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

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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 in a timely manner, and many SCI 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...
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 also includes examination of the peri-anal region ("Clinical S4/S5") 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 analysis was conducted in SPSS (IBM Corp., Version 27.0. Armonk, NY).

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 = 5). 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 ($\chi^2 = 4.169, p = 0.054$), time since injury ($\chi^2 = 0.000, p = 1.000$), and the 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 ($\chi^2 = 23.660, p = 0.001; \Gamma = 1.000, p < 0.001$). 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 |

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 | Δ    | N   | %   | Difference between Self-Report LOI and Initial LOI | 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  |     | Self-report 1 LOI higher                           | 2    | 7.1 |     |
| Self-report 2 LOI lower                            | 7    | 25  |     | Self-report 2 LOI lower                            | 3    | 10.7|     |
| Self-report 3 LOI lower                            | 3    | 10.7|     | Self-report 3 LOI lower                            | 2    | 7.1 |     |
| Self-report 5 LOI lower                            | 1    | 3.6 |     | Self-report 5 LOI lower                            | 2    | 7.1 |     |
| Total:                                             | 28   | 100 |     | Total:                                             | 28   | 100 |     |
There was a strong, significant relationship between clinical and self-reported LT S1 (χ² = 12.253, p < 0.001; Γ = 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 the sharp and blunt ends of a safety pin on the skin of either heel (χ² = 13.741, p < 0.001; Γ = 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” (χ² = 24.040, p < 0.001; Γ = 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.

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 T12. These findings suggest that differences between orthopedic and neurologic injury levels may limit the accuracy of self-reported ROI on surveys.

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].

**Does not include responses of “I don’t know” my AIS grade.

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

| Difference between Clinical LOI and Initial LOI | 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 |

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 |

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 education.

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| 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.

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| S1 LT | Clinical YES | Clinical NO |
|-------|--------------|-------------|
| Self-Report YES | 11 | 1 |
| Self-Report NO | 4 | 12 |

| S1 PP | Clinical YES | Clinical NO |
|-------|--------------|-------------|
| Self-Report YES | 9 | 2 |
| Self-Report NO | 2 | 15 |

| S1 Motor | Clinical YES | Clinical NO |
|----------|--------------|-------------|
| Self-Report YES | 10 | 0 |
| 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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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.

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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.
