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ARTICLE

Accuracy of self-reported severity and level of spinal cord injury

Catherine L. Furbish [1]✉, Raeda K. Anderson [1,2] and Edelle C. Field-Fote [1,3,4]

STUDY DESIGN: Observational.
OBJECTIVES: To assess accuracy of self-reported level of injury (LOI) and severity in individuals with chronic spinal cord injury (SCI) as compared with clinical examination.
SETTING: An SCI Model System Hospital.
METHODS: A 20-item survey evaluated demographics, physical abilities, and self-reported injury level and severity. A decision tree algorithm used responses to categorize participants into injury severity groups. Following the survey, participants underwent clinical examination to determine current injury level and severity. Participants were later asked three questions regarding S1 sparing. Chart abstraction was utilized to obtain initial injury level and severity. Injury level and severity from self-report, decision tree, clinical exam, and chart abstraction were compared.
RESULTS: Twenty-eight individuals participated. Ninety-three percent correctly self-reported anatomical region of injury (ROI). Self-report of specific LOI matched current clinical LOI for 25% of participants, but matched initial LOI for 61%. Self-report of ASIA Impairment Scale (AIS) matched clinical AIS for 36%, but matched initial AIS for 46%. The injury severity decision tree was 75% accurate without, but 79% accurate with additional S1 questions. Self-report of deep anal pressure (DAP) was correct for 86% of participants, while self-report of voluntary anal contraction (VAC) was correct for 82%.
CONCLUSION: Individuals with SCI are more accurate reporting ROI than specific LOI. Self-reported injury level and severity align more closely with initial clinical examination results than current exam results. Using aggregate data from multiple questions can categorize injury severity more reliably than self-report. Using this type of decision tree may improve injury severity classification in large survey studies.

Spinal Cord (2022) 60:934–941; https://doi.org/10.1038/s41393-022-00855-1

INTRODUCTION

There are ~299,000 people in the US living with spinal cord injury (SCI) [1] which is characterized by impaired mobility and sensation. The degree of impairment is influenced by level and severity of SCI. However, the characteristics of SCI can change over time, such that the measured level and severity may change. Understanding the trajectory of impairments as people live, and age, with SCI is essential in providing healthcare.

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) are the gold standard for identifying an individual's neurologic level and severity of injury. However, the standards require a lengthy, invasive examination that must be performed by clinicians with specialized training. Alternative methods have been proposed to reduce the burden associated with the ISNCSCI examination, but, all methods still require a trained examiner [2–4].

There is value in being able to collect information about injury level and severity via self-report, and several studies have used this method [5–8]. Self-report allows data-gathering from large groups of individuals and requires fewer resources than ISNCSCI examination. Data can also be obtained from individuals who lack access to SCI specialists. However, the reliability of self-reporting injury level and severity can be confounded by change in SCI characteristics since time of injury and by participant's inability to recall information from their examination. For this reason, self-report studies often classify injury level and severity dichotomously as tetraplegia vs. paraplegia, and complete vs. incomplete, respectively [9–11]. More detailed information about injury characteristics could help health care workers draw more nuanced conclusions. The aim of this project was to assess accuracy of self-reported injury level and severity in individuals with chronic SCI as compared with data obtained from same-day ISNCSCI examination.

METHODS

The study was approved by the Shepherd Center Research Review Committee. All participants provided written informed consent. Study participants were selected from a convenience sample of individuals with SCI (traumatic or non-traumatic), who were at least 1 year (±1 month) post-injury, seeking outpatient treatment at Shepherd Center between January and October of 2020. All study procedures were performed in person. Data were collected and managed via online survey using a secure web-based data management application (Research Electronic Data Capture) [9, 12]. Participants self-reported demographics, nature and characteristics of their SCI, and current physical abilities via 20-item questionnaire completed on a tablet (iPad, 5th generation, Apple Inc.; Appendix A). Participants selected

[1]Spinal Cord Injury Research Program, Crawford Research Institute, Shepherd Center, Atlanta, GA, USA. [2]Department of Sociology, Georgia State University, Atlanta, GA, USA. [3]Division of Physical Therapy, Department of Rehabilitation Medicine, Emory University School of Medicine, Atlanta, GA, USA. [4]Program in Applied Physiology, Georgia Institute of Technology, Atlanta, GA, USA. ✉email: cathy.furbish@shepherd.org

Received: 1 November 2021 Revised: 29 August 2022 Accepted: 30 August 2022
Published online: 12 September 2022

the anatomical region of their injury ("Self-report ROI") from three options: (1) cervical (neck); (2) thoracic (upper trunk/rib cage area/above the waist); or (3) lumbar (below the waist). Participants also chose a specific level of injury, termed "Self-report LOI" from an inclusive list of levels from C1 to L5. Additionally, participants selected the severity of their injury, "Self-report AIS," from five options: AIS A, AIS B, AIS C, AIS D or "I don't know." Participants chose YES or NO regarding ability to feel a cotton swab or a pinprick at the peri-anal region, ability to feel a finger inserted into the rectum and ability to contract their anus. These responses are termed "Self-report S4/5," "Self-report deep anal pressure (DAP)," and "Self-report voluntary anal contraction (VAC)," respectively.

Responses to six questions were utilized to categorize injury severity into one of three groups: (1) complete; (2) sensory-incomplete; or (3) motor-incomplete. These were considered proxies for classifications of ASIA Impairment Scale (AIS) A, B, and C/D, respectively. We developed an injury severity decision tree (see Fig. 1) that prevented logical inconsistencies in classification [5], We termed the classification derived from this algorithm "Decision Tree Severity class."

After completing the questionnaire, participants underwent ISNCSCI examination by a research clinician with advanced, individualized ISNCSCI training and certification, who had not seen the self-report data. The ISNCSCI is a comprehensive examination of segmental sensory and motor function used to derive standardized neurological classifications. The examination includes an anorectal exam to detect motor and/or sensory sparing at the last sacral segments. Such sparing would indicate incomplete injury. The sensory anorectal exam includes examination of the peri-anal region ("Clinical S4/5") and internal examination of DAP sensation ("Clinical DAP"). The motor portion examines VAC ("Clinical VAC"). The ISNCSCI examination yields a single neurologic level of injury and an AIS classification of injury severity; these were termed the "Clinical ROI", "Clinical LOI", and "Clinical AIS", respectively.

In January 2021, participants answered three additional survey questions (Appendix A) regarding sensation and motor function at the S1 segment, as these have been suggested as less-invasive proxies for DAP and VAC [13]. Chart abstraction was utilized to determine the LOI and AIS grade from ISNCSCI examination at discharge of the participant's initial inpatient rehabilitation admission. These are "Initial LOI" and "Initial AIS."

Data analysis

Analysis was conducted in SPSS (IBM Corp., Version 27.0. Armonk, NY). Descriptive statistics were calculated for all study variables. Difference scores between self-report and clinical parameters were calculated as: $\Delta = \text{parameter}_{\text{clinician}} - \text{parameter}_{\text{participant}}$. Negative values indicate that participants self-reported a lower parameter value than the clinically-measured parameter (e.g., self-report LOI T4, clinical LOI T2), positive values indicate that participants self-reported a higher parameter, and zeros indicate that self-report and clinical parameters are the same. For statistical analysis, relationships between dichotomous nominal and ordinal variables were conducted using a chi-squared test paired with gamma coefficient. Relationships between interval/ratio variables were conducted using a chi-squared test paired with a Spearman rank-order correlation coefficient. Strengths of the relationships, Γ and r_s, were defined as: 0.00, no relationship; 0.01–0.29, weak; 0.30–0.59, moderate; and 0.60–1.00, strong [14].

RESULTS

Twenty-eight individuals participated in this study. Table 1 provides demographic information.

Accuracy of self-report level of injury

Region of injury. Participants' self-reported ROI matched Clinical ROI in 93% ($N = 26$) of cases ($\chi^2 = 23.713$, $p < 0.001$; $\Gamma = 1.000$, $p < 0.001$). There were two exceptions: one participant whose Clinical ROI was cervical self-reported "thoracic," and one whose Clinical ROI was thoracic self-reported "lumbar."

Single neurologic level. When selecting Self-report LOI, only 25% selected the same level as their Clinical LOI, but 75% were accurate or within one spinal cord level (see Table 2). There was a strong, significant relationship between Clinical LOI and Self-report LOI ($\chi^2 = 210.522$, $p = 0.002$; $r_s = 0.922$, $p < 0.001$). The average difference between Clinical LOI and Self-report LOI was −0.3571 with a standard deviation of 1.5448 and ranges from −5 to 2. The median was 0.00. The modes were 1, 0 and −1.00.

When comparing Self-report LOI to Initial LOI, 61% selected the same level as their Initial LOI, and 79% were accurate or within one spinal cord level (see Table 2). The average difference between Initial LOI and Self-report LOI was −0.250 with a standard deviation of 1.174 and ranges from −3 to 2. The median and mode were 0.00.

Clinical LOI vs. initial LOI. Initial LOI and Clinical LOI were similar, with 28.6% being the same level and 53.6% with one level of difference (see Table 3). There was a strong, significant relationship between Initial LOI and Clinical LOI ($\chi^2 = 256.265$, $p < 0.001$; $r_s = 0.907$, $p < 0.001$). The average difference between Initial LOI and Clinical LOI was −0.1071 with a standard deviation of 1.499 and ranges from −5 to 2. The median was 0.00; the mode was 1.

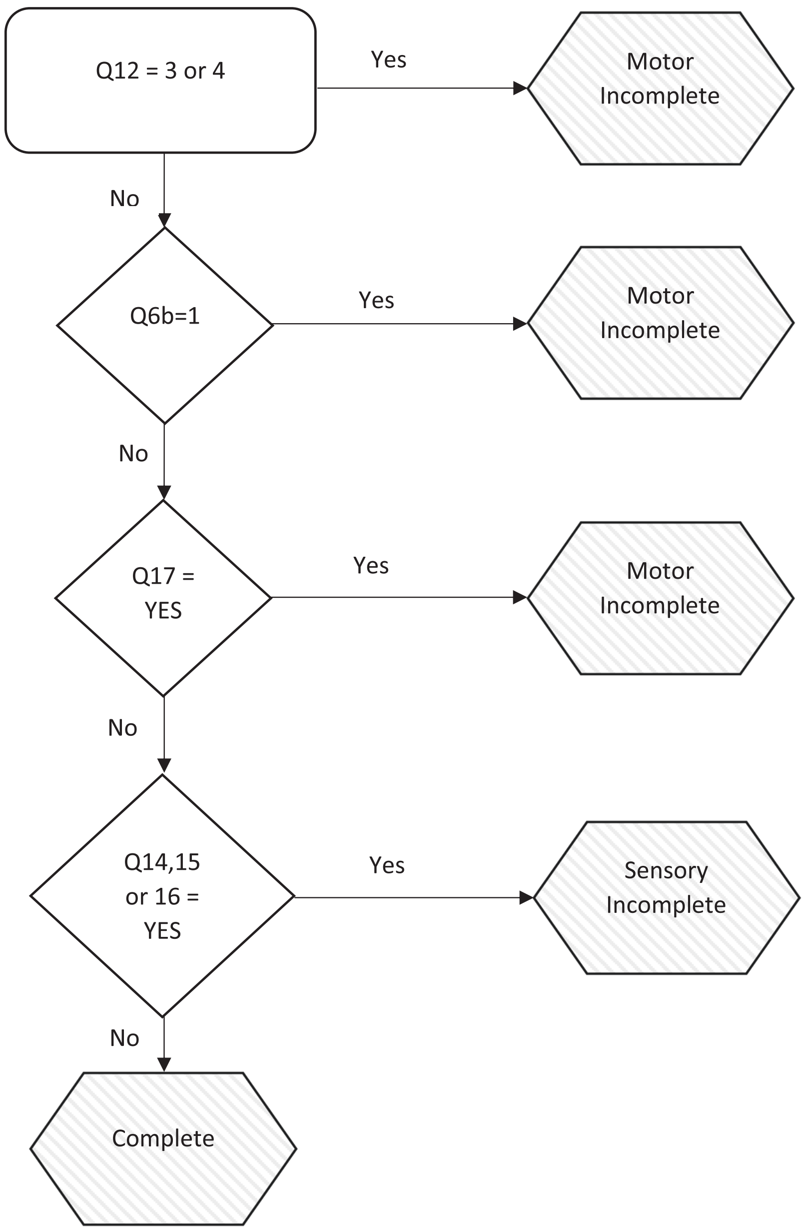
Accuracy of self-report AIS. When asked "Which of these is your ASIA grade?" 50% of participants responded, "I don't know." There was notable variation across AIS Classifications for percent of respondents choosing "I don't know": Clinical AIS A 33.3% ($N = 2$), Clinical AIS B 57.1% ($N = 7$), Clinical AIS C 14.3% ($N = 1$), and Clinical AIS D 87.5% ($N = 7$). There were no significant relationships between not knowing AIS grade and participant age ($\chi^2 = 2.476$, $p = 0.780$), gender ($\chi^2 = 0.000$, $p = 1.000$), household income ($\chi^2 = 4.169$, $p = 0.654$), time since injury ($\chi^2 = 0.000$, $p = 1.000$) or racial group ($\chi^2 = 2.191$, $p = 0.139$).

For the 50% who responded with an AIS grade, there was a strong, significant relationship between Clinical AIS and Self-report AIS ($\chi^2 = 30.00$, $p < 0.001$; $\Gamma = 1.000$, $p < 0.001$). In total, 71% ($N = 10$) self-reported the same AIS grade as their clinical exam including all those with injury classified as Clinical AIS A (100.0%, $N = 4$), Clinical AIS B (100.0%, $N = 3$) and Clinical AIS D (100.0%, $N = 1$). Of the participants who were Clinical AIS C, more than half self-reported as AIS B (66.7%, $N = 4$). The rest self-reported correctly as AIS C (33.3%, $N = 2$) (see Fig. 2). Thus, participants who reported AIS Classification correctly were 36% of the full sample.

Eighty-six percent of participants who reported an AIS grade selected the grade given to them during their inpatient rehab admission. There was a strong, significant relationship between Initial AIS and Self-report AIS classification during the study ($\chi^2 = 23.600$, $p = 0.001$; $\Gamma = 1.000$, $p < 0.001$). For participants with Initial AIS A, 80% ($N = 4$) self-reported AIS A and 20% ($N = 1$) self-reported AIS B. All participants with Initial AIS B (100%, $N = 6$) self-identified as AIS B. Of participants with Initial AIS C, 66.7% ($N = 2$) self-reported AIS C and 33.3% ($N = 1$) as AIS D.

Clinical AIS vs. initial AIS. Eleven of 28 (39%) of participants have a current AIS classification that is different than their classification during inpatient admission. Only one of these changed to a more severe classification. There was a strong, significant relationship between Initial AIS and current Clinical AIS ($\chi^2 = 34.746$, $p < 0.001$; $\Gamma = 0.877$, $p < 0.001$). For participants with Initial AIS A, 66.7% ($N = 6$) are currently classified as AIS A, 11.1% ($N = 1$) are classified as AIS B, and 22.2% ($N = 2$) are classified as AIS C. For participants with Initial AIS B, 62.5% ($N = 5$) are still classified as AIS B and 37.5% ($N = 3$) are now classified as AIS C. Of participants with Initial AIS C, 14.3% ($N = 1$) are now classified as AIS B, 28.6% ($N = 2$) are still classified as AIS C, and 57.1% ($N = 4$) are now AIS D. Of participants with Initial AIS D, all (100.0%, $N = 4$) are still AIS D.

Accuracy of questionnaire/decision tree algorithm for determination of severity classification. Using the injury severity decision tree, 75% of participants ($N = 21$) were classified correctly relative to the Clinical AIS (see Fig. 3). Of Clinical AIS A participants ($N = 6$), 66.7% were classified correctly as complete and 33.3% were



Question KEY:

Q6b (if cervical): Which of these applies to you: (1) I have more function in my legs than in my arms / (2) I have much more function on one side of body than on the other / (99) neither of these or N/A

Q12 Please indicate your primary mode of mobility: (1) Manual wheelchair / (2) Power wheelchair (including power pack / smart drive) / (3) Walking with assistive device and/or bracing / (4) Walking without assistive device or bracing / (5) Other

Q14 Can you feel a light touch with cotton wool on the skin just around your anus? : (1) yes / (2) no

Q15 Can you tell the difference between the sharp and blunt end of a safety pin on the skin just around your anus? : (1) yes / (2) no

Q16 Can you feel the pressure from a gloved finger in your rectum that applies pressure to the wall of your anus? : (1) yes / (2) no

Q17 Can you tighten the muscles of your anus as if you were going to hold in a bowel movement of enema or prevent the passing of wind? : (1) yes / (2) no

Fig. 1 Injury severity decision tree. Individual responses to the questions in the Question Key were used to categorize respondents into one of three injury severity groups. Field-Fote et al. [5], reprinted in accordance with copyright permissions for STM signatory publishers.

Table 1. Participant demographic information.

Participant demographic information		
	N	**%**
Gender		
Male	18	64.3
Female	10	35.7
Age range		
18–25	5	17.9
25–35	5	17.9
36–45	7	25
46–55	3	10.7
56–65	6	21.4
>65	2	7.1
Racial or ethnic group		
White	23	82.1
Black/African American	3	10.7
Hispanic/Latinx	1	3.5
Multiracial	1	3.5
Cause of injury		
Vehicular accident	13	46.4
Fall	8	28.6
Sports/Recreation	4	14.3
Violence/Assault	1	3.5
Non-traumatic	2	7.1
Time since injury		
<1 year	2	7.1
1–2 years	6	21.4
2–10 years	16	57.1
>10 years	4	14.3
Household income level		
<$25,000	9	32.1
$25,000–$49,999	3	10.7
$50,000–$74,999	6	21.4
$75,000–$99,999	1	3.5
$100,000–$124,999	1	3.5
$125,000–$150,000	2	7.1
>$150,000	5	17.9
I don't know	1	3.5

classified as sensory-incomplete. Of Clinical AIS B participants ($N = 7$), 85.7% were classified correctly as sensory-incomplete with 14.3% ($N = 1$) incorrectly classified as complete. Clinical AIS C participants ($N = 8$) were classified correctly as motor-incomplete 57.1% of the time with 14.3% ($N = 1$) incorrectly classified as complete and 28.6% ($N = 2$) incorrectly classified as sensory-incomplete. Clinical AIS D participants ($N = 8$) were classified correctly 87.5% of the time as motor-incomplete and incorrectly classified as sensory-incomplete 12.5% ($N = 1$) of the time. There was a strong, significant ($\chi^2 = 23.747$, $p = 0.001$; $\Gamma = 0.872$, $p < 0.001$) relationship between Decision Tree Severity classes and Clinical AIS grades. There were no significant relationships between accuracy of the injury severity decision tree and participants' age ($\chi^2 = 3.517$, $p = 0.621$), gender ($\chi^2 = 0.207$, $p = 0.649$), race ($\chi^2 = 0.081$, $p = 0.776$), or income ($\chi^2 = 6.435$, $p = 0.386$).

Accuracy of self-report DAP sensation. Participants correctly self-reported ability to feel DAP 86% of the time. There was a strong, significant relationship between self-reported and clinically-classified DAP sensation ($\chi^2 = 11.221$, $p = 0.001$; $\Gamma = 0.939$, $p = 0.005$). For participants without Clinical DAP, most self-reported "no" when asked if they could feel DAP (83.3%, $N = 5$) with only one incorrectly self-reporting "yes" (16.7%, $N = 1$). Inversely, for participants with Clinical DAP present, most self-reported "yes" (86.4%, $N = 19$), but a small proportion incorrectly reported "no" (13.6%, $N = 3$). Of note, 93% ($N = 26$) of participants were correct in Self-Report S4/5 sensation.

Accuracy of self-report VAC. Participants correctly self-reported ability to voluntarily contract their anal sphincter 82% of the time. There was a strong, significant relationship between Clinical VAC and Self-report VAC ($\chi^2 = 11.873$, $p = 0.001$; $\Gamma = 0.938$, $p < 0.001$). For participants without Clinical VAC, nearly all self-reported "no" (93.3%, $N = 14$) with only one self-reporting incorrectly as "yes" (6.7%, $N = 1$). For participants with Clinical VAC, over half (69.2%, $N = 9$) self-reported "yes" while 30.8% ($N = 4$) self-reported incorrectly as "no". Thus, self-reported measures largely aligned with clinical measures for VAC, but participants without VAC were most likely to align their self-report to clinical measures.

Comparison of clinical S1, S4/5 and DAP sensation. In this sample, clinical S1 sensation and clinical S4/5 sensation were in agreement for 86% of participants. Clinical S1 sensation agreed with clinical DAP for 75% of participants and clinical S4/5 sensation agreed with clinical DAP for 89% of participants.

Accuracy of self-report of sensation at S1 (see Fig. 4). Eighty-two percent of participants correctly reported ability to feel light touch

Table 2. Self-Report Level of Injury vs. Clinical Level of Injury and Initial Level of Injury.

Difference between Self-Report LOI and Clinical LOI			**Difference between Self-Report LOI and Initial LOI**		
Δ	***N***	**%**	**Δ**	***N***	**%**
Self-report 2 LOI higher	2	7.1	Self-report 2 LOI higher	2	7.1
Self-report 1 LOI higher	7	25	Self1report 1 LOI higher	2	7.1
Self-report =	7	25	Self-report =	17	60.7
Self-report 1 LOI lower	7	25	Self-report 1 LOI lower	3	10.7
Self-report 2 LOI lower	3	10.7	Self-report 2 LOI lower	2	7.1
Self-report 3 LOI lower	1	3.6	Self-report 3 LOI lower	2	7.1
Self-report 5 LOI lower	1	3.6			
Total:	28	100	Total:	28	100

(LT) at the heel/S1 dermatome. There was a strong, significant relationship between clinical and self-reported LT S1 ($\chi^2 = 12.253$, $p < 0.001$; $\Gamma = 0.941$, $p < 0.001$). Nearly all participants who were clinically classified as "no" for LT S1 also self-reported that they did not have "the ability to feel a LT with cotton wool on the skin on either of their heels" (92.3%, $N = 12$). Only one participant who was clinically classified as "no," self-reported incorrectly that he had LT sensation on his heels (7.7%, $N = 1$). Most participants who were clinically classified as "yes," having LT sensation present, also self-reported "yes" (73.3%, $N = 11$) with a few incorrectly self-reporting "no" (26.7%, $N = 4$).

Eighty-six percent of self-report responses were correct for sharp/dull discrimination at the S1 dermatome (PPS1). There was a strong, significant relationship between clinical PPS1 and participant-reported "ability to tell the difference between the sharp and blunt ends of a safety pin on the skin of either heel" ($\chi^2 = 13.741$, $p < 0.001$; $\Gamma = 0.942$, $p < 0.001$). Of participants who were clinically classified as "no" for PPS1, 88.2% ($N = 15$) reported "no" for ability to tell the difference between sharp and dull, with 11.8% ($N = 2$) incorrectly reporting "yes". Of participants who were clinically classified as "yes," 81.8% also self-reported "yes" (81.8%, $N = 9$) with only two participants, self-reporting "no" (18.2%).

Accuracy of self-report of motor sparing at S1. Ninety-six percent of self-report responses were correct for motor sparing at S1. There was a strong, significant relationship between clinical motor function at S1 (plantar flexion >0) and participant-reported "ability to move either ankle as if pushing down a gas pedal" ($\chi^2 = 24.040$, $p < 0.001$; $\Gamma = 1.000$, $p < 0.001$). All participants who were clinically classified as "no" for Motor S1 also self-reported "no" for Motor S1 (100.0%, $N = 17$). Most participants who were clinically classified as "yes" also self-reported "yes" (90.9%, $N = 10$) with only one participant who was clinically classified as "yes" incorrectly self-reporting "no" (9.1%, $N = 1$).

Comparison of S1 sensory/motor function and DAP/VAC. In this sample, self-report of S1 sensation agreed with Clinical DAP for 79% of participants. Presence of clinical Motor S1 agreed with Clinical VAC for 86% of participants. Self-report of motor function at S1 matches Clinical VAC for 89% of participants.

Table 3. Clinical Level of Injury vs. Initial Level of Injury.

Difference between Clinical LOI and Initial LOI		
Δ	***N***	**%**
Current LOI is 5 LOI higher	1	3.6
Current LOI is 3 LOI higher	1	3.6
Current LOI is 2 LOI higher	1	3.6
Current LOI is 1 LOI higher	6	21.4
Current LOI = Initial LOI	8	28.6
Current LOI is 1 LOI lower	9	32.1
Current LOI is 2 LOI lower	2	7.1
Total:	28	100

DISCUSSION

Injury level

Participants were highly accurate in their knowledge of their region of injury, with 93% correctly selecting ROI. Only 2/28 selected the incorrect ROI. Of these, one had an orthopedic crush injury of L1, and reported "lumbar injury"; this individual had an Initial LOI of L1 but had a current Clinical LOI of T12. Having multiple orthopedic injuries may also result in lack of clarity, as was the case for a participant who had injuries in both cervical and thoracic regions. This individual selected "thoracic injury" for ROI, and self-reported LOI as C6, while Clinical LOI was C6. These findings suggest that differences between orthopedic and neurologic injury levels may limit the accuracy of self-reported ROI on surveys.

Understandably, compared to identifying their ROI, participants were less accurate in identifying their LOI. When asked to select a single LOI, only 25% selected the same level as their Clinical LOI, but 61% selected the same level as their Initial LOI. Persons with SCI may be unaware that their LOI can change over time, or they may simply repeat information as it was told to them initially.

Injury severity

Only half of our participants reported knowing their AIS classification. Only 36% of our participants self-reported the same AIS as their current Clinical AIS, but 43% reported the same AIS as their Initial AIS. It is notable that 39% of our participants had a different Clinical AIS than Initial AIS. Consistent with the literature, participants with injuries initially classified as more severe (AIS A and B) were less likely to experience an improvement in their classification compared to those with less severe injury (AIS C) [15].

Clinical AIS & Initial AIS Vs. Self-Report AIS (N=14)

	Clinical AIS A	Clinical AIS B	Clinical AIS C	Clinical AIS D		Initial AIS A	Initial AIS B	Initial AIS C	Initial AIS D
Self-Report AIS A	**4**	0	0	0	Self-Report AIS A	**4**	0	0	0
Self-Report AIS B	0	**3**	4	0	Self-Report AIS B	1	**6**	0	0
Self-Report AIS C	0	0	**2**	0	Self-Report AIS C	0	0	**2**	0
Self-Report AIS D	0	0	0	**1**	Self-Report AIS D	0	0	1	0

**Does not include responses of "I don't know" my AIS grade

Fig. 2 ASIA Impairment Scale—Self-Report vs. Clinical AIS/Initial AIS. Number of respondents in each Self-Report AIS category who were clinically classified into each AIS group currently (Clinical AIS) or during their acute rehab (Initial AIS). **Does not include responses of "I don't know" my AIS grade.

When using the decision tree, 75% of participants were classified into the same injury severity category as the Clinical AIS. The decision tree relied on self-report S4/5 sensation (93% accurate), DAP (86% accurate) and VAC (82% accurate). In this sample, we found a 95% positive predictive value for self-report S4/5 sensation and 90% positive predictive value of self-report for both DAP and VAC. We did not encounter high false-positive self-report for VAC as has been previously reported [16, 17]. Predictive values were 89% for self-report S4/5 sensation, 83% for self-report DAP and 78% for self-report VAC.

Alternate methods

Evidence has shown that presence of sensation at S1 predicts sacral sensory sparing with 90% accuracy [18]. In our sample, clinical presence/absence of sensation at S1 showed 86% agreement with clinical sensation at S4/5, and 75% agreement with Clinical DAP. Self-report of S1 sensation agreed with Clinical DAP 79% of the time whereas Self-report DAP agreed with Clinical DAP 86% of the time. In this sample, the direct question about DAP was the most accurate.

Evidence shows that preserved S1 motor function can predict VAC with 86% accuracy [18]. In our sample, self-report of S1 motor sparing was 96% accurate. The inaccurate participant had trace muscle contraction at S1, but answered "no" to "Can you move either ankle as if pushing down a gas pedal?" A more comprehensive question may have given a more accurate result. In our sample, Clinical S1 motor sparing showed 86% agreement with Clinical VAC. Self-report VAC agreed with Clinical VAC 82% of the time and self-report of S1 motor sparing agreed with Clinical VAC 89% of the time. In this sample, self-report of S1 motor sparing was the most accurate predictor of VAC.

Addition of S1 motor and sensory sparing questions to the injury severity decision tree allowed 79% of participants to be classified into the same severity category as their Clinical AIS. Other less-invasive proxies for DAP and VAC are also under consideration, including deep pressure sensation at the ischial tuberosities (S3) and motor sparing at the hip adductors and toe flexors [3, 19]. These components are not included in the ISNCSCI examination and have not been studied for self-report accuracy. In the future, adding these items to our decision tree may further improve the accuracy of self-report questionnaires in predicting severity classification.

In comparing Initial LOI and Clinical LOI, it is notable that only 29% of our participants had the same Clinical LOI and Initial LOI, although 82% were within one injury level. Several prior studies have examined inter-rater reliability of the ISNCSCI. These studies have found substantial reliability for motor scores (ICC: 0.96–>0.99), LT scores (0.91–0.99) and pinprick scores (0.89–0.98) [20–23]. DAP (0.95) and VAC (0.93) were also shown to have substantial inter-rater reliability, as were S4/5 sensation measures (LT 0.81/PP 0.84) [21]. Scores among expert examiners have not been as similar in selecting motor level (0.56–0.72), sensory level (0.58–0.74) or neurologic level of injury (0.59) [22, 23]. Precision in determination of level is essential in some cases. Prior work has shown that a gain of 2 motor levels results in significantly greater recovery of self-care activities compared to a gain of ≤1 motor level [24]. Therefore, in intervention studies, precision in measurement is essential for determining whether the inherent risk of the procedure is warranted. Alternatively, in self-report studies wherein a ±2 level difference has a negligible impact on the conclusions, it may be appropriate to tolerate this imprecision.

Limitations

This study enrolled a convenience sample of people scheduled for outpatient appointments at our hospital and who responded to emails about participation. There was no guidance in the questionnaire as to whether participants were to report anatomical or neurologic level of injury. There were also no definitions of the AIS categories. These descriptions of injury are discussed with patients at our particular SCI Model System facility but may be unfamiliar to participants who had not received this type of

Clinical AIS vs. Decision Tree Severity

	Complete	Sensory Incomplete	Motor Incomplete
Clinical AIS A	**4**	2	0
Clinical AIS B	1	**6**	0
Clinical AIS C	1	2	**4**
Clinical AIS D	0	1	**7**

Fig. 3 Clinical AIS vs. Decision Tree Severity. Number of respondents in each Clinical AIS category who were categorized into each Decision Tree Severity class.

Self-Report Vs. Clinical Exam: S1 Light touch sensation (LT), Sharp/dull discrimination (PP), Motor function

S1 LT	Clinical YES	Clinical NO	S1 PP	Clinical YES	Clinical NO	S1 Motor	Clinical YES	Clinical NO
Self-Report YES	**11**	1	Self-Report YES	**9**	2	Self-Report YES	**10**	0
Self-Report NO	4	**12**	Self-Report NO	2	**15**	Self-Report NO	1	**17**

Fig. 4 S1 sensory and motor sparing—Self-Report vs. Clinical Exam. Number of respondents self-reporting presence (YES) or absence (NO) of each modality who were clinically found to have (YES) or not have (NO) sparing of that modality. S1 LT light touch sensation, S1 PP sharp/dull discrimination, S1 Motor motor function (muscle strength ≥1/5).

instruction. As all participants received care at a Model System hospital, results may not be generalizable to the broader SCI population.

ISNCSCI examinations during this study were conducted by expert ISNCSCI examiners; however, the ISNCSCI exams abstracted from inpatient medical records were completed by various clinicians. Routine use of the standards in clinical practice may not reflect the same rigor in training and testing technique [21]. Inter-rater reliability of ISNCSCI scoring has been shown to increase with increased training of examiners [25].

CONCLUSIONS

Individuals with SCI are relatively accurate in reporting the anatomical region of their spinal cord injuries. Self-reports of specific injury level and of injury severity align more closely to initial clinical examination results than to current clinical exam results.

As an alternative to relying on self-report AIS. It is possible to determine injury severity more accurately by questionnaire that relies on aggregate data from multiple questions regarding sensory and motor sparing. The use of the injury severity decision tree was more accurate than AIS self-report. Use of this type of decision tree may help improve injury severity classification in large survey studies.

DATA AVAILABILITY

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

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ACKNOWLEDGEMENTS

We would like to acknowledge the study participants who agreed to meet with us, even during COVID-19 protocols.

AUTHOR CONTRIBUTIONS

CLF was responsible for conceptualization and coordination of the project, data collection and writing the initial manuscript draft; RKA performed statistical analyses and contributed to manuscript development; ECFF contributed to development and revision of the manuscript, and the acquisition of financial support, all authors approved the final version of the manuscript.

FUNDING

The contents of this article were developed under a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90SI5016). NIDILRR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS). The contents of this article do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

The Shepherd Center Research Review Committee approved the study. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during this research.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at https://doi.org/10.1038/s41393-022-00855-1.

Correspondence and requests for materials should be addressed to Catherine L. Furbish.