

Chronicity of pain associated with spinal cord injury: A longitudinal analysis

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Abstract—This study determined the stability of self-reported clinical pain characteristics and pain-induced interference with sleep and daily activities in people with spinal cord injury. The study followed up a previous survey that identified clinical pain patterns (i.e., neuropathic pain below the level of injury; upper-limb pain in tetraplegia; and severe, persistent pain). A confirmatory factor analysis (CFA) of the present study's data confirmed the previously observed pain patterns. The CFA also confirmed positive correlations between the surveys on individual pain characteristics (i.e., number of pain locations [$r = 0.63$, $p < 0.001$], number of descriptors [$r = 0.61$, $p < 0.001$], pain intensity [$r = 0.68$, $p < 0.001$], and temporal aspects [$r = 0.47$, $p < 0.001$]). Despite an overall stable clinical picture of pain, “aching” pain ($p < 0.001$) and sleep interference caused by pain ($p < 0.001$) significantly increased over time.

Key words: chronic disease, chronic pain, longitudinal studies, neuropathic pain, nociceptive pain, pain, pain measurement, somatosensory disorders, spinal cord injury, statistical factor analysis.

INTRODUCTION

Chronic pain is a major challenge for patients, clinicians, and researchers in the aftermath of a spinal cord injury (SCI). Unfortunately, recent studies report that this sequela of SCI has a prevalence close to 80 percent, with one-third of pains rated as severe [1–6]. The refractory nature of pain associated with SCI [7–8] and the fre-

quent interference with sleep and common daily activities [1,9–10] make chronic pain one of the most common reasons for significantly decreased quality of life [11–14].

Various types of pain with presumably different mechanisms have been observed following SCI. Importantly, many people with SCI experience multiple pains simultaneously [3], which complicates the clinical picture. The International Association for the Study of Pain [15] and other investigators [16–18] have proposed the broad categories of nociceptive pain and neuropathic

Abbreviations: Amos = Analysis of Moment Structures, CFA = confirmatory factor analysis, CFI = comparative fit index, EFA = exploratory factor analysis, NFI = (Bentler-Bonett) normed fit index, NNFI = nonnormed fit index, RMSEA = root-mean-square error of approximation, S1 = Survey 1, S2 = Survey 2, SCI = spinal cord injury, SD = standard deviation.

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pain. The different classifications are based on a combination of pain characteristics (e.g., pain locations and pain descriptors) and other injury characteristics (e.g., level of injury). For example, "burning" pain below the level of injury is usually classified as neuropathic pain, while "aching" pain above the level of injury is usually classified as nociceptive pain [3,19]. The development of a standard taxonomy is an important step toward consistent pain classification and subsequent individually tailored therapeutic options.

Widerström-Noga et al. used an exploratory factor analysis (EFA) to analyze clinical features of pain after SCI [20]. Three factors (patterns) emerged from the EFA:

1. Neuropathic pain below the level of injury (widespread pain; burning quality; and pain in thighs, legs, and feet).
2. Upper-limb pain in tetraplegia (aching quality; pain in neck and shoulders; and cervical level of injury).
3. Severe, persistent pain (constant pain; early onset pain; and high-intensity pain).

The first pattern corresponded to neuropathic pain below the level of injury and the second to musculoskeletal shoulder pain in tetraplegia. Both types of pain commonly follow SCI [3,21]. The third pattern included heterogeneous types of pains that were unrelated to the level of injury but were perceived as constant and severe with an onset at or shortly after the SCI.

While cross-sectional studies have extensively studied the clinical characteristics of chronic pain associated with SCI and their correspondence with current pain taxonomies [16–18], very little is known about the persistence of specific types of pain in chronic SCI. In a recent study, Rintala and colleagues found that approximately half of the male participants and three-fourths of the female participants consistently reported having pain over a 10-year study period [22]. While this study did not detail pain characteristics, other longitudinal studies have examined pain characteristics at 6 [3] and 12 months [9,23–24] postinjury. Only one study has examined the evolution of specific types of pain over a longer post-SCI period [21]. This study demonstrated that both at-level and below-level neuropathic pain persisted over a study period of 5 years postinjury. In contrast, musculoskeletal pain varied more in prevalence and severity. For example, prevalence of musculoskeletal pain declined during the first 6 months after SCI but increased later in the study.

People with SCI are generally expected to adapt to the limitations imposed by their injury and to experience

less life interference with increased time after injury. Indeed, Putzke and colleagues showed that reports of pain interference with daily activities decreased in frequency during the first 2 years after injury [25]. However, specific aspects of daily life, such as sleep, may be less influenced by adaptation. For example, pain and paraesthesias were the most commonly reported causes of difficulties in the initiation and maintenance of sleep in the chronic stages of SCI [26]. Similarly, Widerström-Noga and colleagues reported that people with SCIs had a high frequency of pain interference with falling and staying asleep [10]. Poor sleep is interrelated with various chronic pain conditions [27] and associated with high pain intensity ratings, widespread pain, anxiety, and depression in the SCI population [20,28]. Although clear evidence exists that chronic pain persists for many years following SCI, we know of no studies examining the stability of pain types, such as nociceptive shoulder pain and neuropathic pain, and their impact on daily activities in the chronic stages of SCI. The main objective of the present study was to determine the stability of chronic pain patterns and pain-induced interference with sleep and daily activities in the chronic stages of SCI.

METHODS

In a previous study [20], persons over age 18 with traumatic SCI were recruited from The Miami Project to Cure Paralysis database. Survey 1 (S1), consisting of an introductory letter describing the study, an informed consent form, and a pain history form [29], was mailed to 330 of these individuals; 217 completed the survey. In the present study, 18 months later, Survey 2 (S2), consisting of an introductory letter, a new informed consent form, and the pain history form, was sent to the 217 individuals who participated in S1. Seventy-five of these S1 participants could not be contacted because they had moved and had no forwarding address or working telephone number. Of the 142 individuals who were contacted, 123 completed S2. The University of Miami Institutional Review Board approved the study.

Participants completed the pain history form, a paper-and-pencil measure that included questions about various characteristics and related factors of chronic pain experienced for at least 3 months before the study [29]. Participants returned completed questionnaires to The Miami Project to Cure Paralysis using self-addressed,

stamped envelopes. The research staff reviewed questionnaires for completeness and entered data into a database for storage and further analysis. All individuals not responding within 2 months received a reminder and a second copy of the survey.

Demographic and Injury Characteristics

Demographic information and injury characteristics obtained from The Miami Project to Cure Paralysis database included age at time of study, age when injured, time since injury (described in years and fractions of years), sex, and level of injury. If more than one level of injury was reported, the highest level was used. The level of injury was divided into two categories: cervical and below-cervical, i.e., tetraplegia and paraplegia, respectively. Because this data was self-reported, we could not determine whether the injury level reported was skeletal or neurological.

Pain History Form

Because of the subjective nature of pain [30], a comprehensive pain evaluation must consider the patient's perception of his or her pain [31]. The pain history form is a detailed description of the person's pain and is standard in comprehensive pain evaluations. It usually includes a description of pain location (using body maps), descriptive adjectives, pain intensity, temporal aspects of pain, aggravating and relieving factors, extent of interference, and treatment responses (past and present). This combined information gives the evaluator useful information on which to base a treatment plan and prognosis.

In the present study, the following information obtained from the pain history form was used for analysis [29]: location of pain, quality of pain, intensity of pain, temporal aspects of pain (i.e., onset of pain, breaks in pain), and frequency of pain interference with sleep and other daily activities.

Location of Pain

Participants were asked to mark the location of their chronic pain on two body maps (frontal and dorsal views). The body maps were divided into 45 sections, previously described by Margolis et al. [32] but recoded into the following eight principal areas: head, neck and shoulders, arms and hands, frontal torso and genitals, back, buttocks, thighs, and legs and feet [20].

Quality of Pain

Participants were asked to select from a list of 24 adjectives (i.e., sharp, shooting, stinging, electric, stabbing, flashing, shocking, lancinating, crushing, pinching, penetrating, lacerating, burning, pricking, cramping, cutting, aching, throbbing, pressing, pulsating, radiating, dull, cold, and biting) the words that best described their present pain [20]. The words on the list were drawn from previous interviews with persons with SCI and previous studies [33–35].

Intensity of Pain

The intensity of pain was assessed with the use of a numerical rating scale ranging from 0 (no pain) to 10 (most intense pain imaginable) [36]. Participants were asked to recall and rate the intensity of their present pain when most intense and when least intense. The mean values of the most intense and least intense chronic pains were calculated and used for comparison.

Temporal Aspects of Pain

Onset of Pain. Participants were asked to identify when their pain began. Seven response choices were provided: directly after injury, less than 1 month after injury, 1 to 3 months after injury, 3 to 6 months after injury, 6 months to 1 year after injury, 1 to 2 years after injury, and more than 2 years after injury.

For the factor analyses, the data were categorized into two groups: early onset (within the first 6 months postinjury) and late onset (more than 6 months to more than 2 years postinjury).

Breaks in Pain. Participants were asked to describe the duration of breaks from their pain (i.e., periods when they were pain-free) using one of the following choices: continuous without breaks, short breaks (less than 5 minutes), breaks of 5 minutes to 1 hour, breaks of several hours, breaks of 1 day to several days, week-long breaks, and no consistent pattern.

Participants who reported no consistent patterns were excluded from the analysis. For the factor analyses, two categories of data were used: no breaks or short breaks of 1 hour or less, and breaks longer than 1 hour.

Frequency of Interference

The frequency of interference caused by pain was assessed in the areas of sleep and other daily activities. Comparisons were made between the two surveys in both areas.

Sleep Interference. Participants were asked to describe how often they were awoken by pain after falling asleep. Six choices were given: never, 1 to 3 times a month, 1 to 2 times a week, 3 to 6 times a week, every night, and other.

Participants who chose “other” were excluded from the analysis.

Other Daily Activities Interference. Participants were asked how often pain interfered with their other daily activities. Four choices were given: never, sometimes, often, and always.

Remission of Pain

The number of participants who experienced pain at S1 [20] but no pain at S2 was reported. Participants who reported remission of pain were asked to provide a reason (if known).

Data Analyses

Statistical analysis was performed with the SPSS® Base 12.0.0 for Windows® (SPSS Inc, Chicago, Illinois) and SAS OnlineDoc® (version 8) (SAS Institute Inc, Cary, North Carolina) software programs. For pairwise comparisons, parametric and nonparametric methods were applied. In particular, Pearson’s correlations and paired *t*-tests were used for continuous variables, tetrachoric correlations and chi-square tests for dichotomous variables, and polychoric correlations and Wilcoxon Signed Rank tests for ordinal variables. Tetrachoric and polychoric correlations are specifically used when both variables are dichotomous or ordinal but assumed to reflect underlying continuous variables. That is, these correlations extrapolate what the distributions of the categorical variables would be if they were continuous. As such, this estimate is strongly based on the assumption of an underlying continuous, bivariate, normal distribution. All tests were two-tailed and Bonferroni correction was used to adjust for multiple comparisons where indicated. A *p*-value less than 0.05 was chosen to indicate statistical significance.

Pain Patterns: Confirmatory Factor Analysis

We performed a confirmatory factor analysis (CFA) to determine the stability of the previously obtained pain patterns (**Figure 1**). The CFA included the same variables previously included in the EFA:

1. Level of injury (cervical or below-cervical).
2. Number of pain areas selected in pain drawing.
3. Pain in thighs.
4. Pain in legs and feet.

5. Pain in neck and shoulders.
6. Aching pain.
7. Burning pain.
8. Average pain intensity.
9. Onset of pain.
10. Frequency of pain breaks.

A CFA tests how well a theoretical factor structure is substantiated with a different data set. Unlike an EFA, the relationship between the variables in the CFA model is defined a priori based on theory, previous research, or both [37]. In the present study, we used CFA to evaluate the stability of specific pain patterns over time. CFA is superior to EFA for this purpose, since it provides a priori hypothesis testing and gives additional goodness of fit indexes to assess the appropriateness of a hypothesis. These goodness of fit indexes are based on variances and covariances in the data set [38]. Several fit indexes were applied to the present model [37–39]:

1. Bentler-Bonett normed fit index (NFI), which explains the overall proportion of explained variance.
2. Tucker-Lewis, or nonnormed fit index (NNFI), which adjusts the proportion of explained variance for model complexity by incorporating degrees of freedom.
3. Comparative fit index (CFI), which compares the fit of the model with alternative models.
4. Root-mean-square error of approximation (RMSEA), which measures discrepancy per degree of freedom.

The criterion for goodness of fit for each index was set at 0.95 and for RMSEA at <0.08 [38]. The CFA was conducted using the Analysis of Moment Structures (Amos) 4.0 graphics program (SPSS Inc, Chicago, Illinois). Amos 4.0 provides a graphical interface through which the user conducts an analysis by drawing the model on the screen.

RESULTS

Comparison of Study Participants

To determine how representative our subset sample was, we compared study participants (*n* = 123) with the 207 individuals who completed neither survey or only S1 but were part of the original mailing (**Table 1**). The pairwise comparisons showed no significant differences between the groups with respect to age at injury, time since injury, sex, level of injury, and completeness of injury. However, the participants who completed both

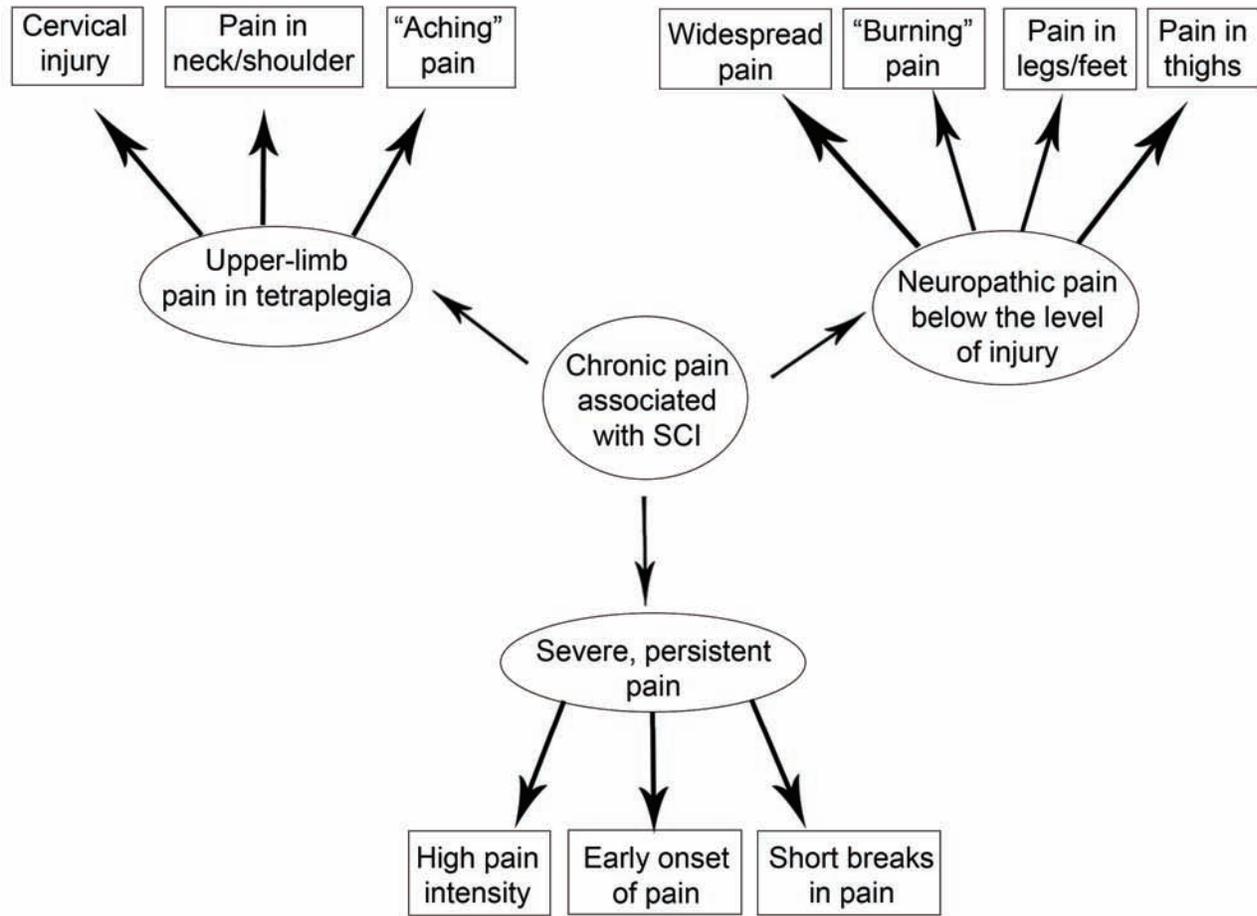


Figure 1.

Hypothesized model of pain patterns following spinal cord injury (SCI) used in confirmatory factor analysis.

surveys were on average 3.5 years older than those who did not ($t = -2.7, p < 0.05$).

Pain Patterns: Confirmatory Factor Analysis

All fit indexes supported an excellent fit of the hypothesized model ($\chi^2(31) = 53.072$, RMSEA = 0.076 [95% confidence interval 0.039–0.110], NFI = 0.97, NNFI = 0.94, and CFI = 0.98). Our findings show that the previous pain patterns (e.g., neuropathic pain below the level of injury; neck and shoulder pain in tetraplegia; and severe, persistent pain) remained stable during an 18-month period.

Pain History Form

Location of Pain

The numbers of body areas (mean \pm standard deviation [SD]) marked in the pain drawing by participants in S1 (3.5 ± 1.7) and S2 (3.7 ± 1.7) were strongly correlated

($r = 0.63, p < 0.001$). The strong, significant tetrachoric correlations in each specific area between the surveys suggest that a participant who experienced pain in a specific region at S1 still had pain in this area at S2 (Table 2).

Quality of Pain

The numbers of pain descriptors (mean \pm SD) used by participants in S1 (6.0 ± 4.0) and S2 (6.3 ± 4.6) were strongly correlated ($r = 0.61, p < 0.001, n = 118$). In both surveys, “burning” was the most commonly selected descriptor (S1 = 59%, S2 = 65%), followed by “sharp” (S1 = 51%, S2 = 53%) and “aching” (S1 = 48%, S2 = 61%). Despite a nonsignificant relative increase in the total number of descriptive adjectives used ($p = 0.465$), a chi-square test showed that “aching” pain significantly increased in S2 by 13 percent ($\chi^2(1) = 15.7, p < 0.001$).

Table 1.

Comparison between study participants ($n = 123$) and individuals lost to follow-up ($n = 207$).

Characteristic	Participant Values	Lost to Follow-Up
Age (yr)*†	40.2 ± 12.5	36.4 ± 10.7
Age at Injury (yr)†	32.0 ± 11.7	29.0 ± 11.1
Time Since Injury (yr)†	8.5 ± 5.9	7.5 ± 5.1
Sex, n (%)		
Men	96 (77.4)	155 (73.4)
Women	27 (21.8)	56 (26.5)
Level of Injury, n (%)		
Cervical	65 (52.8)	116 (55.0)
Below cervical	57 (46.3)	93 (44.1)
Not reported	1 (0.813)	0 (0)
Completeness of Injury, n (%)		
Complete	38 (30.9)	84 (39.8)
Incomplete	79 (64.2)	117 (55.5)
Not reported	6 (4.9)	10 (4.7)

*Bonferroni-adjusted $p < 0.05$.
†Mean ± standard deviation.

Table 2.

Location of pain reported by participants in Survey 1 and Survey 2 ($n = 118$).

Pain Location	Survey 1 (%)	Survey 2 (%)	r^*
Head	10.3	8.6	0.627
Neck and Shoulders	37.4	39.0	0.792
Arms and Hands	35.5	34.3	0.754
Front and Genitals	49.5	48.6	0.754
Back	60.7	64.8	0.826
Buttocks	49.0	58.1	0.895
Thighs	55.1	52.4	0.793
Legs and Feet	56.1	62.9	0.825

*Bonferroni-adjusted $p < 0.001$.

Intensity of Pain

Table 3 displays the means and SDs for the pain ratings, as well as their correlations (Bonferroni-adjusted $p < 0.001$). Although a relative nonsignificant increase in pain intensity occurred over the study period, the significant correlations between S1 and S2 indicate that pain intensities remained relatively stable during the 18-month period.

Temporal Aspects of Pain

Onset of Pain. Approximately 59 percent ($n = 72$) of participants reported experiencing onset of pain within the first 6 months after injury, while approximately

Table 3.

Most, least, and average chronic pain intensity ratings reported by participants in Survey 1 and Survey 2 ($n = 118$).

Chronic Pain Intensity Rating	Survey 1 (Mean ± SD)	Survey 2 (Mean ± SD)	r^*
Most	8.2 ± 1.7	8.5 ± 1.6	0.518
Least	3.4 ± 2.4	3.6 ± 2.6	0.672
Average	5.8 ± 1.7	6.0 ± 1.8	0.677

*Bonferroni-adjusted $p < 0.001$. SD = standard deviation.

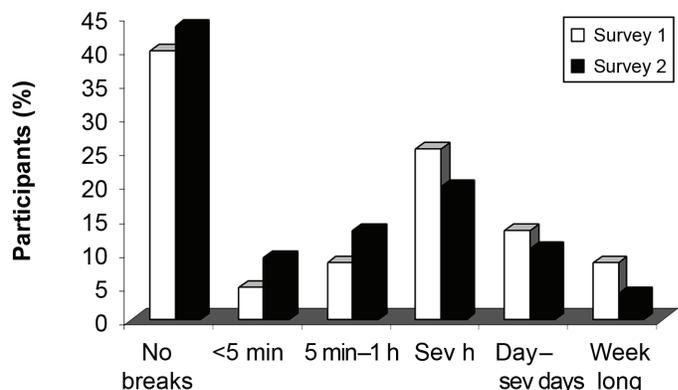
37 percent ($n = 45$) reported that their pain began more than 6 months after injury.

Breaks in Pain. The duration of pain breaks was significantly correlated (polychoric) between the surveys ($r = 0.47$, $p < 0.001$, $n = 83$), indicating that the temporal pattern of pain in these participants was relatively consistent (**Figure 2**). Even though the duration of pain-free periods decreased in S2, these changes did not reach statistical significance.

Frequency of Interference

Sleep Interference. Despite the high correlation between S1 and S2 regarding frequency of sleep interference caused by pain ($r = 0.72$, $p < 0.001$, $n = 98$), a significant increase in the frequency of pain interference with sleep also occurred in S2 ($z = 4.8$, $p < 0.001$) (**Figure 3**).

Other Daily Activities Interference. The frequency of pain interference with other daily activities was also strongly correlated between S1 and S2 ($r = 0.50$, $p < 0.001$, $n = 98$). A slight decrease in frequency of pain interference

**Figure 2.**

Frequency of breaks in pain reported by participants in Survey 1 and Survey 2. Sev = several.

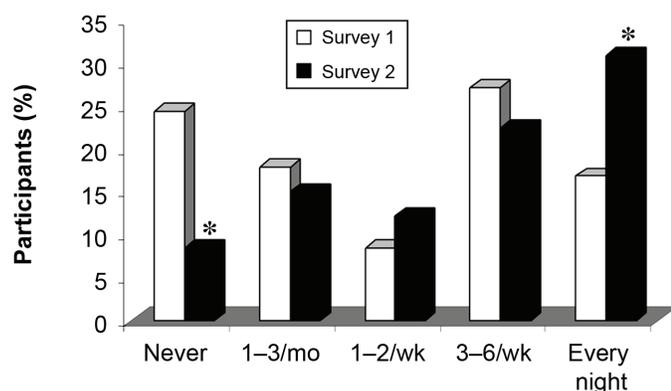


Figure 3. Frequency of sleep interference due to pain reported by participants in Survey 1 and Survey 2. * $p < 0.001$.

with other daily activities over the study period was observed but was not statistically significant (**Figure 4**).

Remission of Pain

Only 4 percent ($n = 5$) of participants who reported pain in S1 reported no pain in S2. Specifically, one participant reported that his pain disappeared after a surgical procedure. The other four participants reported that they no longer experienced pain but did not provide additional explanation.

DISCUSSION

Chronic pain persists many years after the initial SCI [21,40–41] despite the various treatments available [7–8]. The present study confirms this finding. In addition, our results provide further evidence that both individual pain characteristics and specific pain types and patterns remain stable in the chronic stages of SCI. The CFA resulted in excellent fit indexes that suggest that clinical characteristics of pain are relatively stable over an 18-month period. Specifically, the participants consistently experienced the following three patterns:

1. Upper-limb pain in tetraplegia.
2. Neuropathic pain below the level of injury.
3. Severe, persistent pain.

Upper-limb nociceptive pain is common after SCI [42] and is often due to overuse syndromes caused by prolonged use of a wheelchair or by impaired motor function in tetraplegia [2,43–45]. The pain is often described

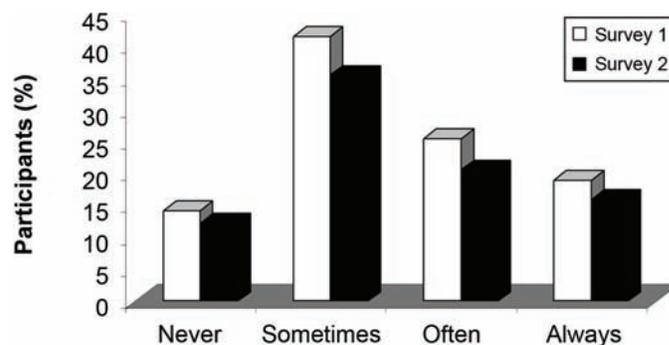


Figure 4. Frequency of daily activities interference due to pain reported by participants in Survey 1 and Survey 2.

as aching and as worsening with continuous use of the involved muscles and joints [15,42]. Interestingly, one of the few significant changes in pain characteristics during the study period was an increase in reports of “aching” pain. This finding is consistent with the study by Siddall and colleagues [21], in which the prevalence of late-onset musculoskeletal pain increased over a 5-year period. An increase in the musculoskeletal nociceptive pain types [43] is clinically important because these pains may respond to a wider range of treatments, such as occupational and physical therapy, analgesics, or nonsteroidal anti-inflammatory medications [15,40].

Neuropathic pain below the level of injury is also common in SCI [3,21]. This type of pain included a combination of widespread pain; “burning” pain; and pain in the thigh, leg, and foot regions. Since more than half of the participants in the present study used “burning” to describe pain below the injury, it appears that the majority of participants continued to experience neuropathic pain types over the 18-month period.

Severe, persistent pain included constant pain with early onset relative to injury and high pain intensity. These characteristics may be associated with various pain types (i.e., above-, at-, or below-level neuropathic). For example, Siddall and colleagues described at-level neuropathic pain as severe, early onset, and persistent [21]. Our findings concur with these results, suggesting that severe, persistent neuropathic pain remains refractory despite the various interventions available for chronic SCI.

Only 4 percent of our study participants reported remission of pain. This number concurs with a previous study in which the remission rate of significant pain and/or dysesthesia was only 5.8 percent over a 3-year period in

people with SCI [46]. In contrast, Siddall et al. reported a relative increase in the prevalence of chronic pain over a 5-year period [21], pointing to the likelihood of pain development rather than pain remission in the chronic stages of SCI.

Consistent with previous SCI findings [10,26], our participants reported frequent sleep interference caused by pain during the study period. However, this is the first study showing a significant increase in pain-induced interference with sleep in chronic SCI. Several investigators have reported high comorbidity of chronic pain and poor sleep in the general population but the causality remains unknown [47–50]. Persistent and intense pains associated with SCI [7–8] may profoundly affect the quality of an individual's sleep [51]. In fact, high pain intensity ratings, widespread pain, anxiety, and depression were all significantly associated with sleep disturbance in people with chronic pain and SCI [10,28]. Since sleep disturbance increased in the present study and sleep quality may profoundly affect both the perception of pain and other sequelae of SCI, sleep dysfunction may be an important target of therapeutic interventions. A sleep diary is a simple, cost-effective adjunct to the evaluation of the chronic SCI pain patient [47]. Such an evaluation may be particularly useful in the clinical assessment of chronic pain associated with SCI, since people with SCI are more likely to suffer from sleep disorders than people without SCI. In particular, people with cervical injuries experience increased sleep dysfunction with increased time since injury [52].

METHODOLOGICAL CONSIDERATIONS

All participants were volunteers who agreed to be included in The Miami Project to Cure Paralysis database. These participants may not represent all people with SCI and may therefore present a selection bias. To elucidate selection bias issues, responders and nonresponders to the survey were compared. After comparing demographic data and injury characteristics of study participants with individuals who were lost to follow-up, no significant differences in age at injury, sex, and completeness of injury were observed. The only difference between the groups was that participants who responded to the pain questionnaire were on average 3 years older than those lost to follow-up. Most participants were male (77.4%) and approximately half had cervical injuries (52.8%). These

figures are very similar to those reported in the national SCI database [53], in which 81.5 percent of patients are male and 54.0 percent have cervical injuries.

CONCLUSION

Despite some limitations, this study not only provides evidence for the continuous presence of pain but also suggests that specific pain patterns corresponding to pain types persist in the chronic stages of SCI. Unfortunately, neuropathic and musculoskeletal pain types are consistent parts of the clinical picture of SCI. These pains depend partly on different pain mechanisms and can therefore be expected to respond differentially to clinical interventions. Thus, evaluation of each type of pain separately in both clinical pain management and research is important. A differentiated evaluation approach for pain associated with SCI will not only provide a basis for tailored treatment interventions but also further the understanding of how different types of pain affect the lives of those with SCI.

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