



## Original Article

# Pain and dysesthesia in patients with spinal cord injury: A postal survey

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**Study design:** A postal survey.

**Objectives:** To assess the prevalence and characteristics of pain and dysesthesia in a community based sample of patients with spinal cord injury (SCI) with special focus on neuropathic pain.

**Setting:** Community. Western half of Denmark.

**Methods:** We mailed a questionnaire to all outpatients ( $n=436$ ) of the Viborg rehabilitation centre for spinal cord injury. The questionnaire contained questions regarding cause and level of spinal injury and amount of sensory and motor function below this level. The words pain and unpleasant sensations were used to describe pain (P) and dysesthesia (D) respectively. Questions included location and intensity of chronic pain or dysesthesia, degree of interference with daily activity and sleep, presence of paroxysms and evoked pain or dysesthesia, temporal aspects, alleviating and aggravating factors, McGill Pain Questionnaire (MPQ) and treatment.

**Results:** Seventy-six per cent of the patients returned the questionnaire, (230 males and 100 females). The ages ranged from 19 to 80 years (median 42.6 years) and time since spinal injury ranged from 0.5 to 39 years (median 9.3 years). The majority (>75%) of patients had traumatic spinal cord injury. Of the respondents, 77% reported having pain or unpleasant sensations, and 67% had chronic pain or unpleasant sensations at or below lesion. Forty-eight per cent reported that P/D could be evoked by non-noxious stimulation of the skin indicating that allodynia is present in almost half of the patients. Forty-three per cent of respondents took analgesics, 7% received antidepressants or anticonvulsants.

**Conclusion:** This survey suggests that pain and dysesthesia are common and serious complaints in SCI patients. Unexpectedly, only 7% of the patients were treated with drugs considered to be most effective in neuropathic pain. This emphasizes the need for a continued research and education on P/D in SCI.

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**Keywords:** pain; dysesthesia; neuropathic; spinal cord injury

## Introduction

Chronic pain and dysesthesia (P/D) are important and frequent complaints in patients with spinal cord injury (SCI) with a reported prevalence varying between 27% and 94%.<sup>1–10</sup> The classification of post-SCI pain is not clarified,<sup>11–13</sup> which in part may explain the large variation in reported pain frequency. The SCI Pain Task Force of the IASP broadly classifies SCI pain into nociceptive (musculoskeletal and visceral) and neuropathic (above-level, at-level, and below-level) pain.<sup>12</sup> Neuropathic types of pain in SCI may include peripheral (nerves and nerve roots) as well as central components. Neuropathic pain is considered to be a particular bothersome symptom in SCI because it often

persists and generally is considered resistant to conventional analgesic treatments. Neuropathic pain has several distinct features: lesion of nervous tissue, pain in an area with sensory deficits, dysesthesia, allodynia (pain due to a stimulus which does not normally provoke pain), hyperalgesia (an increased response to a stimulus which is normally painful) and abnormal spatial and temporal summation. Several of these features are also seen in SCI pain. Although central pain is often said to be burning or 'dysesthetic', it may have any particular pain quality,<sup>13</sup> so classification of patients on basis of symptoms alone is not possible.

A particular striking phenomenon in peripheral and central neuropathic pain syndromes is allodynia, ie the elicitation of pain in the affected area by non-noxious stimulation with light touch or innocuous cold or

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warmth.<sup>13,14</sup> It has previously been shown that testing for allodynia is a simple reliable bedside technique to screen for neuropathic pain.<sup>15</sup> In this study we used self reported allodynia together with other pain characteristics to screen for possible neuropathic pain. Thus the aim of the study was twofold: (1) to determine prevalence and character of pain and dysesthesia in a large group of SCI patients and (2) estimate the proportion of patients with possible neuropathic pain. Part of the present study has been presented previously in abstract form.<sup>16</sup>

## Methods

We developed a questionnaire, which was pilot tested in nine patients. We mailed it to all 436 spinal cord injury outpatients at the spinal cord injury centre of Viborg hospital, which covers the Western half of Denmark with a population of about 2.5 million inhabitants.

The questionnaire comprised 34 questions including cause, level of spinal cord injury, and degree of sensory and motor function below this level. The words pain and unpleasant sensations were used to describe pain (P) and dysesthesia (D). Pain and dysesthesia (P/D) was separated into above level P/D and at or below level P/D based on self-report. All patients suffering from chronic P/D at or below the level of lesion were asked to draw the location of their P/D on a body chart and were asked whether they experienced superficial, deep and/or abdominal pain. The P/D was defined as 'diffuse' if it involved the entire body below the lesion and 'patchy' if it was scattered in at least two separated areas below the lesion level. We assessed intensity of P/D by means of visual analog scales (VAS). The VAS consisted of a 100 mm horizontal line with the words 'no pain or unpleasantness' at the left extreme end of the line and 'worse imaginable pain or unpleasantness' at the right end of the line. Other questions included degree of interference with daily activity and sleep (on a VAS), presence of paroxysms, temporal aspects, intensities of spasms and their relation to P/D and treatment of P/D. Presence of evoked P/D was assessed by asking if touch, for example by clothing, or contact with innocuous cold or warm could provoke pain or unpleasantness. Furthermore patients were provided with a list of 17 possible alleviating and aggravating factors and they filled out the Danish version of the McGill Pain Questionnaire (MPQ).<sup>17,18</sup> The MPQ consists of 78 pain descriptors categorized into four classes (sensory, affective, evaluative and miscellaneous) and 20 subclasses. The pain descriptors within each subclass is given a rank value, the descriptor implying the least pain is given a value of 1, the next word is given a value of 2, etc. Two parameters were derived from the MPQ: the number of words chosen (NWC) and the pain rating index (PRI(R)). The PRI(R) is the sum of rank values of the words chosen and is calculated for each of the four subclasses (sensory, affective, evaluative and miscellaneous) and

for all words together (total PRI(R)).<sup>17</sup> Two scoring systems have been developed in an attempt to consider the true relative intensity of the pain descriptors.<sup>19,20</sup> For comparison with other studies we have used both these scoring systems. The rank values within the subclasses were therefore adjusted between 0% and 100% as suggested by Deschamps *et al*<sup>19</sup> and converted to weighted-rank values which are equivalent to scale values as suggested by Melzack *et al*.<sup>20</sup> Finally patients were asked a few questions regarding P/D above lesion.

The study was approved by the local Ethical Committee and the Danish Data Protection Agency.

## Statistics

We used  $\chi^2$  methods to compare groups and the Mann-Whitney non-parametric two-sample test to analyze differences in medians. We chose *P*-values <0.05 as level of significance.

## Results

### Demographic and injury-related data

Patient characteristics are summarized in Table 1. Three hundred and thirty patients (response rate: 76%) returned the questionnaire. Age ranged from 19 to 80 years (median 42.6 years). Time since spinal injury ranged from 0.5 to 39 years (median 9.3 years). The majority of patients (>75%) had traumatic spinal cord injury. The skeletal level was cervical in 34%, thoracic in 37%, lumbosacral in 24%, and diffuse or mixed in the remaining. Based on the presence of motor and sensory function below lesion level, the injury was categorized as either complete (48%) or incomplete. Patients were not asked for sensory and/or motor

**Table 1** Patient characteristics

Item	Number of patients (%)
Patients	330
Male	230 (70)
Female	100 (30)
<i>Etiology:</i>	
Traumatic	258 (78)
Vehicle accident	137 (53)
Fall from height	43 (17)
Diving	18 (7)
Sport	9 (3)
Gunshot	7 (3)
Struck by falling objects	7 (3)
Miscellaneous	9 (3)
No information	28 (11)
Atraumatic <sup>a</sup>	72 (22)
<i>Skeletal level:</i>	
Cervical	113 (34)
Thoracic	121 (37)
Lumbosacral	79 (24)
Mixed or diffuse	17 (5)

<sup>a</sup>e.g. infection, stroke, tumor, or congenital myelomeningocele

functions in the lowest sacral segments, and therefore, the classification into complete or incomplete may not be in accordance with the ASIA scales.<sup>21</sup>

*Total patient sample*

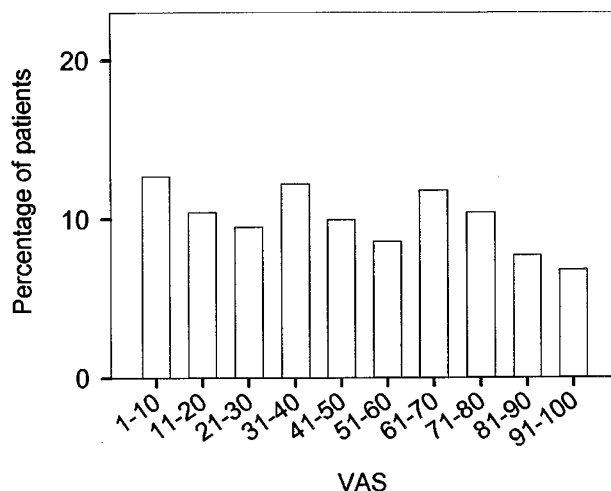
*Prevalence and intensity of pain or dysesthesia* Of the respondents, 77% reported having P/D with a median intensity of 41 on a VAS scale. Sixty-seven per cent of respondents had chronic P/D at or below lesion level with a median VAS of 47. Table 2 shows details of prevalence and intensity of P/D. The intensity of P/D (average over a week) on a VAS among patients with P/D at or below lesion is shown in Figure 1. Ninety-three per cent of patients with P/D at or below lesion reported that the P/D interfered with daily life, 19% of these reported that this interference was 70 or more on a VAS (Figure 2).

Abnormal sensations, which were neither painful nor unpleasant (paresthesia), were reported by 118 (54%) of patients with chronic P/D at or below lesion and by 37 (34%) of patients without P/D.

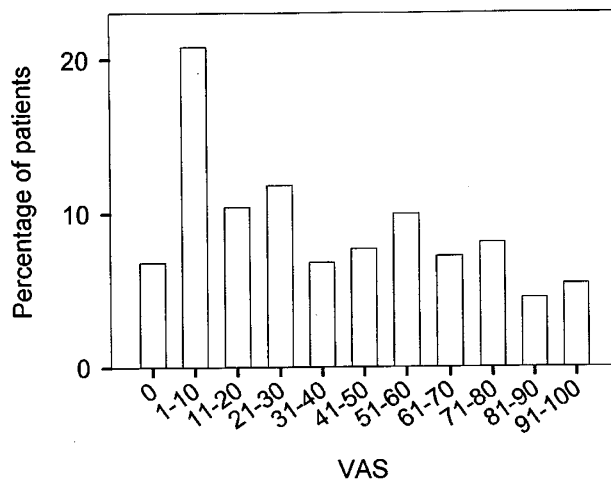
*Patients with P/D at or below lesion level*

*Onset and temporal aspects* In 31% of the 221 patients with P/D at or below lesion, symptoms started immediately after injury in 36% P/D occurred within 6 months, and in 29% P/D was delayed more than 6 months after the spinal cord injury (4% could not recall time of onset). Twenty-one per cent reported decrease of pain intensity since onset, 37% increase of pain and 43% reported that pain intensity had not changed. Thirty-eight per cent reported having P/D constantly, whereas 32% reported having it daily, 22% weekly and 8% less than weekly. One hundred and twenty-four patients (56%) reported intermittent shooting or electric shock-like pain.

*Location and character of P/D* Fifty-five per cent of patients with P/D at or below lesion reported superficial pain, 84% deep pain, 34% abdominal pain, and 29% painful spasms; intensities of each type are shown in Figure 3. Ninety-three per cent



**Figure 1** Pain intensity on a visual analog scale (0-100) among 221 patients with pain or dysesthesia at or below lesion level



**Figure 2** Degree of limitations in daily living on a visual analog scale (0-100) as a result of chronic pain or dysesthesia at or below lesion level

**Table 2** Prevalence and average intensity of P/D in 330 patients with spinal cord injury

	Patients with pain n (%)	Median VAS (25th and 75th percentiles)	Percentage reporting VAS > 70 (%)
Pain and Dysesthesia	255 (77)		
Pain and Dysesthesia above lesion	148 (45)	41 (26:60)	20
Chronic (>3 month) P/D above level <sup>a</sup>	113 (34)		
Chronic (>3 month) P/D at or below level <sup>a</sup>	221 (67)	47 (23:71)	27

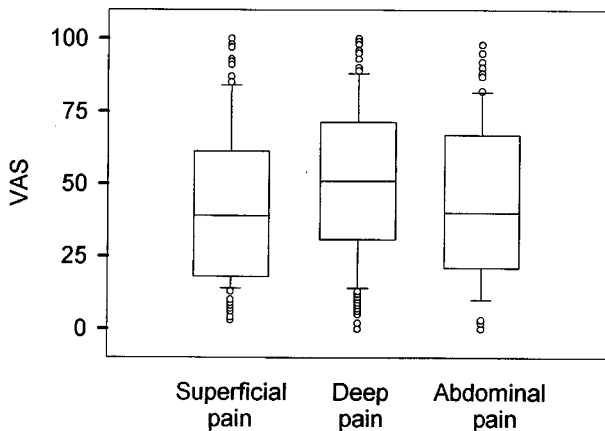
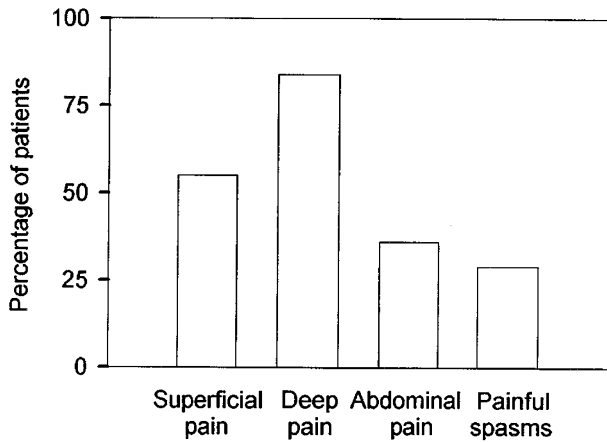
<sup>a</sup>Level refers to level of nervous system disease, 'at or below level' includes two segments above level

reported abnormal unpleasant sensations. Seventy-six per cent reported muscle spasms, of these 38% reported abnormal spasms and 30% experienced change of pain in relation to spasm (in 4% pain improved, in 16% pain worsened and in 10% pain changed character). The most frequent used words to describe P/D are listed in Table 3. Based on pain drawings the location of their P/D was diffuse in 63 patients and patchy in 35. Figure 4 shows examples of pain distribution. Forty-eight per cent reported that P/D could be evoked by non-noxious stimulation of the skin (30% reported pain by touch, 27% by cold and 14% by warm), indicating that allodynia is present in almost half of the patients (Figure 5).

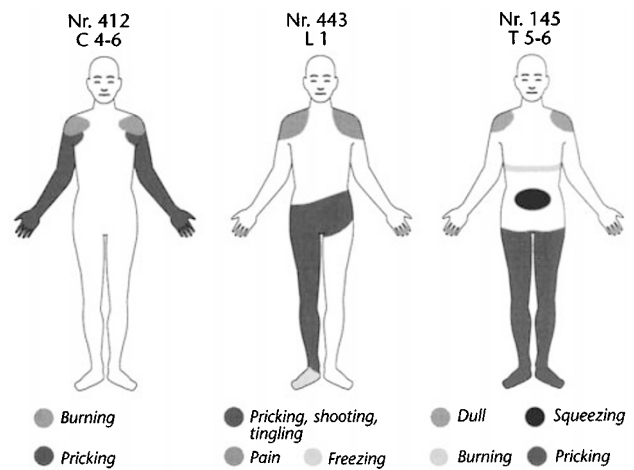
**McGill Pain Questionnaire** The variables derived from the MPQ are summarized in Table 4. Analysis shows that patients with allodynia chose words from the MPQ with a higher total PRI(R) and also a larger total

**Table 3** The most frequent words used to describe pain and dysesthesia (P/D) in patients with P/D at or below lesion level

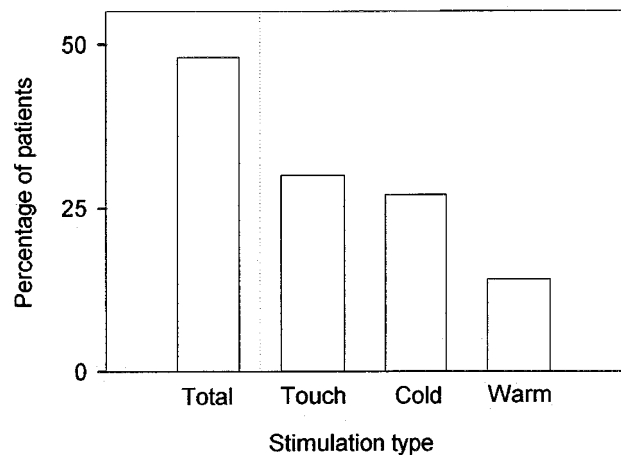
Descriptor	Reported by (%)
Pricking	37
Tingling	36
Shooting	33
Tiring	32
Taut	28
Annoying	28
Burning	23



**Figure 3** Above: Percentage of 221 patients with Pain and Dysesthesia (P/D) at or below lesion level reporting superficial, deep (muscle, bone) and abdominal pain and painful spasms. Below: Intensity of P/D on a visual analog scale (0–100). Boxes represent medians with 25th and 75th percentiles; error bars 10th and 90th percentiles



**Figure 4** Examples of pain distribution. Patient number and skeletal level above each figure, and words chosen by the patient to describe each type of pain/dysesthesia below figures



**Figure 5** Percentage of 221 patients with Pain and Dysesthesia (P/D) at or below lesion level reporting evoked pain or dysesthesia

number of words (NWC) and had a higher average intensity of P/D on a VAS ( $P < 0.02$ , Mann-Whitney test). There were no differences between patients with complete or incomplete injuries or between patients with diffuse or non-diffuse P/D within the MPQ score.

**Influence by external and internal events** The following aggravating factors were most commonly reported: Stress or anxiety (in 49%), tiredness (38%), weather change (30%), and cold (29%). Alleviating factors were rest (51%), physical activity (37%), and alcohol (18%).

**Treatment** Forty-three per cent of patients experiencing P/D at or below lesion took analgesics at the time of survey. The drugs used were simple analgesics (used by 21%), opioids (14%), spasmolytics (14%), non-steroidal anti-inflammatory drugs (6%), and diazepam (4%). Only 4% reported taking antidepressants and 3% taking anticonvulsants for pain relief. Forty-seven per cent reported that they received other non-drug treatment for P/D (most often physiotherapy).

**Table 4** Parameters derived from the McGill Pain Questionnaire

	PRI(R)		PRI in %	Weighted PRI
	Mean	SE		
Rank sum				
Sensory	10.7	7.9	27.1	10.6
Affective	2.7	3.3	19.5	4.6
Evaluative	1.7	1.6	33.9	1.7
Miscellaneous	4.3	4.2	24.7	4.5
Total	19.3	14.7	26.3	21.5
NWC	8.6	5.7		

NWC: total number of words chosen. PRI: the pain rating index. PRI(R) is the sum of rank values; in 'PRI in %' the rank values within the subclasses are adjusted between 0% and 100%<sup>19</sup> and in 'weighted PRI', the rank values for each word is weighted<sup>20</sup>

**Table 5** Relationship between pain and dysesthesia (P/D) at or below lesion level and sex, etiology, and lesion

	Total No.	P/D at or below level			
		No.	%	RR	P-value
<b>Sex</b>					
Male	100	75	75	1.18	0.041
Female	230	146	63		
<b>Etiology</b>					
Traumatic	258	176	68	1.12	0.26
Atraumatic	72	44	61		
<b>Lesion</b>					
Incomplete <sup>a</sup>	170	131	77	1.37	0.0001
Complete <sup>a</sup>	160	90	56		

RR, relative risk. <sup>a</sup>Based on the presence of motor or sensory function below lesion level, see text

**Predictors** Table 5 shows the relationship between P/D and sex, etiology, and completeness of spinal lesion (determined on basis of self reported presence of any muscle function and normal sensibility below lesion). There was an increased risk for P/D in incomplete lesions and men ( $\chi^2$  tests). There was no association between P/D and level of lesion. Seventy-one per cent of patients with lumbosacral lesions described P/D at or below lesion, compared to 65% of patients with thoracic lesions and 64% of patients with cervical lesions. Dichotomized in to patients with lumbosacral lesions and patients with cervical or thoracic lesions, the percentage of patients with P/D at or below lesion in the two groups (71% and 65%) was not statistically different ( $P$  value = 0.30, ( $\chi^2$  test)).

## Discussion

This study showed that chronic pain or dysesthesia at or below lesion level occurs in 67% of patients with spinal cord injury. In 48% of patients mechanical or thermal dysesthesia or allodynia was present, suggesting that neuropathic pain may be a major component of the total pain experience as will be discussed in detail below.

Of the 330 patients answering the questionnaire, 247 returned the first questionnaire sent out and 83 responded on the second questionnaire sent out. To determine whether selection bias had any influence on the present figures we compared the two groups. There was no statistical difference in the two groups with respect to sex, percentage of patients with P/D at or below lesion or percentage with severe P/D (VAS  $\geq 70$ ) ( $P$  values 0.14, 0.49 and 0.54, ( $\chi^2$  test)). The distribution of causes of traumatic spinal cord injury is comparable with results found in a study of new SCI patients admitted to the rehabilitation centre covering the eastern half of Denmark.<sup>22</sup> The only exception was attempted suicide, which was the cause in 8% of traumatic SCI in Eastern Denmark. In our study no patients reported suicide as a cause of injury. Atraumatic lesions were seen in 24% of patients in the eastern study comparable with the 22% seen in our study. These data indicate that our sample with a response rate of 76% is probably representative for the SCI population in Denmark.

The questionnaire focused on P/D at or below lesion level and 67% reported chronic P/D at or below lesion with a median VAS of 47. We determined whether patients had pain or unpleasant sensations at or below lesion by self-report and by drawing. From the present study we cannot determine whether patients not reporting pain or unpleasant sensations at or below lesion in fact do have P/D in this region. The present figures are comparable to a large postal survey carried out by Rose *et al*,<sup>3</sup> who find that 69% of SCI patients reported pain at or below the level of the lesion. In the questionnaire study by Turner and Cardenas,<sup>2</sup> 81% reported a current pain problem, and in a clinical study 66% of SCI patients had chronic



P/D.<sup>8</sup> We found that 27% of patients reporting P/D rated it as severe and interference with daily life was the case for more than 90%. The fraction with severe pain complies with findings in previous studies.<sup>1,23</sup>

Several aspects of the questionnaire suggest that neuropathic pain constituted a large proportion of the pains reported. Patients were not neurologically examined in the present study and self reported allodynia is not a validated test, so it cannot be determined with certainty that those patients with self reported non-noxious evoked pain in fact had neuropathic pain. Nevertheless several factors suggest that this was the case: Firstly, P/D at or below lesion was in an area of sensory deficit. Secondly, most patients (93%) had abnormal sensations suggestive of nervous system lesions. Thirdly, the words most often used to describe P/D (pricking, tingling, shooting, tiring, taut, annoying, burning) are common complaints in neuropathic pain, and 56% of patients reported intermittent shooting or electric shock-like pain, which is also common in neuropathic pain. There may be other aspects of neuropathic pain than allodynia and dysesthesia, so the present 48% proportion with suggested neuropathic pain may be an underestimation. Clinical examination of a sub sample of SCI patients will permit an assessment of the validity of the questionnaire. We are currently doing this as part of another study (Finnerup *et al.* in preparation).

Forty-three per cent of patients experiencing P/D took analgesics at the time of survey. In the study by Turner *et al.*,<sup>2</sup> 60.6% used analgesics, while 38% used analgesics in the study by Nepumoceno *et al.*<sup>1</sup> Surprisingly, patients used spasmolytics for pain relief more commonly than antidepressants or anticonvulsants. It is not clear why only 7% of patients used these drugs, which are considered effective in neuropathic pain.<sup>24–27</sup> It is not known whether these drugs had been tried previously and were stopped because of lack of effect or because of side effects.

Different predictors for developing P/D have been reported and the results are often contradictory. Our study indicated increased risk for P/D and allodynia in patients with incomplete lesions. Similar results have been reported by others,<sup>23,28,29</sup> while Defrin *et al.*<sup>30</sup> found that pain was more intense in complete spinal cord injury patients. Others have not found any association between P/D and extent of injury.<sup>6,8,31,32</sup> We found no relation between level of lesion and pain and no consistent findings concerning this factor have emerged in other studies.<sup>1,2,23</sup>

Values of MPQ subscales in this group were lower than scores reported in three other studies on SCI patients.<sup>28–30</sup> The patients described in the other studies mainly came from pain clinics, and higher scores in the latter may reflect selection towards patients with more severe pain.

The majority of patients with spinal injury reported having pain or unpleasant sensations either constantly

or on a daily basis. Likewise, nearly half of the patients consumed analgesics. Pain and dysesthesia are, evidently, a common and disruptive consequence of spinal cord injury. Therefore, we believe that it warrants further attention for finding effective therapies.

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