Research article

Developing quality of care indicators for patients with traumatic and non-traumatic spinal cord injury (SCI): A feasibility study using administrative health data

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Objectives: (1) to inform the development of health system quality indicators for traumatic and non-traumatic spinal cord injury from acute care admission to community care discharge using administrative data, and (2) to examine characteristics and differences in care among type of care facility, and type of pathology using administrative data.

Design: Retrospective cohort study using administrative health data.

Setting: Ontario, Canada.

Participants: Using administrative health data, we used International Classification codes 10th version Canadian Edition to identify incident cases of SCI from April 1, 2006 to March 31, 2012.

Results: We identified 7,693 cases in our cohort, of whom 1,537 (20.0%) were categorized as traumatic spinal cord (TSCI) and 6,156 (80.0%) as non-traumatic (NTSCI). Of those identified with NTSCI, more than half (54.0%) were diagnosed with either Guillain Barré syndrome and Multiple Sclerosis ($n = 3,326$). More individuals admitted to a trauma/spine center were seen by an orthopedic surgeon or a neurosurgeon (20.3% compared to 5.6% for NTSCI; 77.7% compared to 24.9% for TSCI). Only 25.7% ($n = 724$) of the NTSCI cohort were admitted to a rehabilitation facility from a trauma/spine center, compared to 58.9% ($n = 754$) of those with TSCI.

Conclusions: Important challenges in data completeness and utility were identified. Province wide processes to flag incomplete data and provision of incentives for comprehensive data are urgently needed to develop quality indicators across the care continuum. Consensus on the coding for NTSCI for the purposes of developing health system indicators is required.

Keywords: Spinal cord injury, Diagnostic codes, Health care quality, Health system quality indicators

Introduction

A spinal cord injury (SCI), which stems from an insult to the spinal cord, is associated with motor, sensory and autonomic impairments results in catastrophic lifelong implications.^{1,2} Most individuals experience

significant secondary health complications,^{1,2} chronic conditions and multimorbidities,³⁻⁵ which have substantial impact on overall health and wellbeing, re-integration into the workplace, and quality of life.^{6,7} While many of these secondary health complications are potentially preventable, such as urinary tract infections, pressure ulcers and pain, they are purported to be key precipitants for emergency department (ED) visits, re-hospitalizations and/or mortality in the

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post-acute phase following discharge from inpatient SCI rehabilitation.^{8,9}

Traumatic spinal cord injury (TSCI) is often caused by external events such as a motor vehicle accident, fall or violence. Worldwide, TSCI incidence varies by regions from 16 to 40 persons per million.^{10,11} In Canada, the incidence ranges from 24 to 53 people per million.^{12–14} Damage to the spinal cord from pathology other than trauma has been referred to as non-traumatic SCI (NTSCI), spinal cord myelopathy, or spinal cord damage.¹⁵ NTSCI incidence has been more difficult to ascertain due to lack of a model system for NTSCI and the absence of standardized International Classification Diagnostic (ICD) codes complicating conventional case finding strategies.^{16,17} Recently, Noonan *et al.* have estimated the discharge incidence for NTSCI to be 68 cases per million in Canada.¹² Further, with an aging population, the incidence of NTSCI is anticipated to rise.¹² While the overall incidence of SCI is relatively low compared to other chronic conditions, the financial and health impacts on the individuals, their families, and the health system are significant. Our research team recently identified direct medical costs for TSCI including acute and rehabilitation at an estimated \$1.38 billion per year (CAD).¹⁸ Importantly, a SCI has implications beyond the direct medical care costs, such as the ability to return to employment or vocational pursuits, and the need for attendant care, housing, medical equipment, transportation, and social assistance are significant if third party funds are not available or sufficient. Thus, the total economic burden is substantial, with lifetime estimated costs ranging as high as \$3.03 billion (CAD) for complete tetraplegia to \$1.47 billion (CAD) for incomplete paraplegia.¹⁹

A substantial portion of these costs are attributed to high health care utilization,¹⁸ such as physician/specialist visits, re-admissions to acute care, and ED visits, particularly in the year following the initial SCI.^{20,21} These high rates of health care utilization have been shown to persist beyond the initial year post injury, as the reported rates of ED visits for persons with TSCI were shown to be three times higher than the general population for up to 6 years post injury.²² Moreover, reasons for the visits were mainly to address routine conditions (e.g. pain, urinary tract infections).²² In Ontario, Canada, similar high health care utilization has been shown for persons with NTSCI.²¹

The significant costs and high health care utilization among individuals living with SCI suggest that care delivery across the continuum may not be the most efficient or value-based.^{23–25} Recently, Dejong highlighted

a need for the SCI research community to focus on understanding transitions from inpatient rehabilitation to community care, as well as exploring new innovative systems of health care delivery.²⁶ However, prior to improving quality of care for patients and creating a more efficient health care system, there must be a robust mechanism for the measurement of quality of care.²⁷ Currently, there are no standardized sets of indicators for measuring quality of care (acute care and post-acute care settings) in Canada for individuals with SCI. Evidence-based indicators that are clinically relevant, scientifically robust and feasible within the Canadian context must be identified, developed and/or implemented to drive system performance measurement, clinical practice benchmarking and overall better care.^{27–29}

Objectives

The objectives of this study were: (1) to inform the development of health system quality indicators for TSCI and NTSCI from acute care admission to community care discharge using available administrative data, and (2) to examine characteristics and differences in care among type of care facility (e.g. trauma/spine centers and non-trauma centers), and type of pathology using administrative data.

Methods

Setting

A universal publicly funded health care system in the Province of Ontario, Canada, with over 13 million residents, representing approximately 40% of the Canadian population. In Canada, physician and hospital services are publicly funded through universal health insurance and these administrative data are routinely collected. In the Province of Ontario, the Institute of Clinical Evaluative Studies (ICES) allows for the secondary data analysis of all administrative databases to answer system level questions at the provincial level.

Design

The retrospective cohort study assembled administrative health data for Ontarians with TSCI and NTSCI for the fiscal years (FY) 2006/07 to 2011/12 (April 1st 2006 to March 31st, 2012). To our knowledge, this study is the first attempt to use these datasets in Ontario to identify NTSCI cases.

Privacy/ethics

The University of Toronto Health Research Ethics Board and the Sunnybrook Health Science Centre

Research Ethics Board (Toronto, Ontario) approved this study.

Data sources

Administrative health care databases housed at ICES, Ontario, Canada, were used for this study. Each of the databases contains an anonymous unique patient identifier that can be used for record linkage. Hospitalization records were from the Discharge Abstract Database (DAD), which contains a detailed record of all hospital admissions from over 100 acute hospitals in Ontario. Every hospital record in the dataset contains age, sex, postal code, date of admission, date of discharge, and the most responsible and secondary diagnostic codes (based on International Classification of Disease, Tenth Revision Canada, ICD-10-CA codes). The Ontario Trauma Registry (OTR, Minimal Data Set) captures any acute care hospitalizations in Ontario for cases admitted to a trauma/spine center and provided demographic, diagnostic and procedure data. Outpatient physician visits were identified using the Ontario Health Insurance Plan data. The main data elements related to physician-billing claims are dates of the service/claim, fee code for service provided, and fees paid. The Ontario Registered Persons Database contains basic demographic and vital statistics information, including death date, for each Ontario resident. The National Ambulatory Care Resource System (NACRS) database provides information on all visits to the emergency department (ED) and the main data elements are reasons for the ED visit and patient demographics.

All databases were linked anonymously using the unique patient identifier.

Study population

Individuals who were hospitalized with their initial SCI between April 1, 2006 and March 31, 2012 were included in the cohort. Index cases for TSCI were identified from acute care hospitalization records using ICD-10-CA diagnostic codes for SCI (see Appendix A) that have been previously used to determine TSCI incidence in Ontario.¹³ In order to identify NTSCI cases, we used the recommendations of a group of international SCI experts, who were providing input at the time of this study to the World Health Organization ICD-11 committee. Due to the heterogeneity of NTSCI, we separated NTSCI into three categories: (1) overall NTSCI cohort, (2) NTSCI sub-cohort excluding Guillain Barré syndrome (GBS) and Multiple Sclerosis (MS), and (3) NTSCI sub-cohort of only GBS and MS.

Records were excluded if there was a hospital stay for SCI in the previous year of index injury.

Variables

The initial set of variables chosen for this feasibility study were informed by the *Ontario Spinal Cord Injury Informatics Steering Committee*, funded by the Ontario Neurotrauma Foundation, who provided content and methodological expertise in four main areas: pre-hospital/acute care; rehabilitation; community participation and integration; and continuum of care. Expert guests were also invited to working group meetings to discuss and develop a preliminary list of potentially important clinical characteristics and quality indicators for both TSCI and NTSCI.

Baseline socio-demographic

Individual level variables included the following: age at time of injury, sex, rurality, Charlson comorbidity index Deyo-Adaption for administrative data, region of injury and cause of injury. Rurality was identified using the Rurality Index of Ontario, which is a scaled index based on population factors and distance (ranges 0–100), and communities with higher values (cut point ≥ 45) are more rural.³⁰

Pre-hospital, emergency department care

The OTR provided information on the procedures performed at the scene of a traumatic injury (e.g. type of intubation, cervical spine manipulation, oxygen administration, Glasgow Coma Scale, Revised Trauma Score, Injury Severity Score). The NACRS database had the following variables related to the ED visit: mode of transport, interventions performed (e.g. ventilation, saline), diagnostic interventions of the spinal cord, spinal canal and meninges (e.g. biopsy, inspection, pressure management, specimen collection), central nervous system monitoring, and diagnostic imaging interventions on the spinal cord (e.g. fluoroscopy, nuclear imaging, ultrasound).

Hospital care and post hospital care

Hospital care variables included: type of center (trauma/spine center, non-trauma center), complications during hospital stay, consult by an orthopaedic surgeon or neurosurgeon during stay, total hospital length of stay (LOS), alternate level of care (ALC), and discharge disposition from acute care (community with or without home care, rehabilitation, long-term care). Health care utilization within one-year post discharge was captured with ED visits and subsequent hospitalizations.

Analysis

Descriptive statistics were used to summarize socio-demographic, clinical, procedures and treatments, and health care utilization data. We hypothesized that the type of treatment facility after the index injury might affect clinical care received and outcomes. As such, we stratified by type of treatment facility (trauma/spine center versus non-trauma center), and by type of injury. In Canada, trauma/spine centers are specialized facilities that are usually comprised of interdisciplinary teams with expertise in treating traumatic injuries,³¹ and injuries sustained to the spinal cord. There were 12 hospitals in Ontario identified as being a trauma/spine center, with either specialization in treating traumatic injuries and/or injuries related to the spinal cord. All analyses were conducted at ICES (Toronto, Canada).

Results

We identified 7,693 cases of SCI in our cohort, of whom 1,537 (20.0%) were categorized as TSCI and 6,156 (80.0%) with NTSCI. Of those identified with NTSCI, slightly more than half (54.0%) were diagnosed with either GBS or MS ($n = 3,326$). Patients diagnosed with GBS or MS were younger (mean age 51 years, $SD = 17.3$) compared to those with other NTSCIs (mean age 57 years, $SD = 19.6$) and a higher proportion was female (59.7% compared to 43.3%). In Tables 1 and 2, the characteristics of SCI cases are shown, by the type of treatment facility (trauma-center versus non-trauma center) and type of SCI. Overall, there were no major differences between the baseline characteristics of patients with NTSCI treated at a trauma/spine center versus a non-trauma center (Table 1). However, there were slightly greater proportion of individuals with higher level injuries (cervical and thoracic level) treated at a trauma/spine center (21.1%) compared to a non-trauma center (13.7%). As shown in Table 2, the majority of individuals with TSCI were treated in a trauma/spine center (83.2%; $n = 1,280$) compared to a non-trauma center (17.8%; $n = 257$). Persons with a TSCI treated in a trauma/spine center were younger (median 51 years, $IQR = 32-66$) and had more injuries related to falls (51.5%) compared to those in a non-trauma center (median 67 years, $IQR = 51-78$, and 17.5% injuries related to falls).

Using the OTR database, we identified only 943 trauma cases, which provided specific details of the trauma and care delivered at the scene of injury. However there were a lot of missing data elements within this database. For example, the Revised Trauma Score and Injury Severity Score were missing in 56.4% and 45.1% of cases, respectively.

Additionally, we were unable to acquire complete data on the diagnostic interventions, cerebral nervous system monitoring, and diagnostic imaging.

Tables 3 and 4 show hospital care by type of facility and type of injury, respectively. The most common complications during acute care for SCI were related to renal function (e.g. urinary tract infections and renal complications; see Tables 3 and 4), with more renal complications identified in trauma/spine centers compared to non-trauma centers. There were more individuals seen by an orthopedic surgeon or a neurosurgeon in a trauma/spine center compared to a non-trauma center for both TSCI and NTSCI (77.7% compared to 24.9% for TSCI; 20.3% compared to 5.6% for NTSCI, respectively).

Specifically for NTSCI, those admitted with GBS or MS had shorter median length of stay (median 9 days), irrespective of treatment facility, compared to other NTSCI (excluding MS and GBS). The NTSCI cases, excluding GBS and MS, had a median length of stay of 17 ($IQR = 7-35$) in trauma/spine centers and 16 days in non-trauma centers ($IQR = 7-36$). However, there were notable differences in ALC days by type of facility and type of NTSCI, with more ALC days identified in non-trauma centers and for NTSCI cases excluding GBS and MS (e.g. mean of 9.2 days in a non-trauma center compared to 6.1 days in a trauma/spine center). There were no substantial differences identified in ALC days for TSCI based on type of treatment facility.

Of those with NTSCI (excluding GBS and MS) who were treated at a trauma/spine center, 25.9% ($n = 406$) were admitted to a rehabilitation facility compared to 13% ($n = 164$) who were treated at a non-trauma center. The majority of the individuals admitted with a TSCI (58.9%, $n = 754$) to a trauma/spine center were discharged to a rehabilitation facility compared to 29.2% ($n = 75$) at a non-trauma center. Unplanned ED visits and readmissions to acute care within one-year post discharge were similar for both TSCI and NTSCI, irrespective of type of treatment facility (see Tables 3 and 4). Readmissions varied by type of NTSCI, as fewer persons with GBS and MS had a readmission within one year (26.2%, $n = 329$), compared to other NTSCI cases (39.8%, $n = 623$).

Table 5 summarizes the variables that have the potential to be health system quality indicators of care based on current data availability and potential relevancy for performance measurement at the time of the study (see Table 5). Some of the potential indicators might include the following: percentage of persons with a SCI who receive definitive care in trauma/spine center, percentage who receive an orthopedic/

Table 1 Baseline characteristics by type of facility for non-traumatic spinal cord injury patients (N = 6,165) in Ontario, fiscal years 2006 to 2011

Characteristic	Non-traumatic spinal cord injury						
	Total NTSCI Cohort N = 6,156	Trauma/Spine center			Non-trauma center		
		Overall NTSCI n = 2,820	Excluding GBS and MS n = 1,566	GBS and MS only n = 1,254	Overall NTSCI n = 3,336	Excluding GBS and MS n = 1,264	GBS and MS only n = 2,072
Age							
Mean (SD)	53.8 (18.6)	50.4 (20.3)	53.5 (20.9)	46.5 (18.8)	56.6 (16.6)	61.4 (17.0)	53.7 (15.7)
Median (IQR)	56 (43–67)	53 (39–65)	57 (44–68)	48 (34–60)	57 (45–69)	63 (51–74)	54 (43–65)
Age group, n (%)							
<18	276 (4.5)	239 (8.5)	138 (8.8)	101 (8.1)	37 (1.1)	17 (1.3)	20 (1.0)
18–39	960 (15.6)	500 (17.7)	180 (11.5)	320 (25.5)	460 (13.8)	110 (8.7)	350 (16.9)
40–64	3,041 (49.4)	1,335 (47.3)	721 (46.0)	614 (49.0)	1,706 (51.1)	549 (43.4)	1,157 (55.8)
65+	1,879 (30.5)	746 (26.5)	527 (33.7)	219 (17.5)	1,133 (34.0)	588 (46.5)	545 (26.3)
Sex, n (%)							
Female	3,213 (52.2)	1,375 (48.8)	685 (43.7)	690 (55.0)	1,838 (55.1)	541 (42.8)	1,297 (62.6)
Male	2,943 (47.8)	1,445 (51.2)	881 (56.3)	564 (45.0)	1,498 (44.9)	723 (57.2)	775 (37.4)
Rurality, n (%)**							
Urban	5,298 (86.1)	2,469 (87.6)	1,363 (87.0)	1,106 (88.2)	2,829 (84.8)	1,079 (85.4)	1,750 (84.5)
Rural	855 (13.9)	350 (12.4)	203 (13.0)	147 (11.7)	505 (15.1)	184 (14.6)	321 (15.5)
Comorbidity index, n (%)							
Missing	3,731 (60.6)	1,665 (59.0)	717 (45.8)	948 (75.6)	2,066 (61.9)	532 (42.1)	1,534 (74.0)
0	1,370 (22.3)	611 (21.7)	371 (23.7)	240 (19.1)	759 (22.8)	313 (24.8)	446 (21.5)
1	192 (3.1)	103 (3.7)	74 (4.7)	29 (2.3)	89 (2.7)	53 (4.2)	36 (1.7)
2	264 (4.3)	137 (4.9)	119 (7.6)	18 (1.4)	127 (3.8)	28 (1.4)	99 (7.8)
3+	599 (9.7)	304 (10.8)	285 (18.2)	19 (1.5)	295 (8.8)	28 (1.4)	267 (21.1)
Region of injury, n (%)**							
Cervical	607 (9.9)	307 (10.9)	307 (19.6)	*	300 (9.0)	300 (23.7)	*
Thoracic	398 (6.5)	260 (9.2)	260 (16.6)	*	138 (4.1)	138 (10.9)	*
Lumbar	620 (10.1)	267 (9.5)	267 (17.0)	*	353 (10.6)	353 (27.9)	*
Other	4,531 (73.6)	1,986 (70.4)	732 (46.7)	1,254 (100.0)	2,545 (76.3)	473 (37.4)	2,072 (100.0)
Cause of injury, n (%)**							
Missing	4,973 (80.8)	2,154 (76.4)	1,060 (67.7)	1,094 (87.2)	2,819 (84.5)	990 (78.3)	1,829 (88.3)
Fall	208 (3.4)	83 (2.9)	*	*	125 (3.7)	*	*
MVC	30 (0.5)	21 (0.7%)	*	*	9 (0.3)	*	*
Other	945 (15.4)	562 (19.9)	428 (27.3)	134 (10.7)	383 (11.5)	221 (17.5)	162 (7.8)

*Suppressed for privacy, cell size less than 6.

**Does not add to 100% due to missing or suppressed data.

NTSCI = Non-traumatic spinal cord injury.

SD = Standard deviation.

IQR = Inter-quartile range.

GBS = Guillain Barré syndrome.

MS = Multiple Sclerosis.

MVC = Motor Vehicle Collision.

Table 2 Baseline characteristics by type of hospital for traumatic spinal cord injury patients (N = 1,537) in Ontario, fiscal years 2006 to 2011

Characteristic	Traumatic spinal cord injury		
	Total TSCI cohort N = 1,537	Trauma/Spine center N = 1,280	Non-trauma center N = 257
Age			
Mean (SD)	51.6 (21.3)	49.4 (20.8)	62.7 (20.4)
Median (IQR)	53 (34–69)	51 (32–66)	67 (51–78)
Age group, n (%)			
<18	81 (5.3)	69 (5.4)	12 (4.7)
18–39	388 (25.2)	368 (28.8)	20 (7.8)
40–64	582 (37.9)	496 (38.8)	86 (33.5)
65+	486 (31.6)	347 (27.1)	139 (54.1)
Sex, n (%)			
Female	397 (25.8)	311 (24.3)	86 (33.5)
Male	1,140 (74.2)	969 (75.7)	171 (66.5)
Rurality, n (%)**			
Urban	1,262 (82.1)	1,041 (81.3)	221 (86.0)
Rural	274 (17.8)	238 (18.6)	36 (14.0)
Comorbidity index, n (%)			
Missing	1,164 (75.7)	983 (76.8)	181 (70.4)
0	260 (16.9)	213 (16.6)	47 (18.3)
1	57 (3.7)	38 (3.0)	*
2	26 (1.7)	23 (1.8)	*
3+	30 (2.0)	23 (1.8)	7 (2.7)
Region of injury, n (%)			
Cervical	1,036 (67.4)	847 (66.2)	189 (73.5)
Thoracic	308 (20.0)	277 (21.6)	31 (12.1)
Lumbar	149 (9.7)	122 (9.5)	27 (10.5)
Other	44 (2.9)	34 (2.7)	10 (3.9)
Cause of injury, n (%)			
Missing	*	*	*
Fall	836 (54.4)	659 (51.5)	45 (17.5)
MVC	417 (27.1)	382 (29.8)	177 (68.9)
Other	44 (2.9)	239 (18.7)	35 (13.6)

*Suppressed for privacy, cell size less than 6.

**Does not add to 100% due to missing or suppressed data.

TSCI = Traumatic spinal cord injury.

SD = standard deviation

IQR = Inter-quartile range

MVC = Motor Vehicle Collision.

neurosurgery spine consult, percentage with diagnostic imaging documentation in hospital, and percentage with subsequent unscheduled emergency department visits within one year.

Discussion

In this exploratory study, we were able to identify an overall cohort of 7,693 persons with the majority having a NTSCI (80%). Thus, the ratio of identified NTSCI to TSCI in this study was 4.0. It is important to highlight that this ratio is significantly higher than previously reported ratios of approximately 1.6.^{12,21} We identified that MS and GBS comprised more than 50% of the NTSCI cohort, which raises a few important points for SCI research and the clinical community to consider. Firstly, our study raises the question whether it is clinically appropriate for MS and GBS to be included among the ICD-10 codes for NTSCI unless the patients present with tetraplegia and paraplegia. If so, perhaps it might be appropriate to consider the heterogeneity of

NTSCI,¹⁷ especially in the context of developing quality indicators both at the clinical and system levels.

In this study we were able to identify variables that have the potential to be quality indicators of care based on data availability and potential relevance for assessing health outcomes and system efficiency (see Table 5). For example, we identified that the majority of persons with a SCI were initially admitted to the ED, which may provide an opportunity to target data from the ED for future quality indicator development. However, while the data elements have the potential to be captured in the administrative data, we were limited by issues with data completeness (e.g. diagnostic interventions and treatments) and lack of relevant variables such as neurological status (e.g. measured by the International Standards of Neurological Classification for Spinal Cord Injury (ISNCSCI).³² We know in the SCI population that the Neurological Level of Injury (NLI) and American Spinal Injury Association Classification (AIS, from ISNCSCI) have dramatic differences for sensory, motor

Table 3 Hospital care by type of facility for non-traumatic spinal cord injury patients (N = 6,156) in Ontario, fiscal years 2006 to 2011

Hospital care	Trauma/Spine center			Non-trauma center		
	Overall NTSCI N = 2,820	Excluding GBS and MS n = 1,566	GBS and MS only n = 1,254	Overall NTSCI N = 3,336	Excluding GBS and MS n = 1,264	GBS and MS only n = 2,072
Referred outside health region, n (%)	961 (34.1)	615 (39.3)	346 (27.6)	916 (27.5)	381 (30.1)	535 (25.8)
Isolated spinal injury, n (%)	2,558 (90.7)	1,353 (86.4)	1,205 (96.1)	3,099 (92.9)	1,124 (88.9)	1,975 (95.3)
Complications during stay, n (%)**						
Deep vein thrombosis	55 (2.0)	36 (2.3)	19 (1.5)	37 (1.1)	24 (1.9)	13 (0.6)
Pneumonia	90 (3.2)	60 (3.8)	30 (2.4)	72 (2.2)	36 (2.8)	36 (1.7)
Pressure ulcer	93 (3.3)	76 (4.9)	17 (1.4)	72 (2.2)	53 (4.2)	19 (0.9)
Urinary tract infection	275 (9.8)	198 (12.6)	77 (6.1)	195 (5.8)	113 (8.9)	82 (4.0)
Autonomic dysreflexia	*	*	*	*	*	*
Bowel complications	33 (1.2)	21 (1.3)	12 (1.0)	38 (1.1)	22 (1.7)	16 (0.8)
Renal complications	285 (10.1)	207 (13.2)	78 (6.2)	229 (6.9)	132 (10.4)	97 (4.7)
Length of stay (days)						
Mean (SD)	25.9 (46.0)	31.7 (54.6)	18.7 (30.8)	24.4 (51.4)	34.5 (66.8)	18.2 (37.9)
Median (IQR)	13 (6–29)	17 (7–35)	9 (5–20)	11 (5–24)	16 (7–36)	9 (4–17)
Special care unit						
Mean (SD)	5.1 (29.4)	6.2 (37.6)	3.6 (13.3)	3.8 (30.9)	4.7 (45)	3.2 (17.5)
Median (IQR)	0 (0–1)	0 (0–2)	0 (0–0)	0 (0–0)	0 (0–0)	0 (0–0)
Alternate level of care (days)						
Mean (SD)	5.2 (21.4)	6.1 (23.1)	4.1 (19.1)	6.8 (29.3)	9.2 (33.2)	5.3 (26.5)
Median (IQR)	0 (0–1)	0 (0–3)	0 (0–0)	0 (0–2)	0 (0–4)	0 (0–1)
Intensive care unit stay, n (%)	703 (24.9)	511 (32.6)	192 (15.3)	532 (15.9)	226 (17.9)	306 (14.8)
Consult by orthopedic or neurosurgeon, n (%)	573 (20.3)	524 (33.5)	49 (3.9)	188 (5.6)	136 (10.8)	52 (2.5)
Discharge disposition, n (%)**						
Died	251 (8.9)	226 (14.4)	25 (2.0)	340 (10.2)	254 (20.1)	86 (4.2)
Long-term care	82 (2.9)	29 (1.9)	53 (4.2)	244 (7.3)	82 (6.5)	162 (7.8)
Complex continuing care	234 (8.3)	159 (10.2)	75 (6.0)	392 (11.8)	194 (15.3)	198 (9.6)
Rehabilitation facility	724 (25.7)	406 (25.9)	318 (25.4)	586 (17.6)	164 (13.0)	422 (20.4)
Community with home care	495 (17.6)	245 (15.6)	250 (19.9)	460 (13.8)	154 (12.2)	306 (14.8)
Community no home care	1,034 (36.7)	501 (32.0)	533 (42.5)	1,314 (39.4)	416 (32.9)	898 (43.3)
Health care utilization post discharge, n (%)						
Unscheduled ED visit within 1 year	1,345 (47.7)	748 (47.8)	597 (47.6)	1,597 (47.9)	583 (46.1)	1,014 (48.9)
Unscheduled hospital readmission within 1 year	952 (33.8)	623 (39.8)	329 (26.2)	1,108 (33.2)	489 (38.7)	619 (29.9)

*Cell size suppressed due to $n < 6$.

**Does not add to 100% due to missing or suppressed data.

NTSCI = Non-traumatic spinal cord injury.

GBS = Guillain Barré syndrome.

MS = Multiple Sclerosis.

Table 4 Hospital care by type of treatment facility for traumatic spinal cord injury patients (N = 1,537) in Ontario, fiscal years 2006 to 2011

Hospital care	Trauma/Spine center N = 1,280	Non-trauma center n = 257
Treated outside health region of residence, n (%)	547 (42.7)	86 (33.5)
Isolated spinal injury, n (%)	229 (17.9)	116 (45.1)
Complications during hospitalization, n (%)**		
Deep vein thrombosis/pulmonary embolism	33 (2.6)	*
Pneumonia	96 (7.5)	14 (5.4)
Pressure ulcer	88 (6.9)	10 (3.9)
Urinary tract infection	247 (19.3)	33 (12.8)
Autonomic dysreflexia	*	*
Bowel complications	15 (1.2)	*
Renal complications	253 (19.8)	36 (14.0)
Length of stay (days)		
Mean (SD)	35.5 (72.5)	27.0 (61)
Median (IQR)	19 (9–39)	12 (5–27)
Special care unit		
Mean (SD)	12.9 (53.4)	7.4 (52.7)
Median (IQR)	2 (0–10)	0 (0–1)
Alternate level of care (days)		
Mean (SD)	7.5 (30.7)	8.06 (35.9)
Median (IQR)	0 (0–6)	0 (0–4)
Intensive care unit stay, n (%)	818 (63.9)	71 (27.6)
Consult by orthopedic surgeon or neurosurgeon, n (%)	994 (77.7)	64 (24.9)
Discharge disposition, n (%)**		
Died	125 (9.8)	39 (15.2)
Long-term care	18 (1.4)	*
Complex continuing care	59 (4.6)	*
Rehabilitation facility	754 (58.9)	75 (29.2)
Community with home care	85 (6.6)	23 (8.9)
Community no home care	239 (18.7)	92 (35.8)
Health care utilization post discharge, n (%)		
Unscheduled emergency department visits within 1 year	1,345 (47.7)	116 (45.1)
Unscheduled hospital readmissions within 1 year	327 (25.5)	77 (30.0)

*Cell size suppressed due to $n < 6$.

**Does not add to 100% due to missing or suppressed data.

SD = Standard deviation

IQR = Inter-quartile range

and autonomic impairments which contribute significantly to functional outcomes and health status and the ability to develop quality indicators for sub groups within the SCI population with unique needs will allow for a more responsive health system. Indeed, the data should be available to address the quality indicators used and related performance targets should require specificity beyond whether an injury was TSCI versus NTSCI.

There is a growing recognition that policy and decision makers should develop customized care for individuals based on their respective needs.^{33,34} Our findings showed at the time of injury, more than half of the NTSCI cohort was not admitted to a trauma/spine center. Importantly trauma/spine centers in Ontario are situated in Academic Health Science Centers where there is an aggregated group of highly trained surgeons, including spine surgeons and rehabilitation services to provide care. We identified that there were more reported complications related to renal function and urinary tract infections in the trauma/spine centers compared to the non-trauma centers for all

cases. These differences may be due to more complex patients being admitted to a trauma/spine center, as more isolated spine injuries were admitted to non-trauma centers. It is important to explore further the clinical characteristics of persons (e.g. NTSCI and TSCI) admitted to different hospital types and future indicator work should consider the heterogeneity of complexity within the SCI population.

Table 5 Potential health system level indicators for spinal cord injury based on available data

Sample system level indicators
n (%) of persons treated in a specialized trauma/spine centre
n (%) with orthopedic/neurosurgery spine consult
n (%) with diagnostic imaging in hospital
n (%) of persons who died post hospital care
n (%) discharged to long-term care
n (%) discharged to complex continuing care
n (%) discharged to a rehabilitation facility
n (%) discharged to community with home care
n (%) discharged to community without home care
n (%) with subsequent unscheduled ED visits within one year
n (%) with unscheduled hospital readmissions within one year

The type of injury may also become relevant when considering the type of treatment facility that provided care during the index acute admission.³⁵ Recently, Craven *et al.* reported that persons with NTSCI may require ‘pre-habilitation’, as well as inpatient rehabilitation services within tertiary academic sites, to minimize the risk of mismanagement.⁴ Craven and colleagues argued that NTSCI and TSCI ‘do not equate’ (p.2) and the system needs to acknowledge and be responsive to the unique and similar needs of persons with NTSCI.⁴ In support of Craven and colleagues’ argument, only 26% of individuals with a NTSCI were discharged from an acute trauma/spine center to an inpatient rehabilitation facility compared to 59% with TSCI. Further, a very small proportion of individuals who were discharged to the community from hospital received home care services. The lack of home care support may be an important contributor to readmissions and ED visits, which requires further exploration.

Limitations

There are several limitations to this work that need to be highlighted. There is a need to validate ICD-10 codes used to define SCI, particularly NTSCI, to ensure accurate case identification.¹⁷ Notably, through this feasibility study, we identified that of the NTSCI cases identified; MS and GBS comprised more than half of this group. Indeed this may be only relevant to Ontario and/or other settings with a higher prevalence of MS and GBS; however the implications of these results need to be further explored and discussed. Therefore, we believe that we are inappropriately classifying NTSCI, especially when MS and GBS cases are included in the definition. However, if we could identify the MS and GBS cases with tetraplegia or paraplegia, this would reduce the over-estimation. Further, we are using the Province of Ontario, which is a publicly funded health system, as an example of exploring quality of care indicators. It is important to recognize the importance of context, especially when examining quality of care and health system delivery. Indicators that may be relevant for the Ontario context may not completely translate in different health system contexts. We were restricted to reporting certain age categories based on privacy requirements with administrative health data, which we acknowledge may not align with the current International Spinal Cord Society (ISCOS) recommendations. Importantly, as with all administrative data used for research, there are limitations with respect to completeness and accuracy of diagnostic coding across health care facilities. Finally, we have not yet examined the feasibility of developing other

indicators for inpatient rehabilitation, complex-continuing care, long-term care, home care or primary care.

Conclusions

Important challenges with respect to the population of specific key data elements were identified through our work. In particular, there is a lack of comprehensive neurological assessments (e.g. ISNCSCI)³² which are recorded in the ED and the acute care setting, thus making it difficult to assess standards or compare across trauma/spine and non-trauma centers or regions. Of the injury severity scores that are currently in the OTR database (e.g. Injury Severity Score and the Revised Trauma Score), the majority of cases had missing data. Province-wide processes to flag incomplete data and provide incentives for comprehensive data are urgently needed for this relatively rare population who use substantial resources. Next steps should be a validation study to assess the sensitivity and specificity of ICD 10-CA codes for TSCI and NTSCI as well as codes for diagnostic imaging, comorbidities and secondary health complications.

In the long-term, future work should involve the development of quality indicators that reflect specificity, access, efficiency, effectiveness, quality, integration, value and equity.²⁷ The Canadian Stroke Strategy is a good example of a national approach focused on developing indicators, benchmarks, and implementing quality improvement processes.³⁶ Indicators for SCI should be routinely collected and reported on an annual basis provincially and by relevant regional health planning and service delivery authorities to facilitate evidence-informed decision-making for quality programs and services for the SCI population. Moreover, this work will help inform other quality improvement initiatives that are focused on improving care delivery in Canada.

Disclaimer statements

Contributors All the authors participated in the manuscript elaboration, such as acquisition of the data, interpretation of the data, manuscript writing and final review for submission.

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Conflicts of interest There is no interest conflict regarding this manuscript content.

Ethics approval IRB approval was obtained (protocol number 32917414.5.0000.5404).

Appendix A ICD-10 Codes to Define Spinal Cord Injury

Level of Injury	Description
Cervical	<i>Traumatic</i>
	S14.0 Concussion and edema of cervical spinal cord
	S14.10 Complete lesion of cervical spinal cord
	S14.11 Central cord lesion of cervical spinal cord
	S14.12 Anterior cord syndrome of cervical spinal cord
	S14.13 Posterior cord syndrome of cervical spinal cord
	S14.18 Other injuries of cervical spinal cord
	S14.19 Unspecified lesion of cervical spinal cord
	<i>Non-traumatic</i>
	G82.111 Spastic paraplegia, complete (cervical level)
	G82.121 Spastic paraplegia, incomplete (cervical level)
	G82.191 Spastic paraplegia, unspecified (cervical level)
	G82.211 Paraplegia of unspecified type, complete (cervical level)
	G82.221 Paraplegia of unspecified type, incomplete (cervical level)
	G82.291 Paraplegia of unspecified type, unspecified (cervical level)
	G82.310 Flaccid quadriplegia, complete (at cervical spine level C1 to C4)
	G82.320 Flaccid quadriplegia, incomplete (at cervical spine level C1 to C4)
	G82.390 Flaccid quadriplegia, unspecified (at cervical spine level C1 to C4)
	G82.311 Flaccid quadriplegia, complete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.321 Flaccid quadriplegia, incomplete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.391 Flaccid quadriplegia, unspecified (at cervical spine level C5 to C7, includes: level unspecified)
	G82.410 Spastic quadriplegia, complete (at cervical spine level C1 to C4)
	G82.420 Spastic quadriplegia, incomplete (at cervical spine level C1 to C4)
	G82.490 Spastic quadriplegia, unspecified (at cervical spine level C1 to C4)
	G82.411 Spastic quadriplegia, complete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.421 Spastic quadriplegia, incomplete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.491 Spastic quadriplegia, unspecified (at cervical spine level C5 to C7, includes: level unspecified)
	G82.510 Quadriplegia, unspecified type, complete (at cervical spine level C1 to C4)
	G82.520 Quadriplegia, unspecified type, incomplete (at cervical spine level C1 to C4)
	G82.590 Quadriplegia, unspecified type, unspecified (at cervical spine level C1 to C4)
	G82.511 Quadriplegia, unspecified type, complete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.521 Quadriplegia, unspecified type, incomplete (at cervical spine level C5 to C7, includes: level unspecified)
	G82.591 Quadriplegia, unspecified type, unspecified (at cervical spine level C5 to C7, includes: level unspecified)
Thoracic	<i>Traumatic</i>
	S24.0 Concussion and edema of thoracic spinal cord
	S24.10 Complete lesion of thoracic spinal cord
	S24.11 Central cord lesion of thoracic spinal cord
	S24.12 Anterior cord syndrome of thoracic spinal cord
	S24.13 Posterior cord syndrome of thoracic spinal cord
	S24.18 Other injuries of thoracic spinal cord
	S24.19 Unspecified lesion of thoracic spinal cord
	<i>Non-traumatic</i>
	G82.112 Spastic paraplegia, complete (thoracic level)
	G82.122 Spastic paraplegia, incomplete (thoracic level)
	G82.192 Spastic paraplegia, unspecified (thoracic level)
	G82.212 Paraplegia of unspecified type, complete (thoracic level)
	G82.222 Paraplegia of unspecified type, incomplete (thoracic level)
	G82.292 Paraplegia of unspecified type, unspecified (thoracic level)

Continued

Continued

Level of Injury	Description
Lumbar	<i>Traumatic</i>
	S34.0 Concussion and edema of lumbar spinal cord
	S34.10 Complete lesion of lumbar spinal cord
	S34.11 Central cord lesion of lumbar spinal cord
	S34.12 Anterior cord syndrome of lumbar spinal cord
	S34.13 Posterior cord syndrome of lumbar spinal cord
	S34.18 Other injuries of lumbar spinal cord
	S34.19 Unspecified lesion of lumbar spinal cord
	<i>Non-traumatic</i>
	G82.113 Spastic paraplegia, complete (lumbar level)
	G82.123 Spastic paraplegia, incomplete (lumbar level)
	G82.193 Spastic paraplegia, unspecified (lumbar level)
	G82.213 Paraplegia of unspecified type, complete (lumbar level)
	G82.223 Paraplegia of unspecified type, incomplete (lumbar level)
	G82.293 Paraplegia of unspecified type, unspecified (lumbar level)
Other	<i>Traumatic</i>
	S34.30 Laceration of cauda equina
	S34.38 Other and unspecified injury of cauda equina
	T06.0 Injuries of brain and cranial nerves with injuries of nerves and spinal cord at neck level
	T06.1 Injuries of nerves and spinal cord involving other multiple body regions
	<i>Non-traumatic</i>
	C70.1 Malignant neoplasm of spinal meninges
	C72.0 Malignant neoplasm of spinal cord
	C72.1 Malignant neoplasm of cauda equina
	C76.0 Malignant neoplasm head face & neck
	C79.4 Secondary malignant neoplasm of other and unspecified parts of nervous system
	G35 Multiple sclerosis
	G61.0 Guillain-Barré syndrome
	G82.193 Spastic paraplegia, unspecified
	G82.293 Paraplegia of unspecified type, unspecified
	Q05.5-Q05.8 Spina Bifida

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