

# “I don’t know the correct way to describe it”: neuropathic pain experiences among athletes with spinal cord injury

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## ABSTRACT

**Background** Chronic pain among athletes is often misinterpreted as tissue damage resulting from sport. While researchers have started to examine neuropathic pain among athletes with spinal cord injury (SCI), there is a need to develop a deeper understanding of their neuropathic pain symptoms and experiences, to support the development of evidence-based pain management protocols.

**Objectives** The primary purpose of this study was to describe neuropathic pain experienced by athletes with SCI. A secondary purpose was to compare athletes’ neuropathic pain symptoms when measured by two different clinical pain assessment tools and describe their experiences when trying to communicate their neuropathic pain.

**Methods** 47 athletes with SCI completed the International Spinal Cord Injury Pain Basic Data Set (V.2.0), Douleur Neuropathique 4 (DN4), and two open-ended pain questions over the telephone.

**Results** 66% of participants reported experiencing moderate-intensity neuropathic pain ( $M_{\text{pain intensity}} = 5.32 \pm 1.78$ ) and mild-to-moderate pain interference with activities of daily living ( $M_{\text{pain interference}} = 3.55 \pm 2.11$ ) and sleep ( $M_{\text{pain interference}} = 4.68 \pm 2.92$ ). Overall, participants reported significantly more neuropathic pain symptoms in response to DN4 questions ( $M = 4.62 \pm 1.38$ ) versus open-ended pain questions ( $M = 2.13 \pm 1.08$ ),  $p < 0.001$ . Participants reported difficulty with identifying neuropathic pain, describing their pain symptoms and identifying pain locations.

**Conclusion** Athletes with SCI reported moderate-intensity neuropathic pain. However, they struggled with communicating their neuropathic pain without being prompted with a list of symptoms. To guide the development of effective pain management strategies among athletes with SCI, future research should focus on developing knowledge products to improve awareness of common neuropathic pain descriptors among athletes with SCI and sports medicine personnel.

## INTRODUCTION

Chronic pain among athletes has been historically misunderstood, often being misinterpreted as tissue damage resulting from acute trauma or overuse injuries.<sup>1</sup> Pain experienced by athletes can stem from various sources, including musculoskeletal injuries, neuropathic conditions and visceral syndromes.<sup>2</sup> Nociceptive pain may be a consequence of sport participation (eg, overuse injury), whereas neuropathic pain is

## WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Neuropathic pain has been reported to be the most severe type of pain among the general spinal cord injury (SCI) population. Despite the negative impact of neuropathic pain, it is often misunderstood by clinicians, leading to suboptimal diagnosis and management.

## WHAT THIS STUDY ADDS

⇒ The International Olympic Committee indicated that data on pain management among Paralympians and athletes with a disability is limited. Results from this study provide the first comprehensive description of neuropathic pain experiences among athletes with SCI and highlight their challenges in recognising and communicating neuropathic pain. Furthermore, results highlight the need for sports medicine physicians, therapists and trainers to administer multiple types of neuropathic pain assessments and be aware of common descriptors used by athletes with SCI to describe neuropathic pain.

## HOW THIS STUDY MIGHT AFFECT RESEARCH, PRACTICE OR POLICY

⇒ Research must focus on developing improved, tailored pain management strategies for athletes with SCI who experience neuropathic pain. Training policies must be implemented for parasport personnel to better understand neuropathic pain among athletes with SCI, in order to improve the practice of identifying and diagnosing neuropathic pain in this population.

likely due to an underlying impairment or comorbid condition (eg, spinal cord injury (SCI)). Understanding the root cause of pain is essential for effective management. In 2017, the International Olympic Committee (IOC) issued a consensus statement on pain management in elite athletes, emphasising the importance of an individualised approach to address pain while optimising performance and ensuring athlete well-being.<sup>3</sup> Furthermore, the need for assessing and monitoring pain—in addition to injuries—was highlighted. The negative impact of chronic pain on rehabilitation outcomes, performance and functional independence underscores

the need to develop a better understanding of chronic pain experiences among athletes.

Pain research among athletes has primarily focused on musculoskeletal pain, including its aetiology, risk factors, prevention strategies and treatment modalities.<sup>1</sup> Limited research has investigated neuropathic pain among athletes, despite its significant potential to impede an athlete's ability to train and compete at their full potential. Neuropathic pain is defined as a disease or lesion of the somatosensory nervous system<sup>4</sup> and is characterised by symptoms such as burning, tingling and shooting pain.<sup>5</sup> Anecdotally, not everyone diagnosed with neuropathic pain describes it as 'painful', some describe it as an uncomfortable or disturbing sensation. Proper identification and management of neuropathic pain are critical, given its debilitating nature and likelihood of becoming refractory to treatment.<sup>6</sup> Therefore, pain specialists working with athletes (e.g., sports medicine physicians and therapists) must be trained in identifying signs and symptoms of neuropathic pain and be skilled in interpreting patient descriptions and examination findings.

Neuropathic pain may be particularly prevalent and problematic for athletes with SCIs. Approximately 58% of persons with SCI report neuropathic pain, and it is often cited as the most severe type of pain in this population.<sup>7</sup> While the prevalence of neuropathic pain among athletes with SCI is not clear, research indicates that athletes with disabilities experience nociceptive pain at rates higher than their able-bodied counterparts due to increased biomechanical stress, secondary complications from their disability and rigorous training regimens.<sup>8,9</sup> It is likely that the prevalence of neuropathic pain among athletes with SCI is also even greater than the prevalence in the general SCI population.

The IOC consensus statement on pain management noted that data on pain management among Paralympians and athletes with a disability is limited.<sup>3</sup> In response, the need for researchers to thoroughly investigate neuropathic pain among athletes and understand the methods of screening, diagnosis, evaluation and treatments was identified.<sup>9</sup> While researchers have started to examine neuropathic pain among athletes with SCI,<sup>8,10</sup> there is a critical need to obtain a deeper understanding of neuropathic pain symptoms and experiences among athletes with SCI, to support the development of evidence-based pain management protocols.

To the best of our knowledge, no published study has comprehensively assessed neuropathic pain among athletes with SCI. As such, the primary purpose of this study was to describe neuropathic pain experienced by athletes with SCI. In addition, to address the call for research to support clinicians, sports therapists and trainers in screening, diagnosing and managing neuropathic pain,<sup>3,9</sup> secondary objectives were to compare athletes' neuropathic pain symptoms when measured by two different clinical pain assessment tools and to describe their experiences when trying to communicate their neuropathic pain.

## METHODS

### Design and study overview

Using a cross-sectional study design, both quantitative and qualitative data were collected to describe neuropathic pain symptoms among athletes with SCI. This study is a secondary analysis of data collected for a study among Paralympic and recreational athletes with SCI.<sup>10</sup> Detailed study methods are presented elsewhere.<sup>10</sup> Descriptions of study methods pertinent to data presented herein are provided below.

### Participants

Participants were recruited through social media, email, global parasport organisations and word of mouth. 55 individuals volunteered to participate. Inclusion criteria were: (1) >18 years old; (2) incurred an SCI >12 months ago at the third cervical level or below; (3) experience chronic SCI neuropathic pain; (4) able to read/write in English; and (5) routinely achieved at minimum, the SCI exercise guideline to improve fitness: 20 min of moderate-to-vigorous-intensity aerobic activity (eg, arm crank ergometer at 60%  $\text{VO}_2$ ) two times per week and strength training two times per week, consisting of three sets of 8–10 repetitions of each exercise for each major, functioning muscle group depending on level of injury.<sup>11</sup> After screening, 47 recreational and Paralympic athletes with SCI met the inclusion criteria and participated in this study. Participant demographic information is presented in [table 1](#).

### Equity, diversity and inclusion statement

Our study sample includes athletes with SCI who were located worldwide (ie, Canada, the USA, Africa, Asia, Australia, Great Britain). Our author group includes mixed genders (three women, one man), ages and professional backgrounds. One current member of Team Canada's Paralympic wheelchair rugby team who has SCI neuropathic pain and an executive director of a provincial wheelchair sports association were involved as research partners for the primary analysis of this study.<sup>10</sup> Furthermore, our Paralympic athlete partner supported this study by acting as a pilot participant and completed the entire study procedure. Changes were made to an open-ended pain question after the pilot testing.

### Measures

#### Neuropathic pain

Two measures were used to understand how neuropathic pain is experienced and described by athletes with SCI. First, information on neuropathic pain intensity and interference of participants' top three pain problems were collected using the International Spinal Cord Injury Pain Basic Data Set (ISCI-PBDS) V.2.040.<sup>12</sup> Intensity and interference are both measured on 10-point numerical rating scales (0=no pain/no interference, 10=pain as bad as you can imagine/extreme interference). Additionally, the ISCI-PBDS captures whether participants are currently using treatment for neuropathic pain management.

**Table 1** Demographic characteristics of the sample (n=47)

Demographic characteristic	M±SD	N (%)
Age	38.3±11.8	
Sex		
Male		32 (68%)
Female		15 (32%)
Level of SCI		
Tetraplegia		
C5-C7		21 (45%)
Paraplegia		
T1-T6		7 (15%)
T7-T12		13 (28%)
L1-L5		6 (13%)
Cause of SCI		
Traumatic		44 (94%)
Non-traumatic		3 (6%)
Completeness of injury		
Complete		16 (34%)
Incomplete		30 (64%)
Unsure		1 (2%)
AIS Score		
AIS A		13 (28%)
AIS B		10 (21%)
AIS C		7 (15%)
AIS D		3 (6%)
Unsure		14 (30%)
Mode of mobility		
Manual wheelchair		37 (79%)
Power wheelchair		4 (9%)
Walker		1 (2%)
Braces		3 (6%)
Cane		1 (2%)
Walk independently		1 (2%)
Ethnicity		
White		40 (85%)
Indigenous		2 (4%)
Black		2 (4%)
Asian		3 (6%)
Education		
High school		13 (28%)
College		11 (23%)
University		14 (30%)
Postgraduate		8 (17%)
Other		1 (2%)
Marital status		
Single		21 (45%)
Common law		5 (11%)

Continued

**Table 1** Continued

Demographic characteristic	M±SD	N (%)
Married		20 (43%)
Divorced		1 (2%)
Neuropathic pain within 6 months of injury?		
Yes		37 (79%)
No		10 (21%)
Number of neuropathic pain problems		
One		8 (17%)
Two		16 (34%)
Three		3 (6%)
Four		5 (11%)
Five+		15 (32%)
Overall DN4 Score		
4–6		22 (47%)
7–10		25 (53%)
Weekly minutes of exercise		
Mild	361±371	43
Moderate	292±296	44
Heavy	199±222	41

AIS, Asia Impairment Scale; DN4, Douleur Neuropathique 4; ISCI PBDS, International Spinal Cord Injury Pain Basic Data Set; SCI, spinal cord injury.

Although the ISCI PBDS can be used to collect information about neuropathic, nociceptive and visceral types of pain, participants were instructed to only discuss neuropathic pain problems in this study.

The ISCI PBDS is the internationally recommended method for collecting clinically relevant pain data from persons with SCI<sup>12</sup> but it does not capture detailed neuropathic pain symptoms (i.e., what neuropathic pain feels like). The research team developed two additional open-ended questions to gather additional pain symptom information: (1) *Can you please tell me about your neuropathic pain symptoms?* and (2) *Can you describe your experiences with neuropathic pain (e.g., patterns, or what influences your pain)?* These additional open-ended questions assisted the research team with understanding how athletes with SCI communicate their neuropathic pain without being prompted with a list of symptoms.

To corroborate the presence of neuropathic pain, the Douleur Neuropathique 4 (DN4) was also administered. The DN4 is a diagnostic tool for identifying if pain has a neuropathic component.<sup>13</sup> This symptom-based approach (rather than open-ended) includes seven questions about pain symptoms (eg, ‘tingling’, ‘itching’) and three questions to determine hypoesthesia or allodynia. Each question requires a ‘yes’ or ‘no’ answer (yes=1, no=0). Total DN4 Score is calculated as the sum of the 10 items. Scores on the DN4 can range from 0 to 10, with scores of ≥4 indicating that pain has

a neuropathic component. The DN4 has demonstrated acceptable psychometrics among persons with SCI.<sup>14</sup>

### Procedure

Detailed study information and informed consent forms were emailed to eligible volunteers. After providing informed consent, participants were scheduled for a telephone call with KT. During the phone call, the author administered the ISCIPBDS, followed by the two open-ended questions about pain symptoms, then the DN4. Self-reported minutes per week of physical activity were collected using the Leisure Time Physical Activity Questionnaire (LTPAQ-SCI) for people with SCI.<sup>15</sup> Afterwards, participants were sent a personalised link to complete the remaining questionnaires (e.g., demographic and injury information) online, by themselves, using the REDCAP survey platform. The telephone conversations were audio recorded, and the ISCIPBDS and two open-ended questions were transcribed verbatim by KO. Participants were compensated with \$40CAD Amazon gift cards for study participation. Data were collected between February and April 2021. Participants completed the telephone and online data collection components within a 1-week period.

### Patient and public involvement

An integrated knowledge translation approach<sup>16</sup> was used to design the study protocol. A Paralympic athlete with SCI-related neuropathic pain and an executive director of a provincial wheelchair sports association participated in the entire research process.

### Analyses of ISCIPBDS and DN4 data

Descriptive statistics were computed to summarise data on participants' neuropathic pain collected through the ISCIPBDS and DN4.

### Analyses of responses to the two open-ended pain questions

Analyses were guided by pragmatism, a qualitative approach characterised by intersubjectivity (appreciation of single objective truths and subjective interpretations of experiences), abductive reasoning (deductive and inductive analyses) and transferability of findings.<sup>17</sup> To address how participants described neuropathic pain *symptoms* in the open-ended questions (without being prompted with a list), pain symptoms were defined a priori as any singular adjective used to describe a sensation. If participants used several words to describe a symptom (e.g., 'burning like a stove'), the interviewer responded with a singular adjective to deductively label the symptom (e.g., 'burning'). The total number of symptoms/adjectives reported during the open-ended question was calculated. A paired samples t-test was computed to compare total number of neuropathic pain symptoms reported during the open-ended question versus in response to the DN4 items. Statistical significance was set at  $p < 0.05$ .

To further explore participants' communication of neuropathic pain, an inductive content analysis was

conducted on participants' complete, verbatim responses to the two open-ended pain questions. Inductive content analysis is used to organise and reduce responses into smaller meaningful content categories.<sup>18 19</sup> KT read the interview transcripts several times to become familiarised and then generated initial content categories. Through three iterations, content categories were condensed or removed. A second 'critical friend' researcher (KO) reviewed, discussed and challenged these categories. A final set of content categories was agreed on. The percentage of participants whose neuropathic pain communication aligned with each content category was calculated.

## RESULTS

### Participant characteristics

The majority of participants were men (68%), had paraplegia (55%), experienced a traumatic SCI (94%) and had neurologically incomplete injuries (64%). Participants' average ages were  $38 \pm 12$  years old and were  $14 \pm 10$  years post injury. Average weekly minutes of physical activity varied across activity intensity levels: mild =  $361 \pm 371$  min/week, moderate =  $292 \pm 296$  min/week and heavy =  $199 \pm 222$  min/week. As per the LTPAQ-SCI, mild-intensity physical activity was defined as "activity requiring very light physical effort [...]. It makes you feel like you are working a little bit, but you can keep doing them for a long time without getting tired." Moderate-intensity physical activity was defined as "activity requiring some physical effort [...]. It makes you feel like you are working somewhat hard, but you can keep doing it for awhile without getting tired." Heavy-intensity physical activity was defined as "activity requiring a lot of physical effort [...]. It makes you feel like you are working really hard, almost at your maximum. You cannot do these activities for very long without getting tired. These activities may be exhausting."<sup>15</sup>

### Neuropathic pain symptoms (ISCIPBDS data)

79% of participants reported experiencing neuropathic pain within 6 months of incurring their SCI and 49% reported more than three neuropathic pain problems. Additionally, 87% reported neuropathic pain below the level of injury as their worst pain problem. Buttocks/hips were identified most often as participants' worst neuropathic pain location (30%), followed by lower legs/feet (26%). 66% of participants reported their neuropathic pain intensity to be  $\geq 5$  ( $M = 5.32 \pm 1.78$ ).

The average pain interference score was  $3.55 \pm 2.11$  for daily activities,  $3.85 \pm 2.50$  for mood and  $4.68 \pm 2.92$  for ability to get a good night's sleep. On average, neuropathic pain mildly interfered with activities of daily living and mood and moderately interfered with participants' ability to get a good night's sleep.

62% of participants reported using treatments to reduce neuropathic pain intensity. The main treatments used were pharmaceuticals (eg, gabapentin, tramadol; 38%), exercise (21%) and cannabis (19%). To the

**Table 2** Ranking and location of three worst reported pain problems, as measured using the International Spinal Cord Injury Pain Basic Data Set (V.2.0)

Pain problem by rank	First, n	Second, n	Third, n
Pain types			
At-level neuropathic	6	7	1
Below-level neuropathic	41	32	21
Pain locations			
Head	0	0	0
Neck/shoulders	0	0	0
Arms/hands	1	8	1
Frontal torso/genitals	5	0	4
Back	4	4	2
Buttocks/hips	14	7	3
Upper legs/thighs	7	5	4
Lower legs/feet	12	12	8
Entire lower body	4	3	0
Total	47	39	22

best of our knowledge, cannabis was not prescribed for medical use. 38% of participants reported using no treatment to directly influence their neuropathic pain. Detailed ISCI-PBDS pain data are presented in [table 2](#) and [figures 1–3](#).

### Neuropathic pain symptoms (DN4 data)

All participants scored  $\geq 4$  on the DN4 indicating they did indeed experience neuropathic pain. Participants' symptoms varied; however, most reported their neuropathic pain as tingling (94%), burning (89%) and pins and needles (87%, see [table 3](#)).

### Comparison of symptoms reported: DN4 versus open-ended question

Participants reported experiencing significantly more neuropathic pain symptoms when given forced-choice (yes/no) symptom questions in the DN4 ( $4.62 \pm 1.38$ ) versus responding to the open-ended question "Can you please tell me about your neuropathic pain symptoms?" ( $2.13 \pm 1.08$ ),  $t(46) = -11.049$ ,  $p < 0.001$ .

### Communication of neuropathic pain

Three content categories were identified through inductive content analysis and were labelled: (1) *indescribable pain* (2) *ambiguous pain* and (3) *dislocated pain*. A brief description of each category is presented with supporting participant quotes. Pseudonyms have been used.

#### Indescribable pain

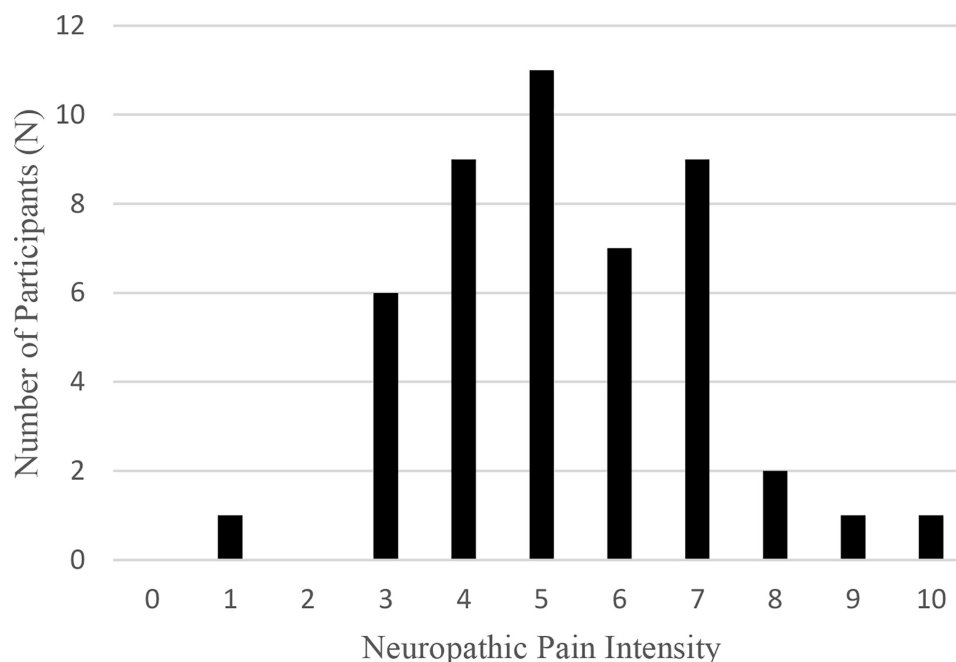
Most participants (60%) reported difficulty describing their neuropathic pain symptoms.

Um, that is sort of a hard one [when asked about NP symptoms]. Um, maybe like- is discomfort super vague? It is so hard to describe. Joel

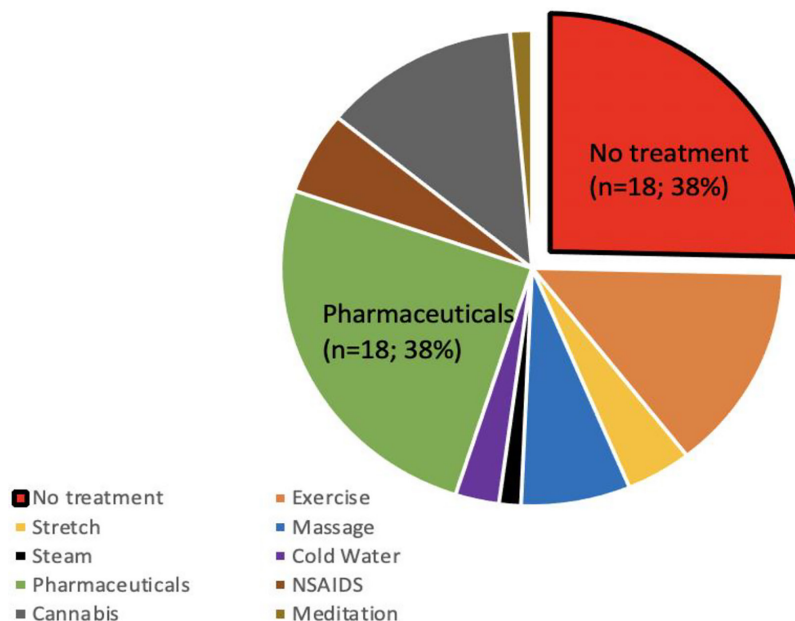
Okay, so define neuropathic pain for me [...]. Cuz after 33 years, I don't know. There should be names because you are living with it, right? It's... dull? But feels weirdly sharp at the same time? [...] It's definitely weird to explain. Evan

#### Ambiguous pain

All participants were confirmed to experience neuropathic pain based on their DN4 scores. Nevertheless, 55% doubted that their symptoms indicated neuropathic pain. Many believed that their symptoms were just a 'regular sensation' associated with having an SCI.



**Figure 1** Histogram for neuropathic pain intensity scores for worst reported pain problem captured by the International Spinal Cord Injury Pain Basic Data Set (V.2.0).



**Figure 2** Type of treatment used for neuropathic pain management.

But, I have a question for you. What are other types of neuropathic pain? Like... what is it? [...] I am just thinking about it right now, and I would say that I have pins and needles in my feet. But, it's not really bothering me much [...] I just figured it was a regular sensation. Kohen

So, I've never been quite sure if it is neuropathic pain [...]. I wouldn't have classified that as a pain because it was, it is not a pain that you would remember. Like poking yourself in the eye or anything like that, you know? It's just really annoying. Sarah

#### Dislocated pain

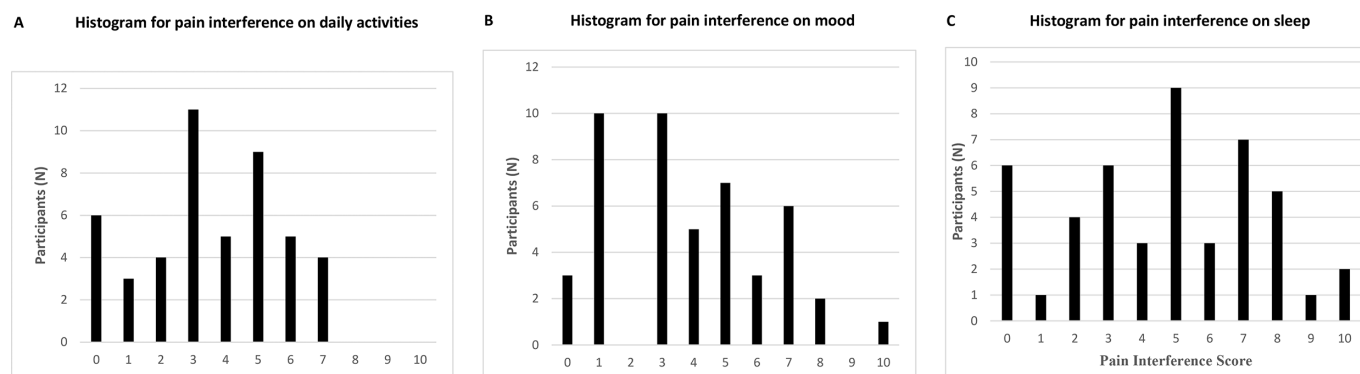
Nearly half (48%) of participants indicated they had difficulty explaining where they feel neuropathic pain.

What confused me sort of when I was trying to describe the different location [of pain] sort of thing, is sometimes it almost feels the same? Between the three regions that I get it, specifically two of them. Kevin

Sometimes, it's hard for me to distinguish. Like, maybe my right hip? My lower back? It's like, I can't really pinpoint it. I have been to multiple doctors to try and figure it out. Miranda

#### DISCUSSION

This is the first study to comprehensively describe neuropathic pain among athletes with SCI. This study is also the first to identify the challenges that athletes with SCI



**Figure 3** Histogram for pain interference on daily activities, mood and sleep. Note: participants were asked to rate their pain interference in response to the questions: (A) In general, how much has pain interfered with your day-to-day activities in the last week? (B) In general, how much has pain interfered with your ability to get a good night's sleep? (C) In general how much has pain interfered with your overall mood in the last week? The x-axis in (C) applies to all figures, whereby (0)=no interference and (10)=worst interference. The y-axis indicates the number of participants who responded with each respective interference score. Data was collected using the International Spinal Cord Injury Pain Basic Data Set V.2.0.

**Table 3** Per cent of participants reporting neuropathic pain symptoms captured by the DN4

Neuropathic pain symptom	N (%)
Burning	42 (89%)
Painful cold	17 (36%)
Electric shocks	35 (74%)
Tingling	44 (94%)
Pins and needles	41 (87%)
Numbness	27 (57%)
Itching	9 (19%)
Hypoesthesia to touch	33 (70%)
Hypoesthesia to pinprick	20 (43%)
Pain caused or increased by brushing	27 (57%)
DN4, Douleur Neuropathique 4.	

experience when communicating their neuropathic pain. On average, participants reported moderate-intensity neuropathic pain and mild-to-moderate pain interference with activities of daily living, mood and sleep. Participants reported challenges associated with classifying their symptoms as neuropathic pain and had difficulty describing their neuropathic pain symptoms and locations.

Research evidence suggests that neuropathic pain greatly interferes with activities of daily living, mood and sleep among persons with SCI.<sup>20–22</sup> However, pain interference scores for our sample of athletes with SCI were lower than those reported in previous studies of the general SCI population.<sup>21–23</sup> These data align with recent research, whereby athletes with SCI reported lower musculoskeletal pain interference than non-athletes.<sup>9</sup> Sport and other types of physical activity can improve sleep and mood and may be a valuable pain distraction tool.<sup>24–27</sup> Distracting oneself from neuropathic pain often results in a change of focus to other tasks and lower perceived pain intensity. The relatively low pain interference scores in the present study may have been the result of the influence of physical activity and sport on mood (e.g., reduced depressive symptoms, increased levels of serotonin<sup>28</sup>) or distraction effects from routinely engaging in large volumes of physical activity.

This study also provided new information on challenges experienced by athletes with SCI in communicating their neuropathic pain. Athletes often have greater bodily awareness compared with the inactive population<sup>29</sup> and are better at identifying painful sensations.<sup>30</sup> However, athletes with SCI in this study had difficulty describing their neuropathic pain symptoms. This finding is consistent with qualitative data from a sample of men with SCI, who shared their memories of pain experienced during the initial acute phase of rehabilitation after incurring their SCI.<sup>31</sup> The men found it very difficult, if not impossible, to articulate their pain experiences. The study authors suggested there may be

insufficient words available to describe such pain. Our finding that participants reported more pain symptoms when presented with a list of symptoms/descriptors on the DN4 questionnaire,<sup>13</sup> than in response to an interview question, suggests that the DN4 provides language for pain symptoms that are not easily articulated. In addition, participants' ambiguous understanding of their symptoms as indicators of neuropathic pain suggests that athletes with SCI lack a basic understanding of what neuropathic pain is and what it feels like. The impaired sensation or total loss of sensation that typically results from an SCI can make the symptoms especially difficult to identify, locate and interpret.

### Scientific and clinical implications

Our findings have important clinical and scientific implications. Athletes with SCI reported moderate-intensity neuropathic pain but found it difficult to communicate their neuropathic pain without being prompted with a list of symptoms. To best support neuropathic pain diagnosis and initiation of pain treatment, sports medicine clinicians and trainers should administer a variety of standardised assessment tools, including symptom-based questionnaires like the DN4.<sup>13</sup> Validated neuropathic pain monitoring tools are yet to be developed; therefore, a more thorough understanding of neuropathic pain symptoms among SCI sports medicine clinicians and parasport personnel may guide early pain management decisions when athletes are forced to abstain from sport participation or are slower than expected in their return to play. Future research should focus on generating knowledge products to support sports medicine clinicians and trainers in becoming familiar with language used by athletes with SCI when communicating their neuropathic pain.

### Limitations

Our study has limitations. First, this study included athletes who participated in various levels of sport (e.g., club, provincial, national, international). Athletes competing at higher levels of sport may have had multiple comorbidities (e.g., overuse injuries or musculoskeletal pain) that confounded their neuropathic pain reports. Second, we did not collect information on participants' duration or location of SCI rehabilitation. Participants who remained in rehabilitation for shorter durations or at non-specialist SCI hospitals may have received minimal pain education which may have influenced their ability to communicate their pain. While an international sample is a strength of this study, because we sampled participants from across the world, quality of pain education likely varied. Third, this study was not statistically powered to test for differences in neuropathic pain experiences across participant subgroups (e.g., gender, sex, injury level, use of medication). Finally, while the most clinically reliable and sensitive

tools were used to diagnose the presence of neuropathic pain, it is possible that participants may have been communicating about other types of pain (eg, nociceptive), rather than neuropathic.

## CONCLUSION

Effective neuropathic pain management among athletes with SCI is essential not only for alleviating discomfort but also for facilitating sport participation and promoting overall well-being. Differentiating neuropathic from nociceptive pain among athletes with SCI is of utmost importance, given that nociceptive pain is more likely to be aggravated by high levels of physical activity. Increased awareness of neuropathic pain symptoms among athletes with SCI and sports medicine physicians can delineate chronic pain from injury and drive further research into innovative treatment approaches and management strategies. Therefore, it is recommended that SCI–neuropathic pain education be improved across parasport organisations, and sports medicine physicians and parasport personnel be encouraged to administer multiple types of neuropathic pain assessments. Obtaining a comprehensive understanding of neuropathic pain among athletes with SCI is foundational to optimal pain management.

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**Contributors** All authors contributed substantially to the development of this article. KT is the guarantor and was responsible for crafting and submitting ethics application to the clinical research ethics board of University of British Columbia, Vancouver; conceiving study design and assisting with designing methods; full participant recruitment; lead investigator responsible for creating online survey material, administering all protocols, measures and data collection; completing majority of data input, analysis and interpretation; supervising undergraduate volunteers who assisted with data input; primary author of manuscript; and collaborating with end users for the primary analysis of this research study to ensure search question was relevant to the spinal cord injury community. KMG provided guidance for all stages of the project, obtained study funding and assisted KT with obtaining ethics approval. KMG and JLKK assisted KT with study design, protocols and measurement selection and interpretation of data. KO assisted KT with data transcription and data input. JLKK, KO and KMG revised and approved final version of the manuscript.

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**Competing interests** None declared.

**Patient and public involvement** Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not applicable.

**Ethics approval** This study involves human participants and was approved by UBC Clinical Research Ethics Board (CREB, H20-02743), whereby all data collection was performed in accordance with CREB guidelines and regulations. Participants gave written, informed consent to participate in the study before taking part.

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**Data availability statement** Data are available upon reasonable request. Deidentified participant data can be requested from the corresponding author (ktodd03@mail.ubc.ca). Reuse will be determined on a case-by-case basis.

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## REFERENCES

- 1 Caneiro JP, Bunzli S, O'Sullivan P. Beliefs about the body and pain: the critical role in musculoskeletal pain management. *Braz J Phys Ther* 2021;25:17–29.
- 2 Alaiti RK, Reis FJJ. Pain in athletes: current knowledge and challenges. *Int J Sports Phys Ther* 2022;17:981–3.
- 3 International Association for the Study of Pain. IASP taxonomy. Pain terms. Neuropathic pain. 2017. Available: [www.iasp-pain.org/Taxonomy#Neuropathicpain](http://www.iasp-pain.org/Taxonomy#Neuropathicpain)
- 4 Rosner J, Negraeff M, Bélanger LM, et al. Characterization of hyperacute neuropathic pain after spinal cord injury: a prospective study. *J Pain* 2022;23:89–97.
- 5 Bates D, Schultheis BC, Hanes MC, et al. A comprehensive algorithm for management of neuropathic pain. *Pain Med* 2019;20:S2–12.
- 6 Felix ER, Cardenas DD, Bryce TN, et al. Prevalence and impact of neuropathic and nonneuropathic pain in chronic spinal cord injury. *Arch Phys Med Rehabil* 2022;103:729–37.
- 7 Zwierzchowska A, Gawel E, Rosolek B. Determinants of the prevalence and location of musculoskeletal pain in elite para athletes. *Medicine (Balt)* 2022;101:e31268.
- 8 Bella GP, Silveira-Moriyama L, Cliquet A. Pain and quality of life in athletes vs non-athletes with spinal cord injury: observational study. *J Spinal Cord Med* 2024;47:181–6.
- 9 AlMakadma Y, Eirale C, Chamari K. Neuropathic pain in athletes: basics of diagnosis and monitoring of a hidden threat. *Biol Sport* 2022;39:943–9.
- 10 Todd KR, Olsen K, Hamamoto G, et al. A comparison of neuropathic pain experiences among paralympic versus recreational athletes with spinal cord injury. *Sports Med - Open* 2023;9:117.
- 11 Martin Ginis KA, van der Scheer JW, Latimer-Cheung AE, et al. Evidence-based scientific exercise guidelines for adults with spinal cord injury: an update and a new guideline. *Spinal Cord* 2018;56:308–21.
- 12 Widerström-Noga E, Biering-Sørensen F, Bryce TN, et al. The international spinal cord injury pain basic data set (version 2.0). *Spinal Cord* 2014;52:282–6.
- 13 Bouhassira D, Attal N, Alchaar H, et al. Comparison of pain syndromes associated with nervous or somatic lesions and development of a new neuropathic pain diagnostic questionnaire (DN4). *Pain* 2005;114:29–36.
- 14 Hallström H, Norrbrink C. Screening tools for neuropathic pain: can they be of use in individuals with spinal cord injury? *Pain* 2011;152:772–9.
- 15 Martin Ginis KA, Phang SH, Latimer AE, et al. Reliability and validity tests of the leisure time physical activity questionnaire for people with spinal cord injury. *Arch Phys Med Rehabil* 2012;93:677–82.
- 16 Gainforth HL, Hoekstra F, McKay R, et al. Integrated knowledge translation guiding principles for conducting and disseminating spinal cord injury research in partnership. *Arch Phys Med Rehabil* 2021;102:656–63.
- 17 Morgan DL. Paradigms lost and pragmatism regained: methodological implications of combining qualitative and quantitative methods. *J Mix Methods Res* 2007;1:48–76.
- 18 Burnard P. Teaching the analysis of textual data: an experiential approach. *Nurse Educ Today* 1996;16:278–81.
- 19 Krippendorff K. Reliability in content analysis: some common misconceptions and recommendations. *Hum Commun Res* 2004;30:411–33.
- 20 Todd KR, Lawrason SVC, Shaw RB, et al. Physical activity interventions, chronic pain, and subjective well-being among persons with spinal cord injury: a systematic scoping review. *Spinal Cord* 2021;59:93–104.



- 21 Werhagen L, Budh CN, Hultling C, *et al.* Neuropathic pain after traumatic spinal cord injury—relations to gender, spinal level, completeness, and age at the time of injury. *Spinal Cord* 2004;42:665–73.
- 22 Noreau L, Cobb JE, Noonan VK, *et al.* Impact of neuropathic pain on participation: perspectives from the Canadian SCI community survey. *Spinal Cord* 2021;59:141–50.
- 23 Mann R, Schaefer C, Sadosky A, *et al.* Burden of spinal cord injury-related neuropathic pain in the United States: retrospective chart review and cross-sectional survey. *Spinal Cord* 2013;51:564–70.
- 24 Henwood P, Ellis J, Logan J, *et al.* Acceptance of chronic neuropathic pain in spinal cord injured persons: a qualitative approach. *Pain Manag Nurs* 2012;13:215–22.
- 25 Albu S, Umemura G, Forner-Cordero A. Actigraphy-based evaluation of sleep quality and physical activity in individuals with spinal cord injury. *Spinal Cord Ser Cases* 2019;5:7.
- 26 Löfgren M, Norrbrink C. "But I know what works" – patients' experience of spinal cord injury neuropathic pain management. *Disabil Rehabil* 2012;34:2139–47.
- 27 Birrer D, Morgan G. Psychological skills training as a way to enhance an athlete's performance in high-intensity sports. *Scand J Med Sci Sports* 2010;20 Suppl 2:78–87.
- 28 Lin T-W, Kuo Y-M. Exercise benefits brain function: the monoamine connection. *Brain Sci* 2013;3:39–53.
- 29 Petkova M, Nikolov V. Gender differences in perception of pain and body awareness in athletes and normally active subjects. *LUMEN Proceedings*; 2018:355–66.
- 30 Bakal DA. *Minding the body: clinical uses of somatic awareness*. 2001.
- 31 Sparkes AC, Smith B. Men, spinal cord injury, memories and the narrative performance of pain. *Disabil Soc* 2008;23:679–90.