ACRM
AMERICAN CONGRESS OF REHABILITATION MEDICINE

Archives of Physical Medicine and Rehabilitation

journal homepage: www.archives-pmr.org

Archives of Physical Medicine and Rehabilitation 2023;104: 63—73

ORIGINAL RESEARCH

Using Clinical Vignettes and a Modified Expert Delphi Panel to Determine Parameters for Identifying Non-Traumatic Spinal Cord Injury in Health Administrative and Electronic Medical Record Databases

Arrani Senthinathan, MSc,[a,b] Shawna M. Cronin, MScOT,[a,b] Chester Ho, MD,[c] Peter W. New, MBBS,[d,e,f,g] Sara JT. Guilcher, PT, PhD,[a,h,i] Vanessa K. Noonan, PT, PhD,[j,k] B. Catherine Craven, MD,[b,l,m] Sean Christie, MD,[n] Eugene K. Wai, MD,[o,p] Eve C. Tsai, MD,[p,q] Vidya Sreenivasan, MD,[r] Jefferson Wilson, PhD, MD,[s,t] Michael G. Fehlings, PhD, MD,[s,u] Blayne Welk, MD,[v] Susan B. Jaglal, PhD[a,b,i,w]

From the [a]From the Institute of Health Policy Management and Evaluation, University of Toronto, Toronto, Canada; [b]KITE (Knowledge Innovation Talent Everywhere), Toronto Rehabilitation Institute - University Health Network, Toronto, Canada; [c]Division of Physical Medicine & Rehabilitation, Faculty of Medicine & Dentistry, University of Alberta, Edmonton, Canada; [d]Spinal Rehabilitation Service, Caulfield Hospital, Alfred Health, Caulfield, Australia; [e]Department of Medicine & Rehabilitation and Aged Services Program, Kingston Centre, Monash Health, Cheltenham, Australia; [f]Epworth-Monash Rehabilitation Medicine Unit, Monash University, Richmond, Australia; [g]Department of Epidemiology and Preventive Medicine, School of Public Health & Preventive Medicine, Monash University, Prahran, Australia; [h]Leslie Dan Faculty of Pharmacy, University of Toronto, Toronto, Canada; [i]Rehabilitation Science Institute, Temerty Faculty of Medicine, University of Toronto, Toronto, Canada; [j]Praxis Spinal Cord Institute, Vancouver, Canada; [k]International Collaboration on Repair Discoveries, Vancouver, Canada; [l]Department of Medicine, University of Toronto, Toronto, Canada; [m]Spinal Cord Rehabilitation Program, Toronto Rehabilitation Institute — University Health Network, Toronto, Canada; [n]Division of Neurosurgery, Dalhousie University, Halifax, Canada; [o]Division of Orthopaedic Surgery and School of Epidemiology and Public Health, University of Ottawa, Ottawa, Canada; [p]Clinical Epidemiology Program, Ottawa Hospital Research Institute, Ottawa, Canada; [q]Division of Neurosurgery, University of Ottawa, The Ottawa Hospital Research Institute, Ottawa, Canada; [r]Physical Medicine and Rehabilitation, The Ottawa Hospital, Ottawa, Canada; [s]Division of Neurosurgery, University of Toronto, Toronto, Canada; [t]St. Michael's Hospital, Toronto, Canada; [u]Division of Neurosurgery and Division of Genetics and Development, Krembil Neuroscience Centre, University Health Network, Toronto, Canada; [v]Department of Surgery and Epidemiology & Biostatistics, Western University, London, Canada; and [w]Department of Physical Therapy, Temerty Faculty of Medicine, University of Toronto, Toronto, Canada.

Abstract

Objective: To obtain expert consensus on the parameters and etiologic conditions required to retrospectively identify cases of non-traumatic spinal cord injury (NTSCI) in health administrative and electronic medical record (EMR) databases based on the rating of clinical vignettes.

Design: A modified Delphi process included 2 survey rounds and 1 remote consensus panel. The surveys required the rating of clinical vignettes, developed after chart reviews and expert consultation. Experts who participated in survey rounds were invited to participate in the Delphi Consensus Panel.

Setting: An international collaboration using an online meeting platform.

Participants: Thirty-one expert physicians and/or clinical researchers in the field of spinal cord injury (SCI).

This study was supported by the Ontario Neurotrauma Foundation and Praxis Spinal Cord Institute under Grant (2017-RHI-NTSCD-1041).
Disclosures: Vanessa Noonan is an employee at the Praxis Spinal Cord Institute. The other authors declare that they have no conflict of interest.

https://doi.org/10.1016/j.apmr.2022.08.002

Main Outcome Measure(s): Agreement on clinical vignettes as NTSCI. Parameters to classify cases of NTSCI in health administrative and EMR databases.

Results: In health administrative and EMR databases, cauda equina syndromes should be considered SCI and classified as a NTSCI or TSCI based on the mechanism of injury. A traumatic event needs to be listed for injury to be considered TSCI. To be classified as NTSCI, neurologic sufficient impairments (motor, sensory, bowel, and bladder) are required, in addition to an etiology. It is possible to have both a NTSCI and a TSCI, as well as a recovered NTSCI. If information is unavailable or missing in health administrative and EMR databases, the case may be listed as "unclassifiable" depending on the purpose of the research study.

Conclusion: The Delphi panel provided guidelines to appropriately classify cases of NTSCI in health administrative and EMR databases.

Archives of Physical Medicine and Rehabilitation 2023;104:63−73

Spinal cord injury (SCI) or dysfunction results from damage to the spinal cord through traumatic or non-traumatic causes and can have a range of etiologies and heterogeneous patterns of impairments.[1-6] Developed countries commonly reported non-traumatic spinal cord injury (NTSCI) has a higher incidence than traumatic spinal cord injury (TSCI).[5,7-11] Despite growing research on SCI, there is less research on NTSCI compared with TSCI.[1] Most research on NTSCI incidence and prevalence are reported from single or multi-center specialized tertiary inpatient rehabilitation units.[1-5,7,12-14] Using data from a single center may inaccurately estimate incidence of NTSCI due to variations in case definitions and inclusion criteria.

The etiology of NTSCI is complex, with a variety of underlying causes, including degenerative disk disease, spondylosis and related spondyloarthropathies, spinal stenosis, tumors, vascular disease, viral illness, and inflammatory conditions.[2,5,7,15] Additionally, the terms used to identify NTSCI in the literature vary and include spinal cord damage, spinal cord dysfunction, spinal cord diseases, spinal cord lesion, medical paraplegia, nontraumatic paraplegia, myelopathy, non-traumatic myelopathy, spinal cord myelopathy,[1,12,16] and spinal cord injury or disease (SCI/D).

A recent series of studies aimed to develop and validate an algorithm to identify cases of NTSCI in administrative databases to obtain population-based estimates revealed the diagnostics coding for NTSCI is unclear, and the use of ICD-10 codes alone may be unreliable, suggesting the need for further refinement for the inclusion and exclusion criteria.[17-19] These studies highlighted the varying terminology and definitions used for NTSCI, making it challenging to identify cases and case counts.[17-19]

The lack of parameters to identify cases of NTSCI is frequently listed as a limitation in NTSCI research[1,5,8,9,12,14-17,19,20] and without established parameters to identify cases of NTSCI, research progress in the area is negatively affected. The use of ICD-9 or 10 codes to identify NTSCI in administrative databases may be limited by potential errors in coding causing cases to be misclassified.[18,21] Furthermore, public health planning, care provision, and resource allocation for NTSCI is difficult, as both incidence and prevalence rates cannot be accurately calculated. The use of health administrative and/or electronic medical record (EMR) databases may provide a source to improve our understanding of NTSCI epidemiology as they provide a better reflection of the population due to larger and heterogeneous sample with a more population coverage.[22,23] Given that health administrative and EMR database usually do not have complete patient information and history, the required parameters to classify cases of NTSCI within the available data need to be determined. The purpose of this paper is to use a modified Delphi process to obtain consensus on the required parameters and etiologic conditions to identify cases of NTSCI in health administrative and EMR databases.

List of abbreviations:

EMR	**electronic medical record**
NTSCI	**non-traumatic spinal cord injury**
SCI	**spinal cord injury**
TSCI	**traumatic spinal cord injury**

Materials and methods

Study design

A 3 round modified Delphi process was conducted to establish consensus on the etiologic conditions and diagnostic parameters needed to identify cases of NTSCI retrospectively. This is an effective process for establishing consensus, when there is little or no definitive evidence, and expert opinion is important.[24,25] Our modified Delphi process included 2 survey rounds and 1 remote consensus panel. The surveys required the rating of clinical vignettes, developed after chart reviews and expert consultation. The study was approved by the Research Ethics Board at the University Health Network (UHN) (UHN: #18-6244) and consent was obtained from participants prior to participation.

Survey item generation

Clinical vignettes were created by members of the study team by identifying a variety of "difficult" cases pertaining to the diagnosis of NTSCI from prior chart reviews. Cases were developed based on examples identified from charts obtained at an adult acute care site, which included acute spine and rehabilitation services, and a primary care database in Canada.[18,26] Charts were identified using a previously developed algorithm[18] and reviewed for appropriateness to develop clinical vignettes. All cases were anonymized, and details of the cases were modified sufficiently to protect the identities of the individuals whose charts were reviewed. Twenty-one clinical scenarios were created by the study team in collaboration with clinician investigators who are familiar with the challenges of identifying NTSCI.

Participants and recruitment

An expert group of orthopedic surgeons, neurosurgeons, physiatrists, who participate in SCI research, and other SCI clinical researchers were recruited to participate in the modified Delphi Panel. To recruit neurosurgeons and orthopedic surgeons, an email

was circulated to members of the Canadian Spine Society on behalf of the study team. A recruitment email was sent to physiatrists currently associated with the Rick Hansen SCI Registry.[27] Clinician investigators also circulated a recruitment email to colleagues. The initial recruitment email included a letter of information and consent, and the Round 1 survey link. The first page of the survey requested consent for participation in the study. Those who completed Round 1 of the survey were invited to participate in Round 2. We aimed to recruit 10-15 survey participants to serve as experts in the Delphi consensus panel. We followed suggestions by Dillman (2000) to maximize the response rate through 3 points of contact with participants: a pre-round invitation email, a thank you/reminder email, and a final reminder email.[28]

The Delphi process

For Round 1 REDCap, an electronic data capture tool hosted at the University of Toronto was used to administer the survey.[29] Experts were asked to rate 21 clinical vignettes using a nine-point Likert-type rating scale ranging from "definitely not NTSCI" (1) to "definitely NTSCI".[9] The use of a 9-point scale provides respondents with a broader range of options, which is recommended in studies where a subsequent face-to-face meeting will be held to reach consensus.[30] In each survey, experts were given the opportunity to provide comments regarding the vignettes. Round 1 survey administration lasted 4 months and reminder emails were sent approximately every 14 days after the initial invitation. Demographic information of survey participants was collected, including type of physician/professional, area of expertise (ie, neurology, rehabilitation), age, sex, and geographic location.

Only experts who completed the survey at Round 1 were invited to participate in Round 2. For Round 2, personalized word document surveys were created for each participant from Round 1. These round 2 surveys included their results from Round 1 compared with the other participants, as well as all comments collected from Round 1 of the survey. Round 2 surveys allowed experts to re-rate the same 21 clinical vignettes using the same 9-point Likert scale from Round 1. Round 2 survey administration lasted 3 months and reminder emails were sent approximately every 14 days after the initial invitation.

Experts who participated in either survey rounds were invited to participate in the Delphi Consensus Panel. The Delphi Consensus Panel was held via Microsoft Teams, an online meeting platform that allows for screen sharing and has a hand-raise function. Two clinicians, from the study team, served as the Delphi Panel moderators. Prior to the meeting, participants were given the aggregated Round 1 and 2 survey results, as well as survey comments from all participants from Round 2. All 21 clinical vignettes were discussed during the Delphi Panel, with more time dedicated to cases with agreement less than 70%. The threshold of 70% is frequently used in Delphi processes with 9-point Likert scales to indicate consensus.[30] The goal of the Delphi Panel was to reach a final consensus of whether the clinical vignettes were NTSCI or not NTSCI, as well as highlight key issues pertaining to identifying and classifying cases of NTSCI.

Analysis

For Rounds 1 and 2 of the survey, descriptive statistics were calculated for each vignette using frequency distributions and proportional percentages. Vignettes scored were recategorized with Likert ratings 7-9 considered "very likely NTSI"; 4 to 6 "somewhat likely"; and 1-3 "likely not NTSI". Descriptive statistics were calculated for the demographic information.

The Delphi Consensus Panel discussion was recorded and transcribed verbatim for easier review of key points. The transcript was reviewed by 3 members of the research team separately and the consensus of each case was determined with key points from the discussion of that case noted. The study team then reviewed findings with each other. Each clinical vignette was labeled "NTSCI", "Not NTSCI", or "unclassifiable". The label "unclassifiable" was used in cases where the panel felt not enough information was available to classify the case as NTSCI or not NTSCI.

Results

Round 1 of the survey had 31 complete responses. See table 1 for expert panel participant self-reported demographic information. Round 1 of the survey had 8 cases with over 70% agreement that the case was or was not NTSCI. Round 2 of the survey had 18 complete respondents and had 11 cases with over 70% agreement if the case was or was not NTSCI. Finally, the Delphi Consensus Panel was 2 hours long and had 11 expert participants as well as members of the study team. During the Delphi Consensus Panel, a final consensus was reached if the clinical vignettes was not NTSCI or NTSCI, except for 3 vignettes that were labeled as "unclassifiable" due to the case description not having enough information to make an appropriate classification. Results of Delphi Process are presented in table 2.

Figure 1 outlines the key steps for the classification of SCI based on Delphi Panel results and literature from the International Standards for Neurological Classification of Spinal Cord Injury and the International Spinal Cord Injury Data Sets for NTSCI.[15,31] The following are the key ideas and concepts identified during the Delphi Panel discussion:

Cauda equina syndrome: There was discussion if cauda equina syndromes should be considered SCI during the review of clinical vignettes 14, 15, and 16. Participants noted patients with cauda

Table 1 Demographic characteristics of participants

	n	%
Age (y)		
Below 50	23	74.2
50 and above	8	25.8
Sex		
Male	19	61.3
Female	11	35.5
Prefer not to say	1	3.2
Years of clinical practice and/or research experience		
Below 10	9	29.0
10-19	13	42.0
20 and above	9	29.0
Location		
Outside of Canada	4	12.9
Canada	27	87.1
Specialty		
Non-Physician Researcher	1	3.2
Neurosurgery	9	30.0
Orthopedic	8	26.7
Physical Medicine and Rehabilitation	13	43.3

Table 2 Results from Round 1, 2, and 3 of Delphi process

#	Case	Score	Round 1 (%)	Round 2 (%)	Round 3 (Final Delphi Consensus)	Explanation of Final Consensus
1	Seventy-year-old man with history of transverse myelitis at T10 in 2005; associated with incontinence, transient paraplegia. This gentleman is now functionally independent, ambulates without difficulty, bowel and bladder fully intact.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	29.0 9.7 61.3	27.8 0 72.2	NTSCI	Recovered NTSCI. However, case still classified as NTSCI, as individual will not present the same as someone who has never had a NTSCI. Classification can change depending on purpose of the research.
2	Fifty-year-old female with history of discectomy L4/5 in 2013. Patient also was diagnosed with cervical spondylosis at C5/6/7 in 2015. Presenting today with new antalgic gait, left food drop, and pins and needles in the left leg. Patient has no history of falls. No reported symptoms in upper extremities, independent for basic ADLs, no reported difficulties of bowel or bladder	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	61.3 16.1 22.6	88.8 5.6 5.6	Not NTSCI	No motor, bowel or bladder impairments. Based on provided information, impairments not substantial for case to be classified as NTSCI.
3	Fifty-seven-year-old man with history of traumatic spinal cord injury in 1998 at T12/L1, resulting in paraplegia with neuropathic pain. In 2017, C1 to C3 laminectomy for rotatory subluxation with myelopathy. Patient uses a wheelchair due to persistent paraplegia, and has no voluntary control of bowel and bladder.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	41.9 19.4 38.7	38.9 33.3 27.8	NTSCI	Based on provided information, it seems loss of voluntary control of bowel and bladder were due to 2017 injury, which had a NTSCI etiology. Individual has both traumatic and non-traumatic SCI. Hence is labelled as NTSCI.
4	Seventy-two-year-old woman with history of motor vehicle accident in December 2014, resulting in concussion, Medical history includes diabetes mellitus. In August 2015, she was diagnosed with cervical spondylotic myelopathy with cord atrophy, followed by C3-6 decompression and laminectomy.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	9.7 16.1 74.2	5.6 16.7 77.7	NTSCI	Clear NTSCI etiology pre-surgery. Since no information if surgery made impairments worse, better, or unchanged, interpretation this as a NTSCI case is acceptable.
5	Forty-two-year-old man with history of back injury causing progressive myelopathy with spastic paresis affecting gait. Patient also reports urinary frequency, and constipation.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	25.8 32.2 41.9	16.7 38.9 44.4	Not classifiable	Cause of back injury is unclear. Not classifiable as back injury cold be non-traumatic or traumatic as cause is unclear.
6	Seventy-year-old woman with diagnosis of spondylosis at C4 to C7. She does not report any pain and appears to have normal gait and upper extremity function.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	93.5 6.5 0	94.4 0 5.6	Not NTSCI	Although patient has a diagnosis of spondylosis, she reports no associated impairments.

(*continued on next page*)

Table 2 (*Continued*)

#	Case	Score	Round 1 (%)	Round 2 (%)	Round 3 (Final Delphi Consensus)	Explanation of Final Consensus
7	34-year-old male with spina bifida, stress incontinence. No motor or sensory impairment reported.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	54.8 25.8 19.4	50.0 33.3 16.7	Not classifiable	Based on information provided unclear if incontinence is related to spina bifida. Also, patient reports no other impairments. More information is needed.
8	Eighty-two-year-old man with history of lumbar degenerative disc disease in 2008, and later was diagnosed with cervical spondylosis. He also has a history of urinary urgency and incontinence, and constipation but the etiology is unknown.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	67.8 29.0 3.2	61.1 27.8 11.1	Not NTSCI	Mild symptoms in an elderly individual may not be related to his spinal cord problem. Urinary issues frequently exist in elderly populations unrelated to spinal cord injury.
9	Seventy-six-year-old woman with diagnosis of diabetes mellitus, presenting with peripheral neuropathy. Ambulates with rollator walker.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	93.6 3.2 3.2	94.4 0 5.6	Not NTSCI	No NTSCI-related etiology.
10	Fifty-nine-year-old man with cervical stenosis and chronic neck pain. Reports urinary frequency.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	74.2 12.9 12.9	77.8 22.2 0	Not classifiable	Unclear if symptoms are related to the cervical stenosis. Case would be classifiable if urinary frequency could be linked to cervical stenosis or if other impairments were mentioned.
11	Forty-three-year old man with cervical myelopathy with incomplete tetraplegia, neuropathic pain, and recurrent UTIs; history of cervical discectomy C5-6, C6-7, C7-T1.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	3.2 6.5 90.3	22.2 5.6 72.2	NTSCI	Clear SCI injury, no mention of a traumatic event, but patient has cervical myelopathy, hence NTSCI.
12	Fifty-three-year-old male with prostate cancer and metastases to spine. He has pain in the lower extremities, is continent of bowel and bladder, and ambulates independently.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	54.8 32.3 12.9	61.1 27.8 11.1	Not NTSCI	Pain may be due to musculoskeletal issues caused by metastatic disease. Still maintains bowel and bladder continence, and no motor impairment, hence not NTSCI.
13	Sixty-one-year-old female with progressive cervical stenosis, but no loss of function as a result of stenosis. However, was admitted to hospital for elective surgical decompression of the stenosis. Experienced post-operative complications, now with sensory, bowel, and bladder involvement, quadriparesis, generalized weakness. Some incontinence, and unable to pass stools (decreased voluntary response).	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI) Refuse to answer	35.5 9.7 54.83 N/A	66.7 11.1 16.7 5.5	Not NTSCI	Pre-surgery did not have any impairments due to stenosis. Impairments are due to surgery, indicating a traumatic cause.

(*continued on next page*)

Table 2 (*Continued*)

#	Case	Score	Round 1 (%)	Round 2 (%)	Round 3 (Final Delphi Consensus)	Explanation of Final Consensus
14	Fifty-two-year-old female with an intra-dural tumour at conus, causing cauda equina syndrome. Had paraparesis, some generalized weakness, bladder incontinence and also diminished bowel motility. Underwent T11 to L2 laminectomy with tumor resection. Post-op, patient had improved strength, some return to bowel function, and ongoing difficulty with bladder function.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	12.9 3.2 83.9	0 0 100.0	NTSCI	Issues are linked to NTSCI etiology. Even after surgery impairments related to NTSCI etiology are still ongoing.
15	Forty-three-year-old female with workplace injury causing acute lumbar disc herniation, presenting with weakness and saddle anesthesia consistent with cauda equina syndrome. Underwent urgent decompression surgery. Postoperatively, weakness and numbness resolved.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	64.5 9.7 25.8	72.2 0 27.8	Not NTSCI	Workplace injury most likely due to traumatic incident. Information indicates traumatic cauda equina syndrome.
16	Seventy-year-old man with degenerative spine disease and cauda equina syndrome, presenting with intermittent weakness and numbness in the lower extremities, and urinary retention.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	38.7 6.5 54.8	44.4 5.6 50	NTSCI	Non-traumatic etiology resulting in impairments; hence NTSCI.
17	Forty-five-year-old male who went skydiving and had a rough landing, but no immediate neurological issues then. Two days later, developed neurological deficits including pain and weakness in his legs, presented to the hospital. Imaging confirmed anterior wedge fracture at L1 and significant epidural hematoma.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	87.1 0 12.9	88.9 0 11.1	Not NTSCI	Although impairments and symptoms were delayed, they were the result of a traumatic event, hence traumatic SCI.
18	Seventy -two-year-old man with prior diagnosis of cervical spondylosis with some motor weakness. Patient was admitted to hospital due to ground level fall while intoxicated, now with central cord syndrome. Continent of bowel and bladder. At discharge patient had numbness to the hands, motor loss to upper extremities.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	54.8 19.4 25.8	61.1 22.2 16.7	Not NTSCI	Current impairments are the result of a traumatic event, hence traumatic SCI.

(*continued on next page*)

Table 2 (*Continued*)

#	Case	Score	Round 1 (%)	Round 2 (%)	Round 3 (Final Delphi Consensus)	Explanation of Final Consensus
19	Fifty-two-year-old female involved in motor vehicle accident causing brain injury and C2 fracture, which was deemed to be non-operative. Admitted to the hospital 3 months later with fatigue, and motor coordination problems causing a fall from ground level. During inpatient stay, diagnosed with cervical myelopathy and underwent C3-6 fusion, laminectomy. She has maintained bowel and bladder continence throughout. Patient was discharged back to group home.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	32.3 38.7 29.0	38.9 44.4 16.7	NTSCI	Patient has both non-traumatic and traumatic injuries to the spinal cord. Hence, it can be categorized as NTSCI.
20	Seventy-eight-year-old male with generalized weakness and sensory changes in all four limbs, previous diagnosis of degenerative disc disease (DDD). MRI confirmed multi-level DDD without cord compression, with vascular myelopathy ruled out. Patient was then put on dialysis, and symptoms improved, concluded that this was a medical event.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	80.7 3.2 16.1	83.3 5.6 11.1	Not NTSCI	Symptoms improved after dialysis, indicating they were not related to the degenerative disc disease.
21	Twenty-nine-year-old female with history of substance use disorder, rolled out of bed one night, and slept with neck in hyper-flexed position for several hours. Admitted with transverse myelitis; quadriparesis, with some numbness, urinary incontinence and diminished bowel motility. Patient was transferred to inpatient rehab.	1 to 3 (Not NTSCI) 4 to 6 7 to 9 (NTSCI)	25.8 22.6 51.6	27.8 22.2 50	NTSCI	Impairments seem to be the result of transverse myelitis, a NTSCI etiology. Rolling out of bed and sleeping with neck in hyper-flexed position does not seem like sufficient force to cause a traumatic injury.

DDD, degenerative disk disease

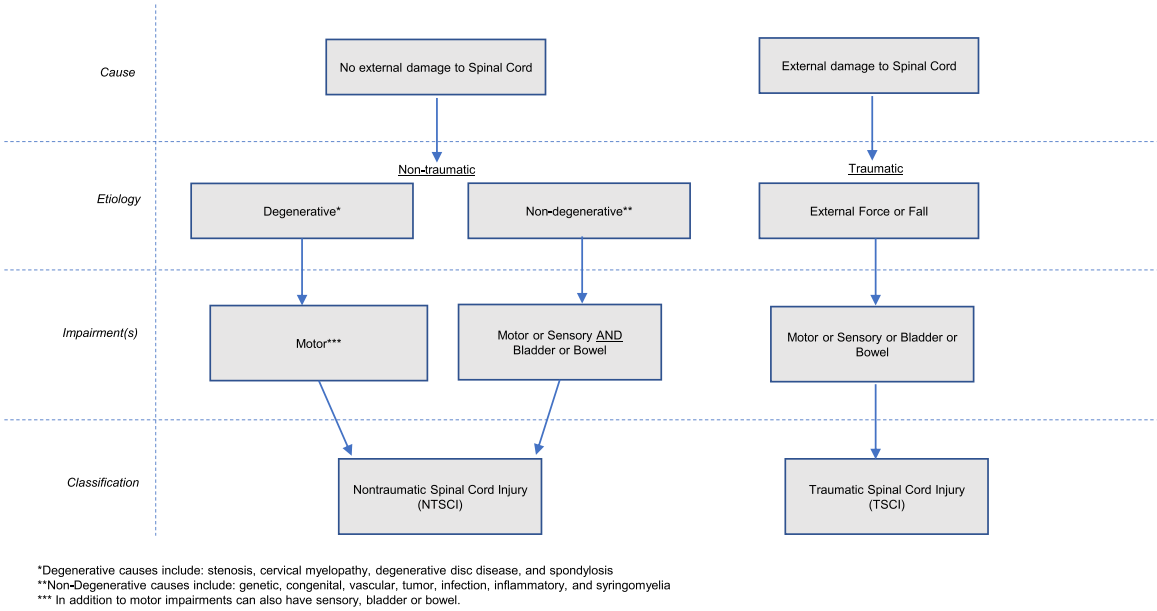

Fig 1 Principles and steps for classifying NTSCI and TSCI. Principles and steps for classification were developed based on Delphi Panel results and literature from the International Standards for Neurological Classification of Spinal Cord Injury and the International Spinal Cord Injury Data Sets for non-traumatic spinal cord injury.[15,31]

equina syndrome present with different symptoms and pathologies compared with SCI at higher levels. Because the current NTSCI guidelines indicate spinal cord refers to the structures within the vertebral canal and the cauda equina is located within the vertebral canal, cauda equina syndromes should be considered an SCI.[6,31] The inclusion of cauda equina syndrome in SCI is also in line with the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI).[15] Agreement was reached that cauda equina syndromes should be SCI and can be classified as an NTSCI or TSCI based on the mechanism of injury if available.

Identifying a traumatic mechanism of injury: Participants agreed that for a TSCI there must be an external cause that damages the spinal cord, as seen in clinical vignettes 15, 17, and 18. There must be a temporal relationship between a traumatic event with sufficient force, and the onset of neurologic impairments, even if the impairments are delayed the etiology should be considered TSCI, such as in clinical vignettes 17. If no trauma is associated with the onset of neurologic impairments, or if the trauma described does not feature enough force to damage the spinal cord, then the etiology should be classified as NTSCI.

Connecting neurologic impairments to etiologies: To be classified as SCI, in addition to an etiology, the presence of neurologic impairments is required. There are a range of neurologic impairments and severities associated with SCI. For cases of degenerative NTSCI, the expert panel agreed the condition needs to progress to the extent of motor impairments. There may also be sensory, bowel, and bladder impairments present in degenerative NTSCI, such as clinical vignettes 11 and 16. For example, in clinical vignettes 2, 6, and 8, with cervical spondylosis, a common condition in the elderly, these were not considered NTSCI because no motor issues were present. If there are no motor issues, the severity of the etiology is not sufficient to be classified as NTSCI.

In the case of non-degenerative NTSCI, bowel or bladder impairments, and motor or sensory impairments must be identified, such as clinical vignettes 1, 14, and 21. Participants felt the threshold to be classified as NTSCI required non-degenerative etiologies cases to have either a bowel or bladder impairments, as having a diagnosed etiology and motor or sensory impairments was insufficient to constitute an injury to the spinal cord. Furthermore, the neurologic impairments must be linked to the diagnosed etiology to be classified as NTSCI. This may be challenging in the case of bowel or bladder dysfunction, as non-neurogenic causes often overlap in prevalence with many NTSCI-related disorders. For example, in clinical vignette 10, the etiology of cervical stenosis could not be linked to the chronic neck pain and urinary frequency, based on the provided information; hence, the vignette was unclassified due to the lack of information. Similarly, clinical vignettes 5 and 7 could not link the impairments to the diagnosed etiology, hence were labeled as unclassifiable. Additionally, listing spinal or back surgery does not automatically indicate SCI, because surgery can be preventive as seen in clinical vignette 13. Sufficient impairments must be identified in the charts pre-surgery to be classified as NTSCI. Table 3 outlines keywords associated with types of neurologic impairments that can be used to identify cases as NTSCI in EMR databases.

TSCI and NTSCI: It is possible for individuals to sustain both a TSCI and NTSCI. For classifying purposes, the most acute event that triggered the most recent spinal cord damage or impairment should be used such as in clinical vignettes 3 and 19. However, patients with non-traumatic etiologic conditions, who had surgery to manage the etiology and associated impairments, but the surgery exacerbated impairments, should still be classified as NTSCI, which is also outlined in the ISNCSCI.[15] Clinical vignette 13 was decided as not NTSCI due to the patient not having any clinical features of NTSCI prior to surgery.

Recovered NTSCI: Finally, those with recovered NTSCI, where impairments are no longer present, such as in clinical vignette 1 with acute transverse myelitis, or clinical vignette 14 improvement post-surgery, are still considered NTSCI, as panelists indicated these individuals may have different presentations than a person who has never had NTSCI. However, the

Table 3 Keywords associated with types of neurologic impairments that can be used in EMR databases

Neurological Impairment	Keywords
Motor	loss of fine motor movement, weakness, use of mobility aids, functional loss of arms or legs, paralysis, spasticity, paraplegia, tetraplegia, quadriplegia
Sensory	pain, burning sensations, tingling, weakness, loss of sensation, numbness
Bladder	incontinence, catheterization, urinary retention, bladder urgency, neurogenic bladder, spastic bladder
Bowel	bowel routine, bowel incontinence, loss of sensation in bowel area, neurogenic bowel

Table 4 Approaches and limitations to identifying key constructs for NTSCI in health administrative databases

Construct	Approaches to Identify in Administrative Databases	Limitations of Identification in Administrative Databases
NTSCI etiologies	• Use ICD-10 codes associated with NTSCI etiolgies • Include codes associated with cauda equina • For list of codes see Table 1A in Appendix of Ho et al. 2017 (18)	• Not all NTSCI etiologies may be coded, hence cannot be identified using diagnostic codes
Mechanism of injury	• Use ICD-10 codes to determine cause ○ Canada has ICD-10CA codes that can be used to determine causes • If cause codes for injury are available, complete, and accurate, can be potentially used to differentiate between TSCI and NTSCI	• Mechanism of injury or associated codes may not be available or complete in discharge abstracts • NTSCI cases are usually identified using etiology diagnoses, hence will not have a mechanism of injury code
Impairments	• Motor impairments can be identified using codes for paraplegia and tetraplegia/ quadriplegia	• Use of codes for paraplegia and tetraplegia/ quadriplegia limits to identification of severe motor impairments • No clear method to identify bowel, bladder, or sensory impairments with use of codes
Recovered NTSCI	• Procedure codes for hospitalization can be used to determine if surgery was conducted to identify potential cases of recovered NTSCI • Codes to identify NTSCI etiology of transverse myelitis may indicate a recovered NTSCI	• Use of hospitalization procedure codes for surgery is not specific to NTSCI • Also, unclear if surgery indicates a recovered NTSCI • Timeframes for conditions or impairments are not always available, hence identification of recovered NTSCI can be difficult

categorization of these cases may be dependent on the purpose of the classification. For example, tracking prevalence vs incident cases of NTSCI may warrant different categorizations.

Discussion

The Delphi panel provided valuable insight on principles associated with retrospectively classifying cases of NTSCI in health administrative and EMR databases, where available information is often limited. Many of the findings are consistent with the definition of NTSCI established in previous published literature.[6,15,17-19,31] Table 4 outlines potential approaches and limitations to identify NTSCI in health administrative and EMR databases based on the key ideas and concepts identified during the Delphi Panel discussion.

The inclusion of cauda equina as a part of the spinal cord is outlined in the the International Spinal Cord Injury Data Sets for NTSCI, and this is also consistent with the ISNCSCI.[6,15,31] As such, cauda equina syndrome should be considered an SCI and should be categorized as NTSCI or TSCI based on the mechanism of injury.[31] However, it maybe warranted to flag cases of cauda equina, as a subcategory of NTSCI, to allow for exploration of clinical differences between cauda equina and other NTSCI.

Previous literature also outlined that TSCIs are the result of external forces damaging the spinal cord and resulting in impairments, even if the impairments are delayed.[15,31] Any damage to the spinal cord without an identified external force, and resulting in impairments should be considered an NTSCI.[15,31]

Numerous NTSCI etiologies are associated with aging, such as spondylosis and related spondyloarthropathies, degenerative cervical myelopathy, stenosis, or spondylosis.[5,8,9,13,31,32]

Impairments associated with NTSCI, such as motor, sensory, bowel, and bladder, are frequently found in elderly individuals unrelated to NTSCI, and many NTSCI etiologies are associated with aging. As such it may be harder to attribute impairments to diagnose NTSCI etiologies in elderly patients. Future research should evaluate the effect of aging on retrospectively classifying NTSCI in more depth.

Another important finding from this process was the ongoing difficulty in agreeing on cases of NTSCI retrospectively when available information is limited. Having sufficient information to link impairments to etiology is key in classifying NTSCI; however, this information may not always be available, even when a full clinical chart is accessed.[17,18] It may be easier to determine motor or sensory impairment, with keywords like paraplegia or tetraplegia, but uncovering bladder or bowel impairments was particularly challenging. As such, cases of non-degenerative NTSCI, which require the identification of bladder or bowel impairments, may not be identifiable in health administrative databases. Additionally, perhaps, the creation of an unclassifiable category may help with accurately classifying cases of SCI without the rigidity of having to place them in either TSCI or NTSCI. Beyond research, the addition of an unclassifiable category would be particularly helpful to inform public health planning and surveillance.

Alternatively, full chart audits compared with health administrative and EMR databases may be able to provide adequate information about etiologies, mechanisms of injury, and associated impairments, to determine cases of NTSCI. The findings from the Delphi process may assist in classifying NTSCI using chart audits. Chart audits have shown utility to create and validate algorithms used to identify NTSCI cases in administrative databases.[17-19] However, more research is needed as the utility of chart audits to identify and classify cases of NTSCI is still unclear, although may be infeasible long term due to the time requirements needed for full chart audits.

In general, when classifying cases of NTSCI in health administrative and EMR databases, it is important to determine how including or excluding certain cases would affect the warranted outcome, and if this is inline with the intended purpose of a given study. Recovered cases of NTSCI may not be considered "active" cases of NTSCI, and excluding them for certain purposes may be warranted, for example, research studies tracking health care utilization of individuals with NTSCI. As discussed in the Delphi Panel, impairments associated with NTSCI are on a spectrum, and it is important to be aware of this fact when classifying case of NTSCI, as the severity of impairments is rarely clear in health administrative and EMR databases. Any research study that uses health administrative and EMR databases to retrospectively identify cases of NTSCI needs to highlight the inclusion and exclusion criteria and justify why they were chosen based on their objectives. Future research is still needed to refine the process of identifying cases of NTSCI, and a validation study should be conducted to verify these findings.

Limitations

The study did have some limitations. The COVID-19 pandemic delayed the time between the rounds. Additionally, it limited the number of experts who were able to participate in the Delphi process due to competing priorities, as well as the available time for discussion. Clinical vignettes were created based on cases from only 1 adult acute care site and from a primary care database in Canada, as such may lack generalizability with potential issues not identified. Therefore, there may have been concepts associated with determining NTSCI that were potentially overlooked or not discussed. Due to differences in cultural norms or health care system, and other influences on charting practices, each health administrative database may differ in the extent and type of information available, as such criteria needed to identify NTSCI in various databases may differ and this concept should be investigated in future research.

Conclusion

The findings from this work advance the knowledge of NTSCI by providing insight to improve the accurate identification of NTSCI cases in health administrative and EMR databases. However, it also highlighted the complex nature of determining cases of NTSCI due to the limited information available in health administrative and EMR databases. Overall, the Delphi process has provided much needed guidelines to appropriately classify cases of NTSCI in health administrative and EMR databases, and this can be used for further research.

Keywords

Database; Degenerative diseases; Electronic medical record; Rehabilitation; Spinal cord; Spinal cord diseases; Spinal cord injuries; Spinal stenosis; Spondylosis

Corresponding author

Arrani Senthinathan, Rehabilitation Sciences, 500 University Ave, Toronto, ON, M5G 1V7 *E-mail address:* arani.senthinathan@utoronto.ca.

References

1. New PW, Guilcher SJT, Jaglal SB, Biering-Sørensen F, Noonan VK, Ho C. Trends, challenges, and opportunities regarding research in non-traumatic spinal cord dysfunction. Top Spinal Cord Inj Rehabil 2017;23:313–23.
2. Citterio A, Franceschini M, Spizzichino L, Reggio A, Rossi B, Stampacchia G. Nontraumatic spinal cord injury: an Italian survey. Arch Phys Med Rehabil 2004;85:1483–7.
3. Rouleau P, Ayoub E, Guertin PA. Traumatic and non-traumatic spinal cord-injured patients in Quebec, Canada: 1. Epidemiological, clinical and functional characteristics. Open Epidemiol J 2011;4:133–9.
4. McCammon JR, Ethans K. Spinal cord injury in Manitoba: a provincial epidemiological study. J Spinal Cord Med 2011;34:6–10.
5. McCaughey EJ, Purcell M, McLean AN, et al. Changing demographics of spinal cord injury over a 20-year period: a longitudinal population-based study in Scotland. Spinal Cord 2016;54:270–6.
6. Fraser S, Roberts L, Murphy E. Cauda Equina syndrome: a literature review of its definition and clinical presentation. Arch Phys Med Rehabil 2009;90:1964–8.
7. New PW, Reeves RK, Smith É, et al. International retrospective comparison of inpatient rehabilitation for patients with spinal cord dysfunction: differences according to etiology. Arch Phys Med Rehabil 2016;97:380–5.
8. New PW, Sundararajan V. Incidence of non-traumatic spinal cord injury in Victoria, Australia: a population-based study and literature review. Spinal Cord 2008;46:406–11.

9. New PW, Cripps RA, Bonne Lee B. Global maps of non-traumatic spinal cord injury epidemiology: towards a living data repository. Spinal Cord 2014;52:97–109.
10. Noonan VK, Fingas M, Farry A, et al. Incidence and prevalence of spinal cord injury in Canada: a national perspective. Neuroepidemiology 2012;38:219–26.
11. Guilcher SJT, Munce SEP, Couris CM, et al. Health care utilization in non-traumatic and traumatic spinal cord injury: a population-based study. Spinal Cord 2010;48:45–50.
12. AZ Lekoubou Looti, Kengne AP, VdP Djientcheu, Kuate CT, Njamnshi AK. Patterns of non-traumatic myelopathies in Yaounde (Cameroon): a hospital based study. J Neurol Neurosurg Psychiatry 2010;81:768–70.
13. McKinley WO, Seel RT, Hardman JT. Nontraumatic spinal cord injury: incidence, epidemiology, and functional outcome. Arch Phys Med Rehabil 1999;80:619–23.
14. van den Berg MEL, Castellote JM, Mahillo-Fernandez I, de Pedro-Cuesta J. Incidence of nontraumatic spinal cord injury: a Spanish cohort study (1972−2008). Arch Phys Med Rehabil 2012;93:325–31.
15. New PW, Marshall R. International spinal cord injury data sets for non-traumatic spinal cord injury. Spinal Cord 2014;52:123–32.
16. New PW, Delafosse V. What to call spinal cord damage not due to trauma? Implications for literature searching. J Spinal Cord Med 2012;35:89–95.
17. Jaglal SB, Voth J, Guilcher SJT, et al. Creation of an algorithm to identify non-traumatic spinal cord dysfunction patients in Canada using administrative health data. Top Spinal Cord Inj Rehabil 2017;23:324–32.
18. Ho C, Guilcher SJT, McKenzie N, et al. Validation of algorithm to identify persons with non-traumatic spinal cord dysfunction in Canada using administrative health data. Top Spinal Cord Inj Rehabil 2017;23:333–42.
19. Guilcher SJT, Voth J, Ho C, et al. Characteristics of non-traumatic spinal cord dysfunction in Canada using administrative health data. Top Spinal Cord Inj Rehabil 2017;23:343–52.
20. Guilcher SJT, Parsons D, Craven BC, Jaglal SB, Verrier M. Developing quality of care indicators for patients with traumatic and non-traumatic spinal cord injury (SCI): a feasibility study using administrative health data. J Spinal Cord Med 2015;38:765–76.
21. Lee SW, Werner B, Holt J, Lohia A, Ayutyanont N, York H. Clinical characteristics, hospital course, and disposition of patients with non-traumatic spinal cord injury in a large private health care system in the United States. J Spinal Cord Med 2022: 1–10.
22. Drees M, Gerber JS, Morgan DJ, Lee GM. Research methods in healthcare epidemiology and antimicrobial stewardship: use of administrative and surveillance databases. Infect Control Hosp Epidemiol 2016;37:1278–87.
23. Mazzali C, Duca P. Use of administrative data in healthcare research. Intern Emerg Med 2015;10:517–24.
24. Fink A, Kosecoff J, Chassin M, Brook RH. Consensus methods: characteristics and guidelines for use. Am J Public Health 1984;74:979–83.
25. Dalkey N, Helmer O. An experimental application of the DELPHI method to the use of experts. Manag Sci 1963;9:458–67.
26. Tu K, Mitiku TF, Ivers NM, et al. Evaluation of Electronic Medical Record Administrative Data Linked Database (EMRALD). Am J Manag CARE 2014;20:7.
27. Noonan VK, Kwon BK, Soril L, et al. The Rick Hansen Spinal Cord Injury Registry (RHSCIR): a national patient-registry. Spinal Cord 2012;50:22–7.
28. Dillman DA. Mail and Internet surveys : the tailored design method. 2nd ed. New York: John Wiley; 2000.
29. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)—a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009;42:377–81.
30. De Meyer D, Kottner J, Beele H, et al. Delphi procedure in core outcome set development: rating scale and consensus criteria determined outcome selection. J Clin Epidemiol 2019;111:23–31.
31. Biering-Sørensen F, DeVivo MJ, Charlifue S, et al. International spinal cord injury core data set (version 2.0)—including standardization of reporting. Spinal Cord 2017;55:759–64.
32. Badhiwala JH, Ahuja CS, Akbar MA, et al. Degenerative cervical myelopathy — update and future directions. Nat Rev Neurol 2020;16:108–24.