

ORIGINAL ARTICLE

Patient and caregiver knowledge of severity of injury among youth with spinal cord injury

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Design: Multicenter cross sectional study.

Objectives: Describe patient and caregiver knowledge of severity of injury and examine the relationship between AIS status and patient/caregiver report.

Setting: United States

Methods: Participants were between 1 and 21 years of age with a stable spinal cord injury (SCI). Participants underwent ISCSCI exams and were interviewed with the following questions: 1. Did the patient/caregiver know the difference between complete and incomplete spinal cord injury before participation? 2. What level of injury does the patient/caregiver report? 3. What severity of injury does the patient/caregiver report? 4. If a severity is given, who told them and how was it tested?

Results: Overall, 16% of patients and 20% of caregivers knew the difference between complete and incomplete SCI. Older patients were more likely to know the difference and caregivers of patients with shorter durations of injury were more likely to know the difference. Those who reported a severity of injury different from their actual severity were more likely to have a complete spinal cord injury and a higher injury severity as measured by the AIS impairment scale. Only 18% of people who were able to report a severity of injury stated that an ISCSCI exam was how the doctor gave them the diagnosis.

Conclusion: Many patients and caregivers do not understand the difference between complete and incomplete SCI. It is vital that an AIS diagnosis only be given following the ISCSCI exam based on agreed standards.

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Introduction

In the realm of spinal cord injury (SCI), patients, caregivers and even health care professionals often fixate on several terms including walking, recovery, independence and whether the injury is complete or incomplete. The completeness or incompleteness of a spinal cord injury, otherwise known as severity of injury, is often misunderstood when discussing spinal cord injuries in people of any age. For the knowledge of prognosis and for possible inclusion in clinical trials, patients and caregivers are very interested in knowing the severity of their injury and typically want to hear that their injury is incomplete. Unfortunately, many healthcare professionals in the spinal cord injury field do not use the terms complete and incomplete correctly and therefore patients and families are often misinformed about the type of spinal cord injury they have.

When healthcare professionals or patients and families use the term severity of injury, they are typically referring to completeness or incompleteness of the spinal cord injury. However, many healthcare professionals and patients/families think that if a spinal cord injury is 'complete' it means that the spinal cord is completely transected as evidenced by radiographic images. Alternatively, if they are given a diagnosis of 'incomplete' spinal cord injury, many assume that this means the spinal cord was not completely transected in the injury. Fortunately, the majority of spinal cord injuries do not completely transect the spinal cord; however, this does not mean that they are incomplete injuries, in fact—the majority are complete despite the fact that they are not completely transected.¹ The confusion over what determines complete vs incomplete injuries is partly due to historical reasons, as the operational definition of severity of injury has changed over the last 40 years.

In 1969, the classification of spinal cord injuries was created by Frankel.² In this original classification, patients with sensory function three or more levels below the level of

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injury were classified as incomplete. In 1982, the American Spinal Injury Association (ASIA) published the Standards for Neurological Classification of Spinal Cord Injury that became the accepted language for describing the level of injury (both sensory and motor).³ These standards were based on the original Frankel classification and adopted the Frankel classification for describing severity of injury. In 1992, the ASIA standards committee made another revision to create the ASIA Impairment Scale (AIS). This revision redefined complete vs incomplete injuries. It was at this time that a person could only be classified as having an incomplete spinal cord injury if they had sacral sparing—perianal sensation, anal–rectal sensation or voluntary anal sphincter contraction.¹ Also, at this time the zone of partial preservation was designed to describe sensation or motor below the level of injury if there was no sacral sparing. The current form of the exam which provides standardization for motor and sensory testing is referred to as the International Standards for Neurological Classification in Spinal Cord Injury (ISCSCI).⁴

The results derived from the ISCSCI exam can help with injury prognosis,^{5–7} help determine the eligibility for clinical trials^{8,9} and assist in ongoing evaluation of neurological symptoms.^{10–12} Despite the clinical usefulness of the ISCSCI, it may be an unreliable exam in young children in determining whether an injury is complete or incomplete.¹³

Purpose

The purpose of this study is to assess patient and caregiver knowledge of severity of injury in a sample of youth with SCI. This study is part of a larger multicenter research effort aimed at establishing the utility of the International Standards for Neurological Classification of Spinal Cord Injury (ISCSCI) in children and youth and is reporting on patient and caregiver knowledge of severity of injury (complete vs incomplete) in this sample of children. It is important to understand patient and caregiver knowledge about spinal cord injury and associated terminology to improve education about severity of injury.

Materials and methods

Participants

In all, 215 subjects were enrolled in this multicenter research effort. Participants were eligible for the study if they were between the ages of 1 and 21 with a stable SCI as evidenced by no neurological change within the past 3 months. The participants had all received care at the SCI Programs of Shriners Hospitals for Children in either Chicago or Philadelphia. All participants who met the above criteria, who presented to the hospital for admission or an outpatient clinic visit were approached about the study.

Procedure

The study protocol, consent, assent and Health Insurance Portability and Accountability Act forms were all reviewed and approved by the Institutional Review Board at each participating center. Informed consent was obtained from all

participants and their caregivers as appropriate, and the ethical treatment of human subjects was followed throughout the research process.

Instruments

Demographic information was collected from the medical records for all participants including gender, ethnicity, and date of birth, date of injury, severity of injury, age at injury, injury etiology, and level of injury. Subjects underwent four repeated ISCSCI motor and sensory exams including the anorectal exam by two separate health care professionals as part of the study. Each of the examiners was responsible for two of the four exams. Between the two sites, there were seven health care professionals who were trained in the examination and classification techniques of the ISCSCI and were responsible for conducting all of the exams.¹⁴ In addition, patients and families were asked four questions about severity of injury. The questions asked were as follows: 1. Did the patient/caregiver know the difference between complete and incomplete spinal cord injury before participation in the study? For the patient or caregiver to get a ‘yes’ for this question, they had to include knowledge about the anorectal exam being the proper way to diagnose complete vs incomplete injury. 2. What level of injury does the patient/caregiver report? 3. What severity of injury does the patient/caregiver report (complete vs incomplete)? 4. If a severity is given, who told them and how was it tested (such as an MD gave them the information through an ISCSCI exam)? This final question was added part way through the study and the information was not collected on every subject enrolled.

Data analysis

The Statistical Package for the Social Sciences (SPSS, version 15.0) was used to analyze the data. Descriptive statistics were used to describe knowledge of severity of injury among patients and caregivers, and χ^2 analyses were used to examine differences between subgroups including race, gender, etiology of injury, age at injury, level of injury and AIS classification. Independent samples *t*-test was used to compare means.

Results

Results are presented in the following sections: participant demographics and secondly, information on the relationship between knowledge of severity of injury and demographic and injury-related factors according to patients and caregivers. The demographics of the study sample are presented in Table 1.

Question 1. Does the patient/caregiver know the difference between complete and incomplete spinal cord injury before participation in the study?

Only 16% of patients and 20% of caregivers overall knew the difference between complete and incomplete spinal cord

Table 1 Participant demographics

Characteristics	Percentage of participants (n = 215)
Sex	
Male	59
Female	41
Race	
Caucasian	76
Hispanic	11
African American	8
Asian	2
Type of injury	
Tetraplegia	54
Paraplegia	45
Severity of injury	
Complete	51
Incomplete	49
Cause of injury	
Vehicular	48
Medical/surgical	23
Sports	14
Violence	9
Falls/flying objects	6
Watercrafts	1
Mean age at injury	9.1 years

injuries at the beginning of the study. For the majority of injury and demographic-related factors, no significant associations were found in either the patient or the caregiver group. The only significant differences found were mean age at follow up in the patient group and duration of injury in the caregiver group. Older patients were more likely to know the difference between complete and incomplete spinal cord injury and caregivers of patients with a shorter duration of injury were more likely to know the difference between complete and incomplete than caregivers of patients who had been injured for a longer period of time (Table 2).

Relationship between AIS status and patient/caregiver report

Although a majority of patients and caregivers were accurate in their reporting of severity of injury, 23% of patients and 14% of caregivers reported the injury was complete when it was actually incomplete. 24% of patients and 27% of caregivers reported that the injury was incomplete when it was in fact complete. Significant differences were found in the patient group for both severity of injury (complete vs incomplete) and AIS classification between those who were correct and those who were incorrect in their reporting. For severity of injury, $\chi^2 = 6.31$, $P = 0.012$ and for AIS classification, $\chi^2 = 9.12$, $P = 0.028$. Those who were incorrect in their reporting were more likely to have a complete spinal cord injury and a higher injury severity as measured by the AIS.

Source of information of injury severity

If patients and or caregivers were able to say whether they thought they or the patient was complete or incomplete, we

then inquired about the source of their answer. Although the ISCSCI exam is the standard and internationally agreed upon method to determine clinical completeness of an injury, only 18% of these people stated this was how the doctor gave them the diagnosis; 19% said it was through a radiology report (Table 3).

Discussion

The purpose of this study was to explore patient and caregiver knowledge about severity of injury and to examine how patients and families are given information about injury severity or AIS classification.

Our findings showed that a surprising number of patients and caregivers do not know the clinical definition of complete vs incomplete SCI. There are many reasons as to why this may be the case.

First of all, some patients and caregivers may simply not remember what they were told, if anything, about injury severity. This may be partially due to time since injury or may also be due to the amount of information patients and families are bombarded with soon after injury during initial rehabilitation. In addition to this, patients and families may be reporting what they were told and since then they may have had a change in neurological status or may have had a different outcome in the ISCSCI test because of poor reliability of the anal/rectal exam as a recent publication suggests.¹⁵ It is also possible that the test was done incorrectly in the first place. Also, some patients and caregivers reported that they had never had a formal neurological exam as defined by the ISCSCI in the past and without this, medical professionals would be unable to give them correct information on injury severity. In addition, although not specifically tested, there were some patients and families who stated that they assumed the patient had an incomplete SCI because they had some sensation or motor below their neurological level of injury and did not know that sacral sparing was important. Finally, as stated above, the definition of severity changed in 1992 and therefore patients with older injuries may have been given information that was accurate at that time, but has since changed.

It is not surprising that patients who were older at the time of the exam were more likely to know the difference between complete and incomplete SCI. Caregivers of patients with a shorter duration of injury were more likely to know the difference between complete and incomplete SCI probably because they had been more recently educated about the difference.

Although a majority of patients and caregivers alike were accurate in their reporting of whether the injury was complete or incomplete, we still found a surprising number that were inaccurate and did not know the severity of their injury. In addition, only 18% of patients and caregivers said that they were given information on severity of injury from a healthcare provider by an ISCSCI examination and 31% were given this information from a physician by another method of examination. Some of the patients and caregivers reported

Table 2 The relationship between knowledge of severity of injury and demographic and injury-related factors

Characteristics	Patient knows Caregiver knows complete and incomplete	P-value	Caregiver knows difference between complete and incomplete	P-value
Gender		$\chi^2 = 0.971, P = 0.324$		$\chi^2 = 0.440, P = 0.507$
Male (n = 127)	14%		18%	
Female (n = 88)	19%		23%	
Race		$\chi^2 = 7.67, P = 0.104$		$\chi^2 = 4.78, P = 0.511$
Asian (n = 4)	33%		0%	
Black (n = 18)	0%		18%	
Hispanic (n = 24)	4%		6%	
Caucasian (n = 163)	19%		24%	
Etiology		$\chi^2 = 2.05, P = 0.152$		$\chi^2 = 2.01, P = 0.157$
Traumatic (n = 166)	18%		23%	
Non-traumatic (n = 49)	8%		13%	
Age at Injury (years)		$\chi^2 = 2.86, P = 0.240$		$\chi^2 = 3.17, P = 0.205$
0–5 (n = 84)	10%		14%	
6–13 (n = 53)	17%		22%	
14–21 (n = 78)	20%		28%	
Level of injury		$\chi^2 = 0.038, P = 0.845$		$\chi^2 = 0.254, P = 0.615$
T6 and above (n = 156)	17%		20%	
Below T6 (n = 43)	15%		16%	
ASIA classification		$\chi^2 = 4.81, P = 0.186$		$\chi^2 = 2.24, P = 0.524$
A (n = 105)	12%		24%	
B (n = 46)	12%		15%	
C (n = 30)	26%		11%	
D (n = 21)	26%		21%	
Severity of Injury		$\chi^2 = 2.06, P = 0.152$		$\chi^2 = 2.31, P = 0.128$
Complete (n = 105)	12%		24%	
Incomplete (n = 103)	20%		14%	
Mean age at follow up (years)		$P = 0.047$		$P = 0.817$
Knows difference	15.8		12.1	
Does not know the difference	13.9		11.9	
Duration of injury (years)		$P = 0.297$		$P = 0.001$
Knows the difference	4.1		3.0	

Table 3 Who told them they were complete/incomplete and how?

Method	Percentage of participants (n = 100)
MD by any other method	31
Does not remember where information came from	20
MD by radiology report	19
MD/PT by ASIA exam	18
Never told	9
PT by any other method	2
Have been told both by different doctors	1

that the patient had never had a rectal exam and that they were unaware that this was an important part of a neurological test. This is suggesting that the standard of care for children and adolescents with spinal cord injuries is not the same throughout the country and some patients and families are given misleading information. Psychologically

this miscommunication can be damaging especially when patients and families think that the injury is incomplete (AIS B, C or D) and then must be told that the injury is in fact complete (AIS A). It is important that young patients and their families understand that AIS scores can change over time and although those with incomplete lesions are more likely to recover than those with complete lesions, having a complete SCI does not rule out the chance of recovery.^{10,16,17}

Pediatrics also presents unique issues related to conduction and interpretation of the ISCSCI exam. Testing a very young child for severity of injury may present problems, which could include—not understanding how to let the tester know if the sensation is normal vs not normal (as compared with their face) and attention span. In addition, if the child has had an injury from birth and never been potty trained, they may not understand how to contract their anal muscles. It is vital when an ISCSCI exam is attempted on a younger patient, that deviations of the exams or unusual situations be documented.

Conclusion

Most patients, parents and some clinicians associate incompleteness with better chance of recovery and it is true that patients with incomplete spinal cord injuries may have higher AIS scores 1 year post injury.

For the best communication among clinicians, researchers and patients and families, it is vital that a standard language be used. The definition that a patient is considered to have a complete SCI unless there is sacral sparing (motor or sensory function at S4-5) should become the standard use of complete (AIS A) and incomplete (AIS B, C, D and E) and this should be the terminology used with patients and caregivers. In addition, an AIS diagnosis should only be given following the ISCSCI exam that is based on agreed standards. As discussed earlier, giving an AIS diagnosis to a young child may be extremely difficult and maybe even impossible. It is important that caregivers be aware of this and that future exams will be required for definitive diagnosis. Finally, when describing the extent of an injury on MRI reports, radiologists should use 'intact' rather than 'incomplete' and 'not intact' rather than 'complete' as many patients and caregivers may misinterpret things such as MRI reports.¹⁸⁻²⁰

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