referral (0.2 estimate)	0.4	0.3	1	0.2	0.5	0.9	0.5	4 (0.2 – 0.5)
<i>Therapy intensity</i>										
Days per week therapy available	5	5	5	5	5	5	5	7	7	5 (5–5)
Estimated average hours per day of therapy patients receive ^a	2	2.5	4	5	>2	2–3	2	5	3.5	2.5 (2–4)

Abbreviations: EFT, effective full time staff; HCA, health care assistant; OT, occupational therapist.

^aIncluding all direct individual and group activities. Not including activities patient performed independently or volunteer assisted therapy.

All units admitted patients with malignant tumour causing their NTSCI and there was a similarity of screening parameters: prognosis of 3 months or longer, stable medical condition and for many not needing additional treatments. It has been reported that the primary barriers to rehabilitation for cancer patient were the neurological status, their oncologic and medical conditions (in particular their prognosis and the medical stability) and pain.¹⁹ Some of these criteria also represented part of the screening parameters of the units. Obviously the neurological status and the presence of pain do not represent a limitation to the admission of NTSCI patients and this is an advantage of referring patients to specialised SCI units. An influential factor in this respect might also be that SCI rehabilitation teams are familiar with pain management as it is a common aspect of SCI care. The admission of patients with cancer to rehabilitation is still a matter of debate for some. A study of rehabilitation centres in France reported that some facilities did not admit cancer patients due to poor experience or lack of concern by the unit.²⁰ However, about half of the deceased patients with metastatic spinal cord compressions in one study died because of complications of SCI (such as pressure sores and pneumonia) rather than because of progression of neoplastic disease.²¹ Patients with spina bifida are admitted in only half of the centres due to the need to prioritise for patients with recent onset SCI.

Only one previous comparative report of the services and types of programs offered to SCI patients in SRU has been located.¹⁵ This compared units in Denmark, Russia, Lithuania and Israel. A wide range in staff ratios and facilities were described. A recent publication has highlighted differences between units in the Netherlands, Norway and Australia regarding the provision of physiotherapy and occupational therapy to patients with NTSCI and traumatic SCI.²²

The results presented here mirror those in the above studies regarding there being many differences in the organisation of care, particularly with regard to intensity and staff ratios. Although the variety of services varied, our study illustrates that patients admitted to SRU have access to a many specialist services that are not available in general rehabilitation facilities. The implications of this have been discussed previously.¹⁷

A limitation of this report is that the units were selected in a non-random manner and the results would not necessarily be generalisable. Because the inclusion criteria required a minimum of 50 NTSCI patients over three years, and units admitted both traumatic SCI and NTSCI patients, the results serve as a useful benchmark for comparison for larger centres. We acknowledge that the levels of experience and exposure staff have to training and development opportunities relating to SCI is another variable that can influence patient outcomes. Also, many patients with SCI in developing countries are often cared for by family members, even within rehabilitation units, often due to a lack of resources and staff. We did not consider staff experience and training opportunities or family involvement with direct patient care in our survey.

It is well recognised that rehabilitation medicine is a complex, multi-faceted intervention, which has been described as a 'black box'.²³ In recent years there have been a number of projects that have sought to 'unwrap' the complexity of rehabilitation,²⁴ including SCI.²⁵ These projects, however, have not explored in detail the complexity of hospital systems, including the organisation of care, available services, referral processes or patient selection, but have tended to focus on intensity and types of therapy.

The results presented here highlight the enormous variation in non-clinical factors that can potentially influence rehabilitation

Table 4 Availability of secondary staff, ancillary services and support programs

	Australia	Canada	Italy	Ireland	India	Netherlands	Pakistan	Switzerland	USA
<i>Secondary staff</i>									
Neuropsychology	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Psychiatry	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Dietician	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Music therapy	No	Yes	No	No	No	Yes	No	Yes	No
Recreation therapy	No	Yes	No	Yes	Yes	Yes	No	Yes	Yes
Orthotist	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sexual therapist/councillor	No	Yes	No	Yes	No	Yes	No	Yes	Yes
Vocational therapist	No	Yes	No	Yes	No	No	Yes	Yes	No
Peer support	Yes	Yes; 0.8	No	Yes	No	No	No	Yes	Yes
Group therapy (n)	Yes (8)	Yes (3)	Yes (1)	Yes (5)	Yes (2)	Yes (12)	Yes (1)	Yes (3)	None routine
<i>Ancillary Services and supports</i>									
Formal SCI education	Yes	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes
	Patient manual	Formal 1 h group sessions 2/week		Patient manual and individual teaching from nursing staff	Staff		Pre-discharge session with ward resident	Patient manual and sessions	Patient book, DVD, web-based content
Urodynamics	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Specialist wheelchair prescription	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes
Objective pressure mapping seating clinic	No	Yes	No	Yes	No	Yes	No	Yes	Yes
Post-discharge medical review clinic	Yes	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Post-discharge multi-disciplinary allied health review clinic	No	Limited	Yes	Yes	No	No	Yes	Yes	Yes
Post-discharge outpatient allied health and nursing rehabilitation	Yes	Limited	Yes	Yes	No	Yes	No	Yes	Yes
Post-discharge home-based rehabilitation	Yes	Limited	No	No	No	No	No	Yes	Yes
Transitional living programme	No	No	No	No	No	Yes	No	Yes	No

outcomes. These non-clinical factors have been poorly reported to date. Repeating this survey across many different rehabilitation settings, including general rehabilitation, as well as spinal and other types of specialty rehabilitation, would give a more complete framework for understanding of the outcomes of rehabilitation. An implication of our findings is our suggestion that a framework be developed, possibly as part of the international spinal cord society data set project,²⁶ to standardise the collection of these non-clinical variables. It is proposed that this information could be submitted with manuscripts and made available to readers as supplementary information via the web. This would help improve an understanding of the context of rehabilitation in the different settings.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflicts of interest

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