# **A prospective study of pain and psychological functioning following traumatic spinal cord injury**

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Study design: Longitudinal study.

**Objectives:** To study prospectively pain characteristics, change in pain over time and the associations between pain and psychological functioning in adults with traumatic spinal cord injury (SCI).

**Setting:** Neurosurgical departments, SCI rehabilitation centres and the community.

**Methods:** Adults with traumatic SCI admitted over a 3-year period to two neurosurgical departments underwent clinical examination and questionnaires within 3 months after injury (baseline) and at 6, 12 and 42 months following SCI. Pain intensity and interference within the last 7 days, a global quality of life (QoL) item, the 5-item Mental Health Index and the 6-item Catastrophizing scale were used.

**Results:** Ninety individuals were recruited, of which 81 completed a telephone interview on average 3.5 (s.d., 0.6) years after the SCI. Pain was present in 75% at 3.5 years. Baseline pain catastrophizing scores did not predict pain intensity at 3.5 years. Both psychological functioning and QoL increased over time. QoL scores increased less in participants who reported an increase in pain intensity from baseline to the 3.5-year follow-up, and the change in QoL score correlated with the change in pain interference. Neuropathic pain had an onset within the first 12 months and tended to become persistent, whereas musculoskeletal pain more often had a late onset or resolved in cases of early onset.

**Conclusions:** A large proportion of SCI participants continue to experience pain many years after SCI. Teaching individuals with SCI skills to minimise pain's impact on function as soon as possible following injury may prove beneficial.

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# INTRODUCTION

Spinal cord injury (SCI) is associated with functional loss, physical dependence and chronic pain.<sup>1</sup> Chronic pain is usually defined as pain that persists for >3 months. SCI is also associated with psychological morbidity such as depressive mood, anxiety, fatigue and posttraumatic stress disorder.<sup>2–4</sup> Longitudinal studies have shown that a large proportion of individuals with SCI continue to experience pain many years following SCI.<sup>5–7</sup> Particular neuropathic pain tends to become persistent despite treatment attempts.<sup>5</sup>

Negative psychological effects associated with SCI appear to be related to a number of moderating factors such as genetic predisposition, coping strategies, elevated levels of hopelessness, low self-efficacy, cognitive impairment and the presence of comorbidities, including pain.<sup>3,8</sup> Studies support an association between pain and poorer psychological functioning and life interference.<sup>5,7,9–14</sup> Moreover, both functional impairment and pain have been suggested to affect quality of life (QoL) via the effects on participation.<sup>15–17</sup> Some of the studies examining the interaction between pain, psychological functioning and QoL have been prospective,<sup>3,5–7,13,16</sup> and few<sup>5</sup> have examined these effects separately as a function of underlying pain mechanisms. Further knowledge of the course of pain and its impact is critical to

determining the need for treating pain during this period of time and in particular for identifying the specific problems (for example, catastrophizing and psychological functioning) to target with treatment.

The purpose of the current study was to address this knowledge gap using data from an ongoing prospective study of SCL.<sup>18</sup> Specifically, we sought to (1) determine the prevalence and severity of pain 3–4 years following injury in a sample of adults with SCI, (2) identify the factors that predict long-term pain and change in pain intensity over time and (3) estimate the associations between psychological functioning, QoL and pain over time. We hypothesised that pain would be common, that any neuropathic pain that developed would maintain from the 12-year follow-up, but that musculoskeletal pain would vary over time, and that the presence of pain would be associated with poorer psychological functioning and lower QoL.

# SUBJECTS AND METHODS

#### Subjects

Individuals with a traumatic SCI aged  $\geq$  18 years admitted consecutively from October 2007 to December 2010 to the Department of Neurosurgery, Aarhus University Hospital, Denmark, and the Department of Neurology, Karolinska

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University Hospital, Stockholm, were eligible for study inclusion. The participants were examined at baseline within 3 months of injury (n = 90) with follow-up visits at 6 (n = 78, 19 by telephone interview) and 12 months (n = 88, 29 by telephone interview) post injury and a telephone follow-up 3–4 years after the injury performed by a physician (LW, KT or NBF; n = 81). The study was approved by the local ethical committees (Regionala etikprövningsnämnden Stockholm no. 2007/1558–32 with amendment 1843–32 and the National Committee on Health Research Ethics for Central Region Denmark no. M-20070090) and the Danish Data Protection Agency (no. 2007–41–0605). All participants provided written informed consent. Further details of the recruitment and part of the findings using data from the 12-month follow-up have been presented elsewhere.<sup>18</sup> The focus of this paper is the 3.5-year follow-up and pain and psychological functioning data.

### Assessments

Participants were interviewed about any pain that was present within the last 7 days before the visit/interview. Pain was classified according to the International Spinal Cord Injury Pain Classification.<sup>19</sup> Average pain intensity in the past 7 days was rated separately for each pain type: at-level neuropathic pain, below-level neuropathic pain, visceral pain and musculoskeletal or other nociceptive pain on a numeric rating scale from 0 (no pain) to 10 (worst pain imaginable). Such 0-10 numerical rating scales are recommended for assessing pain intensity in SCI research, and a recall period of 7 days was selected to balance the need for obtaining a reliable score representing average pain (given that pain intensity can vary markedly over short time periods) while minimising the potential for recall bias.<sup>20</sup> Intensity of overall pain was defined as the average intensity of the worst pain problem, if patients reported more than one pain type. In addition, participants were asked to provide information about any medications they took and about non-painful sensations. Participants with neuropathic pain were also asked to describe their pain by selecting descriptors from a list provided to them.

Participants rated the extent to which overall pain interfered with functioning within 7 domains: general activity, mobility, normal work, relations with others, mood, enjoyment of life and sleep on an numeric rating scale ranging from 0 (does not interfere) to 10 (completely interferes) using the modified Brief Pain Inventory (BPI).<sup>21,22</sup> The original BPI item assessing interference with 'walking ability' was modified to 'mobility, that is, your ability to get around' for use with populations who were not ambulatory.<sup>21</sup> The BPI total interference score was calculated as the average of the 7 domains; the BPI affective interference score was calculated as the average of the following items: mood, relations and life enjoyment; and the BPI activity interference score was calculated as the average of the following items: general activity, mobility and work, while sleep was assessed separately.<sup>23,24</sup> Internal consistency (Cronbach's alpha) of the total BPI score in the current sample was 0.9, the BPI affective interference score was 0.91 and the BPI activity interference score was 0.88, indicating a good to excellent level of reliability.

QoL was assessed using a single item by asking 'How would you judge your own QoL the past week' rated on an numeric rating scale (0–10), with 0 ='worst QoL possible' and 10 ='best QoL possible'.<sup>25,26</sup>

The Mental Health Index (MHI-5) of the 36-item Short Form Health Survey (SF-36)<sup>27</sup> was used to assess psychological functioning. The MHI-5 consists of 5 questions:<sup>27</sup> Over the last 7 days, how often: (1) 'Have you been a very nervous person?'; (2) 'Have you felt so down in the dumps that nothing could cheer you up?'; (3) 'Have you felt calm and peaceful?'; (4) 'Have you felt downhearted and blue?'; (5) 'Have you been a happy person?' Each item has six possible responses ranging from 'all the time' to 'none of the time.' The final MHI-5 score is calculated by summing the item scores (ratings in the third and the fifth items are reverse-scored) and transforming this summary score to a T-score that ranges between 0 and 100, with higher scores indicating better psychological functioning. The internal consistency of the MHI-5 (Cronbach's  $\alpha$ ) in the current sample was 0.88, indicating a good level of reliability.

The 6-item Catastrophizing Scale of the Coping Strategies Questionnaire (CSQ-CAT)<sup>28,29</sup> was used to assess pain catastrophizing. The CSQ-CAT items reflect different pain-related catastrophizing thoughts, for example, 'I worry all the time about whether it will end', and respondents rate how often they respond to pain with each of these thoughts on a scale of 0 'never do that' to

6 'always do that'. The responses are averaged into a CSQ-CAT summary score, with higher scores reflecting more catastrophizing. Participants were asked to answer the questionnaire considering their pain within the past 7 days, and thus only participants with pain within the past week completed the CSQ-CAT. In the current sample, the Cronbach's alpha score associated with the CSQ-CAT was 0.91, indicating an excellent level of reliability.

#### Statistical analysis

All statistical analyses were performed using SPSS version 13 (IBM, Armonk, NY, USA). The study variables were described by computing their means and s.d's. Paired and unpaired *t*-tests were performed, and Pearson's correlation coefficients were used to describe the associations among variables. In addition, binary logistic regression analyses and multiple regression analyses were performed to identify the factors that contributed to the prediction of change in pain and QoL, and to the presence of pain, defined as reporting pain or not within the preceding week at 3.5-year follow-up. Estimates are given with 95% confidence intervals. *P*<0.05 was considered statistically significant. All analyses only included data that were provided by the study participants; missing data were not replaced.

#### Statement of ethics

We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

#### RESULTS

#### Subjects

Ninety individuals with SCI (50 from Denmark and 40 from Sweden) were recruited from October 2007 to December 2010. One participant died before the second visit, and one left the country before the third visit, leaving 88 available for the 12-month follow-up. Seventy-eight participants completed the 6-month follow-up. Pain phenotypes and sensory abnormalities using data from the 12-month follow-up have been presented elsewhere.<sup>18</sup> Before the 3.5-year follow-up, an additional four participants had died, one had left the country and two did not respond to telephone or mail contact, leaving 81 participants who completed a telephone interview on average 3.5 (s.d., 0.6) years after SCI onset. Clinical characteristics of the study participants are presented in Table 1. As can be seen, 75% reported at least one pain problem at the 3.5-year follow-up.

#### Prevalence, severity and treatment of pain

Following SCI, 91, 82, 83 and 75% reported at last some pain in the previous week at baseline and at 6, 12 months and 3.5 years, respectively. At 3.5 years, musculoskeletal pain was present in 66% (no other type of nociceptive pain was reported), neuropathic SCI pain in 49%, at-level pain reported in 30% and below-level pain in 25% (29% if excluding participants with cauda equina lesions) of the sample (Figure 1). Other neuropathic pain was present in one and visceral pain in two participants. Average pain intensities are presented in Figure 1. Interference of overall pain is presented in Figure 2; there were no statistically significant differences between interference at baseline and 3.5 years in those with pain at both time points.

The most common descriptors used to describe at-level and belowlevel SCI neuropathic pain at 3.5 years were tingling/pins and needles (59 and 90%, respectively), pain evoked by touch (59 and 30%), warm/burning (45 and 55%), shooting (55 and 40%), pressing/ squeezing (50 and 70%), cold/freezing (23 and 25%) and itching (14 and 5%). Below-level pain was more often reported as tingling/ pins and needles compared with at-level pain (P=0.023). Abnormal non-painful sensations were reported in 53/81 participants (65%).

 Table 1 Clinical characteristics and study measures of the 81

 participants available at 3.5-year follow-up

	Follow-up, n=81		
Sex, male, <i>n</i> (%)	71 (88%)		
Age at follow-up, years, mean (s.d.), range	51.8 (15.6), 21–80		
Time since injury, years, mean (s.d.)	3.5 (0.6)		
SCI impairment <sup>a</sup>			
Complete SCI, n (%)	24 (30%)		
Incomplete SCI, n (%)	55 (68%)		
Paraplegia, n (%)	34 (42%)		
Tetraplegia, n (%)	45 (56%)		
Pain, <i>n</i> (%)	61 (75%)		
Average pain intensity, NRS, mean (s.d.), $n = 61^{b,c}$	5.3 (2.3)		
BPI total interference, mean (s.d.), $n = 56^{\circ}$	3.1 (2.4)		
BPI activity interference, mean (s.d.), $n = 57^{\circ}$	3.6 (2.6)		
BPI effective interference, mean (s.d.), $n = 56^{\circ}$	3.0 (2.6)		
Pain catastrophizing, CSQ-CAT, mean (s.d.), $n = 54^{c,d}$	0.99 (1.2)		
Psychological functioning, MHI-5, mean (s.d.), $n = 72^{d}$	80.4 (18.6)		
QoL, NRS 0–10, mean (s.d.), <i>n</i> = 79 <sup>d</sup>	6.5 (2.0)		

Abbreviations: BPI, brief pain inventory; CSQ-CAT, catastrophizing scale of the coping strategies questionnaire; MHI-5, mental health index; NRS, numeric rating scale; QoL, quality of life; SCI, spinal cord injury.

<sup>a</sup>Two participants had a normal neurological examination.

<sup>b</sup>Average intensity in the past 7 days of the pain type with the highest average pain intensity.

<sup>c</sup>Among participants with pain. <sup>d</sup>Some participants had difficulty in cooperating to answer questions related to CSQ-CAT, MHI-5 and QoL over the phone; the number of participants for whom data are available for each measure is indicated.

For a description of the entire sample of the 90 participants at inclusion, please see Finnerup  $\textit{et al.}^{18}$ 

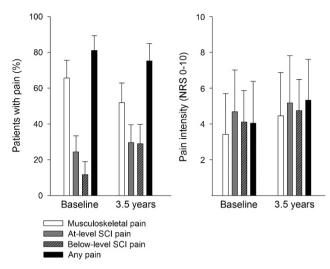
In 14 patients, these were not unpleasant (paraesthesia) and in 39 they were unpleasant (dysaesthesia).

At the 3.5-year follow-up, 62% (38/61) of participants who indicated that they had at least some pain reported that they had taken the following medications for pain: pregabalin (15), gabapentin (14), tramadol (12), paracetamol (10), tricyclic antidepressants (7), Nonsteroidal anti-inflammatory drugs (6), strong opioids (4), codeine (2) and duloxetine (2).

#### Persistence of pain

One participant reported pain classified as at-level pain at 3.5 years that was not present at 12 months, whereas one participant reported pain classified as at-level pain at 3.5 years but had experienced below-level pain extending to the at-level region at 12 months. Only one participant had below-level pain at 3.5 years that was not present at 12 months. However, the sensations that were labelled as pain at the 3.5-year follow-up assessment were also present at 6 and 12 months in the same locations; at those earlier assessment points these sensations were less severe and reported as dysaesthesias and not pain. In contrast, 8 (10%) participants reported musculoskeletal pain at 3.5 years that was not present at 12 months. Three participants reported at-level SCI pain and six experienced below-level pain at 12 months that was no longer present at 3.5 years. Seven of these 9 participants, however, reported dysaesthesia at 3.5 years and one reported paraesthesia. Sixteen participants experienced musculoskeletal pain at 12 months that was not present at 3.5 years. In short, the onset of neuropathic pain was generally within the first 12 months following SCI and tended to become persistent, whereas musculoskeletal pain more often had a late onset or resolved in cases of early onset.

There was a significant correlation between the intensity of at- and below-level neuropathic pain at 3.5 years and the intensity of pain at 6 and 12 months (r=0.68 and 0.68 for at-level pain and 0.59 and 0.76



**Figure 1** Prevalence (95% confidence interval) and intensity of any pain, musculoskeletal pain and at- and below-level SCI neuropathic pain at baseline (n=90) and 3.5 years (n=81) following SCI. Prevalence of below-level pain is presented for participants with spinal cord lesion (n=77 (86%) at baseline and n=69 (85%) at 3.5 years). Intensity is indicated as average (s.d.) intensity of pain in those reporting the specific pain, and intensity of 'any pain' is indicated as the average intensity of the worst pain.

for below-level pain, respectively, Ps < 0.0001) but not with the intensity at baseline (r = 0.12 and 0.07, respectively, Ps = 0.28 and 0.54, respectively). There was also a significant correlation between the intensity of musculoskeletal pain at 3.5 years and the intensity of musculoskeltal pain at baseline (r = 0.40, P < 0.001), 6 months (r = 0.32, P = 0.006) and 12 months (r = 0.36, P = 0.001).

#### Factors associated with pain at 3.5-year follow-up

Younger age (OR 0.96 (0.92–0.996), P = 0.029), but not sex, baseline CSQ-CAT, MHI-5 or QoL scores predicted the presence of pain at 3.5 years, when correcting for intensity of overall pain at baseline in binary logistic models.

#### Factors associated with change in pain intensity

There was a nonsignificant positive association between overall pain intensity (intensity of the worst pain type) at baseline (those without any pain rated as 0) and overall pain intensity at 3.5 year (r = 0.19, P = 0.086). Seven participants did not have pain at baseline and at 3.5 years; in eight participants the average intensity of their worst pain did not change, in 39 it increased and in 27 it decreased from baseline to the 3.5-year follow-up. The average intensity of the worst pain increased on average 0.99 points (s.d., 3.6) on the 0-10 numeric rating scale from baseline to the 3.5-year follow-up. In univariate analyses, neither the CSQ-CAT score (r=-1.0, P=0.45), MHI-5 score (r = -0.016, P = 0.89), QoL score (r = -0.19, P = 0.086) or age (r=0.068, P=0.55) at baseline predicted a subsequent change in the overall pain intensity, and there was no significant difference as a function of sex (t (79) = -1.4, P = 0.16), whether the participants had a complete or an incomplete injury (t (79) = -1.5, P = 0.14) or paraplegia or tetraplegia (t (79) = 0.60, P = 0.55) at baseline. Including the CSQ-CAT score, MHI-5 score, QoL score and age at baseline in a forced entry multiple regression also did not find any of these to be independently associated with the change in pain intensity.

In a forced entry regression predicting change in overall pain score, changes in the BPI total pain interference score, the CSQ-CAT score and the MHI-5 score were entered in the 1st step. The model was

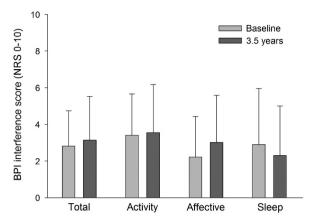


Figure 2 Pain interference during the past 7 days for the total average interference score, activity-related functions (general activity, mobility and work), affective-related functions (mood, relations with others and enjoyment of life) and sleep measured on the modified BPI at baseline and 3.5 years. Interference is indicated as mean (s.d.).

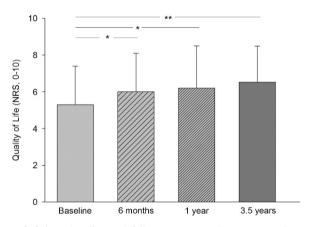


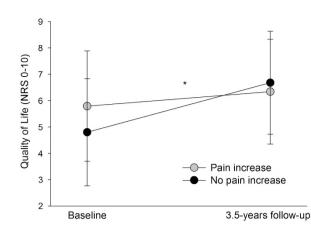
Figure 3 QoL at baseline and follow-up, measured on an numeric rating scale (0–10). \*P<0.01 and \*\*P<0.001.

significant (P=0.005) explaining 30% of the variance. Change in the BPI total interference score was the only factor associated uniquely with the change in the pain score ( $\beta=0.55$  (0.25–0.85), P=0.001).

#### Psychological functioning

There was a slight but statistically significant improvement in QoL over time (mean 5.3 (s.d., 2.1) at baseline to mean 6.5 (s.d., 2.0) at 3.5 years, (t (78) = -4.4, P < 0.001; Figure 3) and the MHI-5 score increased significantly from a mean of 73.4 (s.d., 18.1) at baseline to 80.4 (s.d., 18.6) at 3.5 years, (t (71) = -2.8, P = 0.007). The psychological scores at 3.5 years are summarised in Table 1. Neither the MHI-5 score nor the QoL score correlated significantly with average pain intensity (r=-0.10, P=0.40 and r=-0.11, P=0.31), but they did correlate significantly with the BPI total interference score (r=-0.39, P=0.004 and r=-0.36, P=0.007, respectively), BPI affective interference score (r=-0.45, P=0.001 and r=-0.45, P=0.001, respectively) and to a lesser extent the BPI activity interference score (r=-0.29, P=0.04 and r=-0.27, P=0.04, respectively).

QoL scores increased less in participants with an increase in overall pain intensity from baseline to the 3.5-year follow-up (mean (s.d.), 0.55 (2.5)) compared with those with either a decrease or an unchanged pain intensity (1.88 (2.4)) (t (77) = -2.4, P=0.018; Figure 4).



**Figure 4** QoL scores at baseline and 3.5 years in those with no change (n=15), decrease (n=26) and increase (n=38) in pain intensity from baseline to 3.5-year follow-up. \*There was a significant difference in the QoL change score (from baseline to 3.5-year follow-up) between the two groups, P=0.018.

Table 2 Results from a one-step forced entry multiple regression for the QoL change score

		Change in QoL		
	В	s.e.	Beta	P-value
Change in pain intensity	0.076	0.16	0.08	0.63
Change in BPI pain affective total score	0.11	0.24	0.12	0.65
Change in BPI pain activity score	-0.36	0.16	-0.47	0.031
Change in CSQ-CAT score	-0.45	0.28	-0.30	0.11

Abbreviations: BPI, brief pain inventory; CSQ-CAT, catastrophizing scale of the coping strategies questionnaire; QoL, quality of life; s.e., standard error. R=0.49,  $R^2=0.24$ , F(4,36)=2.89, P=0.036.

In a forced entry regression predicting change in QoL scores, changes in overall pain intensity, BPI affective interference score, BPI activity interference score and CSQ-CAT score were force entered in 1 step. The model was significant (Table 2) explaining 24% of the variance. Change in BPI activity interference score was the only unique predictor.

# DISCUSSION

Our study confirms that a large proportion of individuals with SCI continue to experience pain 3–4 years following SCI. In our sample, 75% experienced pain on average 3.5 years after injury. Musculoskeletal pain was present in 51% and neuropathic pain in 49%. At 12 months post injury,<sup>18</sup> we previously reported that below-level SCI neuropathic pain had a later onset than at-level SCI pain, as was shown originally by Siddall *et al.*<sup>5</sup> Only one participant in our sample reported neuropathic pain at 3.5 years that was not present as pain or dysaesthesia at 12 months. This suggests that both at- and below-level neuropathic pain, if they are going to occur, develop within the first 12 months after injury. In addition, and also consistent with the longitudinal study by Siddall *et al.*,<sup>5</sup> we found that there was a strong correlation between the presence of both types of neuropathic pain in the chronic phase and neuropathic pain assessed at earlier time points.

Younger age, but not sex, pain catastrophizing, psychological functioning or QoL at baseline predicted the presence of any pain at 3.5 years, when controlling for overall pain intensity at baseline. There was an increase in overall pain intensity over time averaged across the sample as a whole, although some individual participants reported decreases in pain intensity over time. Change in total pain interference was associated with the change in pain intensity, whereas neither change in pain catastrophizing nor psychological functioning was associated with the change in pain intensity. Pain catastrophizing has previously been reported to below following SCI,<sup>30</sup> and our study suggests that high pain catastrophizing scores do not predict the presence of pain at 3.5 years or increase in pain intensity.

Both psychological functioning and QoL improved over time, consistent with previous findings.<sup>17</sup> At 3.5 years, the measures of psychological functioning correlated with pain interference but not pain intensity. However, QoL scores increased less in participants who reported an increase in pain intensity from baseline to the 3.5-year follow-up, relative to those reporting either a decrease or no change in pain intensity. Change in the pain-related activity interference score was the only individual predictor for change in QoL scores.

An important limitation of the current study is its reliance on self report measures for assessing all outcomes. This could have resulted in larger associations between variables due to shared method variance. Future research should in addition use objective measures of those domains (for example, activity level) than can be measured objectively, when possible. In addition, we only assessed one domain of pain: pain intensity. Other pain-related domains such as pain site and extent of pain, and to a lesser extent ambulatory status, can be important for understanding the influence of pain on SCI individuals' daily life and psychological functioning.<sup>31</sup> In addition, several factors that we did not assess, such as more psychological stress and lower levels of social support, have been shown to predict persisting pain.<sup>6</sup> As our study documented, many SCI individuals report dysesthesia, which can be very unpleasant, and it is possible that these sensations have an impact on QoL and psychological functioning. Another important limitation is that QoL was assessed using a single item using a recall period of the past 7 days. Recently, the International SCI QoL Basic Data Set was developed and validated for the use in individuals with SCI.<sup>32,33</sup> The data set includes three items that assess satisfaction with life as a whole, satisfaction with physical health and satisfaction with psychological health during the past 4 weeks. Future research using these items in samples of individuals with SCI and chronic pain would help determine the reliability of the findings presented here.

Despite the study's limitations, the current findings replicate and extend previous research regarding pain and its role in functioning 3–4 years following SCI. We confirmed that once neuropathic pain develops in this population, it does not appear to resolve. As a new finding, we document that – if it is going to develop – pain is most likely to develop within the first 12 months following injury. Therefore, it is important to consider other types of pain or progression in the underlying disease, such as development of a syrinx, if patients develop pain > 12 months after the SCI. The finding that changes in the activity interference score was the only individual predictor for change in QoL scores suggests the potential importance of teaching individuals with SCI skills in minimising the impact of pain on function early on (that is, within the first 12 months following injury) to improve long-term QoL. Research to examine the benefits of such treatment is warranted.

#### DATA ARCHIVING

There were no data to deposit.

# CONFLICT OF INTEREST

The authors declare no conflict of interest.

#### ACKNOWLEDGEMENTS

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