

Pain profiles in a community dwelling population following spinal cord injury: a national survey

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Abstract

Context: Up to 60% of patients develop chronic pain following a spinal cord injury (SCI), limited data currently exists on the prevalence and profile of pain post SCI in community dwelling populations.

Study Design: A cross-sectional population survey.

Setting: Primary care.

Participants: Community dwelling adults with SCI.

Methods: Following ethical approval members registered to a national SCI database (n=1,574) were surveyed. The survey included demographic and SCI characteristic items, the International Spinal Cord Injury Pain Basic Data Set (version 1), the Douleur Neuropathique en 4 Questions (interview) and questions relating to health care utilisation. Data were entered into the Statistical Package for the Social Sciences (version 20). Significance was set $P < 0.05$ for between group comparisons.

Results: In total 643 (41%) surveys were returned with 458 (71%) respondents experiencing pain in the previous week. Neuropathic pain (NP) was indicated in 236 (39%) of responses and nociceptive pain in 206 (32%). Common treatments for pain included medications n=347 (76%), massage n=133 (29%) and heat n=115 (25%). Respondents with NP reported higher pain intensities and increased healthcare service utilisation ($P = < 0.001$) when compared to those with nociceptive pain presentations. A higher proportion of females than males reported pain ($P = 0.003$) and NP ($P = 0.001$) and those unemployed presented with greater NP profiles compared with those in education or employment ($P = 0.006$).

Conclusion: Pain, in particular NP post SCI interferes with daily life, increases health service utilisation and remains refractory to current management strategies. Increased availability of multi-disciplinary pain management and further research into management strategies is warranted.

Introduction

The global annual incidence of spinal cord injury (SCI) ranges from 10 to 83 per million population

(1). On survival, patients are faced with many significant secondary health complications (SHCs) including pain, urinary tract infections, pressure ulcers and spasticity (2, 3). A recent European survey of over 1,500 community dwelling adults with SCI, reported pain as the most problematic SHC (4) affecting mood, sleep and quality of life (5, 6). National prevalence rates of pain after SCI range from 64% in Sweden (7), 73% in Denmark (8), 77% in the Netherlands (9), and 80% in the United States (10), with pooled prevalence rates estimated at 61% (11).

Of the established prevalence studies, large disparities exist in the standardisation of SCI pain classification, definition and diagnosis, making it problematic to pool data (11-13). Some studies discussing pain management strategies fail to classify the specific type of SCI pain, making translation of study findings to clinical practice difficult (12, 14). To address this problem, international SCI experts developed recognised methods for standardised reporting which now includes the International Spinal Cord Injury Pain (ISCIP) classification (15) and the International Spinal Cord Injury Basic Pain Data Set (ISCIPDS:B) (16).

The ISCIIP classification categorises SCI pain as nociceptive pain, neuropathic pain (NP) and other pain and includes the International Association for the Study of Pain (IASP) definitions of NP and nociceptive pain (17). Nociceptive pain includes musculoskeletal, visceral and other pain.

Musculoskeletal pain occurs in an area with preserved sensation either above, at, or below the level of injury with a prevalence rate of 49% in SCI (12). Visceral pain arises from the visceral structures and prevalence rates range from 3-5% (18) initially, increasing to 30% in those with long term SCI (19). Other pain includes nociceptive pain which does not fit the former categories. Neuropathic pain, defined as “pain caused by a lesion or disease of the somatosensory system” (17), is reported by convention as at or below SCI level (15). Pooled prevalence rates of NP are estimated at 53% (13). Neuropathic pain below the SCI lesion is a form of deafferentation pain similar to central post-stroke

pain or phantom limb pain, representing cortical reorganisation (20, 21). It also may present above the level of injury where NP unrelated to SCI exists (22). Patients can have mixed pain presentations post injury, with those reporting increased pain severity more likely to report poorer sleep quality, life satisfaction and depression (23, 24). Neuropathic pain is often cited as the most severe pain post SCI (2, 19) and is associated with lower quality of life (QoL) when compared to those presenting without NP (8). It has an extensive and negative impact on physical, psychological and social health and has been described by patients as more debilitating than the SCI itself (25).

Pharmacotherapy is the first line and most commonly used treatment for SCI pain, however, despite medication prescription and usage, pain intensity ratings remain high (9, 14, 26, 27). Patients frequently seek other, non-pharmacological treatments such as acupuncture, massage and transcutaneous electrical nerve stimulation (TENS) (28) which are, to date, unsupported by high quality research trials (29). Whilst national studies have established rates of pain and use of pain management strategies in individuals post SCI (7-9) to the best of our knowledge, none has compared management strategies amongst those with nociceptive pain to those with NP from the same SCI population sample. To provide adequate health care services for patients presenting with SCI pain now, and into the future, profiling their demographics and current management strategies by pain classification is important.

In Ireland, neither prevalence of pain nor pain management strategies and healthcare utilisation have been established. Hence, the current study will establish the prevalence of overall pain and the prevalence as classified by nociceptive and NP in the Irish population using the ISCIP classification (15) and the ISCIPDS:B (16) and determine its impact on pain interference, current healthcare utilisation and management strategies.

Methods

All adult members (>18 years, n=1,574), of Spinal Injuries Ireland (SII) were surveyed. This organisation is the national support group for individuals with SCI. Post SCI and acute management, all patients in Ireland are treated in one national SCI rehabilitation centre and are routinely referred to SII on discharge. The membership of SII comprises the largest national database of individuals with a SCI in Ireland and can be considered representative of the national SCI population.

A questionnaire pack, including an information sheet and stamped self-addressed envelope was mailed to all adult members. An online version of the questionnaire was provided for those with limited upper limb function. Surveys were coded to protect the anonymity of members. The master sheet of codes with corresponding names and addresses was maintained by SII with researchers unable to access these details. Non-respondents from the first mailing round received a reminder and a second survey pack after eight weeks. Non-responders to this mail round received an email reminder via SII four weeks later.

Questionnaire

The questionnaire comprised three sections: i) demographics and SCI characteristics, ii) pain presence or absence, profile and intensity, where present, and iii) healthcare utilisation for pain management, described in detail below as guided by the ISCIP classification (15) and the ISCIPDS:B. (16) (Appendix 3.1). Participants were encouraged to complete the questionnaire whether they had pain or not.

i) Demographics and SCI characteristics

Demographic characteristics included age, sex, mobility status and employment status. Specific SCI characteristics data requested included the year and cause of injury, the neurological level of injury (NLI) where known, the American Spinal Injury Association Impairment Scale (AIS) (30) where

known, and a further question related to the completeness of injury. Tetraplegia was characterised as a NLI reported in the cervical region, NLIs reported below the cervical region were classified as paraplegia (30).

ii) Pain characteristics

a) Pain history

Respondents were asked if they experienced pain in the last seven days, and if so, were instructed to continue with the pain specific section of the questionnaire. Questions investigating pain included the location in relation to the NLI and progression patterns over time.

Those experiencing pain were also asked to select all pain descriptors which matched their worst pain presentation from a list comprising 23 terms from the short-form Mc Gill Pain Questionnaire (SF-MPQ), (31) the ISCIIP classification of SCI pain (15) and items of common NP characteristics from a non-SCI population (32).

b) Definition and classification of neuropathic pain

Neuropathic pain was defined and classified according to the IASP definition of NP (17) and the ISCIIP classification (15). Patients were asked to report descriptors and location of their worst pain, whether it occurred above, at or below the level of SCI.

c) Validated pain questionnaires

International spinal cord injury basic pain data set (ISCIBPDS) (version 1.0) (16)

The dataset, validated for self-reported use in the SCI population (33), contains questions on pain intensity using a numeric rating scale (NRS) (0-10), pain frequency and location. It includes six pain interference items (sleep, mood and activity limitations in the previous week) scored from zero (no interference) to six (extreme interference). Mean scores were calculated as per guidelines (16), an overall score is calculated in addition to two further sub-categories interference with activities, mood and sleep (AMS) and limits in activity and changes in social and recreational activity and family related activity (LSF). Originally designed to investigate respondents' three worst pain problems, to minimise respondent burden, the dataset was shortened to report the worst pain only.

The Douleur Neuropathique en 4 questions (DN4)

The Douleur Neuropathique en 4 Questions (DN4 Interview) (20) determined the presence of NP, and has been validated with high diagnostic accuracy in the SCI population (34). The DN4 interview is validated for postal survey use (35) and has been previously used in the SCI population (8). A score of three or more indicates NP (20, 35).

iii) Healthcare utilisation

To analyse healthcare utilisation, questions relating to pain medications, non-pharmacological treatments including physical agents and exercise therapy usage in the previous six months were included. Common treatments were listed, informed by the guidance of a specialist physiotherapist in SCI rehabilitation (A.C) and the existing literature in the area (14, 29, 36, 37).

Additionally, respondents were asked to indicate the number of health care professionals (HCPs) they had consulted about their pain in the previous six months. Attendance at a multi-disciplinary pain clinic and/or engagement with a pain management programme was recorded.

Analysis

All demographic and questionnaire scores were entered into the Statistical Package for Social Sciences (SPSS) (Version 20), and subsequently cleaned. Participant characteristics were reported using descriptive statistics [mean (standard deviation) (sd), median (range), frequency (percentage)]. Point bi-serial correlation coefficients explored linear relationships between continuous variables in demographic and SCI profiles and the presence of pain and pain type (defined as neuropathic or nociceptive).

A correlation co-efficient $r > 0.3$ was considered to show a moderate or stronger linear relationship between these variables (38). Independent t-tests, Mann Whitney U tests and χ^2 tests explored whether significant differences existed in demographic and SCI profiles (parametric, non-parametric and categorical variables respectively) of those presenting with pain and those who did not report pain and between NP and nociceptive pain profiles. Significance was determined at $P < 0.05$.

Ethics

Ethical approval from the UCD Human Research Ethics Committee (LS-E-14-152-Burke-Lennon on the 24th of November 2014) was granted (Appendix 1.1) and permission to contact the SII database was approved (Appendix 3.2). Authors certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed in conducting this research.

Results

Of the 1,574 posted surveys, 643 (41%) surveys were fully completed and returned. A further 55 surveys were returned but not included in the analysis (n=27 returned to sender due to incorrect address, n=18 incorrectly completed and n=10 returned where SII members were deceased).

Respondent Characteristics

Demographic and SCI characteristics of participants are summarised in (Table 3.1). Data are presented in relation to four groupings; (i) all participants, (ii) those who did not experience pain in the previous seven days, (iii) those with pain who scored less than three on the DN4, indicating a nociceptive pain presentation and (iv) those scoring ≥ 3 on the DN4, indicating NP.

Mean age of respondents was 52 years (sd 14.3; range 18-87), 70% (n=447) were male, and the mean time since injury was 16 years (sd 12.4; range 1-68). Traumatic SCI accounted for 71% (n=456) of the spinal injury mechanisms reported. Neurological levels of injury (NLI) were more frequently distributed across the cervical (34%, n=218) and thoracic regions (34%, n=219). Half of all injuries were reported as incomplete (50%, n=321). Of note three quarters of respondents (76%, n=491) were unsure of their AIS classification (30) and as a result AIS classification is not reported.

International Spinal Cord Injury Basic Pain Data Set (ISCIBPDS)

Pain Prevalence and Characteristics

Pain was commonly reported; 71% (n=458) of respondents experienced pain in the previous seven days. Pain characteristics are summarised in (Table 3.2) as i) respondents who experienced pain ii) those who experienced nociceptive pain and iii) those who experienced NP (as diagnosed by the DN4). The DN4 was not completed in 3% (n=16) of those reporting pain and as such the second two categories in (Table 2) do not equal the first.

Pain Location

Those reporting pain commonly reported multiple pain sites with a mean of 3 (sd 1.3) distinct pain regions noted. When respondents documented the region of their worst pain, the most common areas were upper and/or lower back (50%, n= 231), lower legs or feet (40%, n=181), and neck and shoulders (38%, n=171). Pain was most frequently reported below the neurological level of injury (NLI) (61%, n=277).

Pain Rating

The average pain intensity reported was 6.3 (sd 2.2), and almost half of respondents (47%, n=210) reported severe pain (7-10). For most respondents their pain had remained the same in presentation (49%, n=221), or had deteriorated (19%, n=87) since onset.

The most commonly chosen pain descriptors included aching (40%, n=183), hot or burning (38%, n=174), and tiring or exhausting (35%, n=162).

Pain Interference

The total mean pain interference score was 3 (sd 1.8) out of a worst possible score of six, amongst respondents reporting pain. Increased interference was recorded in the activities, mood and sleep category [Mean 4 (sd 1.5)] compared to the social, recreational and family related activity category [Mean 3 (sd 2.1)] in those experiencing pain. The highest rated interference item amongst those with nociceptive pain was interference with activities [Mean 3 (sd 6.5)], whilst the NP group reported sleep as the most affected item [Mean 4 (sd 1.7)].

Differences in Pain Classifications

When the presence of pain was dichotomised as present or absent in the last seven days and pain type dichotomised as NP or nociceptive pain, no association was noted with age or time since injury and pain presence or pain type. Of note when the presence and type of pain were considered across categorical variables (Table 1), a higher proportion of females reported pain ($\chi^2=8.58$; $P = 0.03$) and NP ($\chi^2=13.10$; $P = 0.001$). While no proportional difference was noted by employment status in pain presentation, a higher proportion of those with NP type pain were currently unemployed ($\chi^2= 10.08$; $P = 0.006$). When SCI characteristics (complete versus incomplete SCI, traumatic versus non-traumatic SCI and paraplegia versus tetraplegia) and mobility status (walkers versus wheelchair users) were considered, no significant proportional differences were found between categories in pain presentation or pain type.

Healthcare Utilisation for Pain Management

Reported healthcare utilisation for pain management in the previous six months is summarised in (Table 2). Three quarters of respondents (76%, $n=347$) reported taking pain medication(s). Just over half of respondents used non-pharmacological treatment options (52%, $n=237$) for pain

management. Respondents visited general practitioners (44%, n=201) and physiotherapists (26%, n=118) most frequently for pain management. Over one quarter of patients (28%, n=128) had attended a pain clinic, and 17% (n=77) had attended a pain management programme.

Neuropathic Pain versus Nociceptive Pain Presentations

The DN4 was completed by 97% (n=442) of respondents who reported pain. Over half of respondents with pain (53%, n=236) were classified as having NP (≥ 3).

Almost two thirds (63%, n=148) of the NP cohort reported their NP below their NLI and 23% (n=53) reported their NP at their NLI. Pain characteristics, healthcare utilisation and pain interference in those with NP versus non-NP profiles are summarised in (Table 3). Statistically significant differences were found between these groups across all items.

Respondents with NP reported higher pain intensities and more days with pain ($P = < 0.001$), more pain problems ($P = 0.002$) and increased contact with healthcare professionals and medication use ($P = < 0.001$) when compared to those reporting nociceptive pain. Neuropathic pain also caused more limitation in social, recreational and family related activities and greater interference with day-to-day activities, mood, and sleep profiles ($P = < 0.001$).

Discussion

This cross-sectional population survey recorded pain prevalence in community dwelling individuals with SCI. The high rates of pain overall (71%), nociceptive pain (32%) and NP (37%) demonstrate how common this secondary health complication (SHC) is, and reflects internationally reported rates (9, 11, 39-41). To our knowledge, this is the first study to explore differences in pain intensity, interference and healthcare/medication utilisation in those with nociceptive and NP post SCI from the same population sample. Results demonstrated higher levels, reaching statistical significance, in

all of these indices among those with NP when compared to nociceptive pain presentations. Of note, despite high usage of both pharmacological and non-pharmacological treatments, pain intensity and interference with daily life remained high for both nociceptive and NP pain presentations.

Research supporting management strategies for SCI pain remains limited. No other study has reported the specific health care setting in which SCI pain is managed to allow comparison with the findings in this survey (8, 9, 42). Our results highlighted low numbers of those with nociceptive (21%) and NP (36%) accessing multi-disciplinary pain clinics. This does not reflect international best practice that advocates multi-disciplinary management approaches for chronic pain (43). Published guidelines for SCI NP also recommended that, due to the unique and individual needs of people with SCI, specialised multi-disciplinary management in SCI-specific rehabilitation facilities should be provided (44, 45). Currently only four published studies in Australia (46), Sweden (47), the Netherlands (48), and most recently Canada (49), have investigated the efficacy of PMPs for SCI reporting, beneficial effects on mood, pain coping and acceptance. However, it is unclear whether these empirically proven programmes are now routinely available in the clinical setting. No dedicated PMP for SCI pain exists in Ireland. Thus, in this current study the low numbers of respondents who had attended programmes, engaged in PMPs not specifically tailored for SCI. No evidence to date supports the efficacy of non-specific PMPs in SCI. The lack of peer support and ability to cater to individual participants' needs, previously highlighted as beneficial in SCI modified PMPs, may potentially impact on outcome (46).

Similar to previous literature, the back (43%) and neck and/or shoulders (37%) were the most commonly cited locations for nociceptive pain (12, 50). At present no international best practice guidelines for the management of nociceptive pain after SCI have been published. Effective management strategies proposed from clinical trials for musculoskeletal pain, include exercise programmes, in addition to postural review and advice on correct wheelchair use (51-54). In the current study less than half of respondents with nociceptive pain reported participating in any form of exercise therapy for pain and documented low interaction with physical therapy services (23%).

Physiotherapeutic interventions including TENS and massage have been shown to provide pain relief after SCI and should be considered as an important adjunct to medication use (42, 54, 55). Although exercise prescription is central to improving cardiovascular fitness and functional outcomes after SCI, (56, 57) further effort by specialists in SCI rehabilitation is required to promote ongoing engagement in regular exercise in the prevention/management of musculoskeletal pain after SCI (51, 54).

Medication was commonly used in nociceptive pain management (72%). All respondents reporting pain documented usage of simple analgesics (acetaminophen and non-steroidal anti-inflammatories (NSAIDs)), similar to previous studies (9, 26, 40, 42). It is noteworthy however that 34% of these respondents with nociceptive pain were using anti-convulsant medications for pain relief despite no indication for their use in nociceptive pain presentations. This may reflect poor diagnostic accuracy in the assessment of pain in individuals with SCI and highlights the need for thorough clinical examination with appropriate classification of pain post SCI using the ISCI-PDS:B (58).

As NP is commonly cited as the most excruciating pain post SCI (9, 19, 40), the increased pain intensity noted by respondents with NP, was anticipated. Pain interference and rates of sleep interference were significantly higher in those with NP when compared with nociceptive pain. Pain intensity has been previously associated with poorer sleep quality after SCI (59). The negative effect of continuous pain on sleep quality after SCI has also been linked with increased levels of anxiety and depression (5, 59). Chronic pain and sleep are noted to have a bidirectional relationship (60, 61), therefore monitoring changes in sleep quality after SCI should be considered a core outcome when assessing the efficacy of pain management interventions.

Anti-convulsants are the first line of treatment for alleviation of SCI NP (62), and were the most frequently documented medication amongst those with NP. Pregabalin was the most commonly used anti-convulsant in the current study, again similar to published data (63). However, despite its

frequent use in line with current best practice, respondents continue to report poor sleep quality and high pain intensity and interference. This highlights a need to investigate multimodal treatment approaches including multi-disciplinary pain management clinics or programmes for NP after SCI (64).

A higher proportion of female respondents reported pain and NP and those who were unemployed reported higher rates of NP. These findings are in keeping with results of a recent cross-sectional survey in SCI from Denmark (8). Women in general are noted to report more pain when compared to men (65) and sex together with age, housing tenure and employment status are noted, in the epidemiological literature, to be predictive of chronic pain presentations in the community (66). While difficult to discern in this current study whether unemployment was a direct consequence of NP, the presence of chronic pain and NP has previously been associated with lower return to work rates post SCI (67, 68). Based on these findings, employment status is recommended to be included in a minimum dataset in pain assessment after SCI.

Currently, limited evidence from interventional studies supports non-pharmacological treatments for SCI pain presentations, with studies in this area reported to have poor methodological quality and small sample sizes (29, 37, 64). However, despite this, non-pharmacological treatments are commonly sought due to the absence of negative side effects (37) and due to the improved pain relief and prolonged effectiveness subjectively reported by users (9, 26, 69). Transcranial direct current stimulation (tDCS), visual illusion and transcutaneous electrical nerve stimulation (TENS) have evidence to support them as third and fourth line therapies after medication recommendations for NP (64). However in this current study, the uptake of TENS (14%) and visual imagery (7%) was low in respondents reporting NP and no reported use of tDCS was documented. Exercise, massage and heat have low quality evidence supporting their efficacy and require further investigation (64). Nonetheless, in the current study massage and heat were again found to be frequently used non-pharmacological agents (26, 28, 42). Compared with medication prescription for NP which is largely in line with evidence-based practice, uses of non-pharmacological agents were more likely to be

patient driven choices. Interpretive phenomenology suggests patient centered treatment choices are more likely to be non-pharmacological agents, and this need to be considered in the co-design of future interventional studies for NP following SCI (25).

This study should be considered in light of the following limitations. The response rate was 41%, however it is in keeping with previously published surveys in this population (9, 26). Authors also acknowledge that as a cross-sectional survey, data collected is self-reported and requires memory recall. Finally although the DN4 interview is a validated measure for postal use, a further clinical examination recording pain history and sensory testing would be optimal to confirm pain presentations (70).

In conclusion this study recorded prevalence rates of pain in people post SCI in Ireland. It established current management strategies and healthcare utilisation amongst those with nociceptive pain and NP after SCI. High pain intensities and the negative implications of ongoing pain (interference with daily life and increased health service utilisation), particularly in NP are evident, and largely refractory to current treatment regimens actively employed by individuals. In line with international best practice guidelines and to allow patient centred care, key areas of focus for the future should include further high quality randomised controlled trials to investigate the effectiveness of pharmacological, non-pharmacological and multimodal interventions on specific SCI pain types. Additionally, increased availability of tailored MDT PMPs for SCI pain and improved referral systems in line with best practice guidelines in the area may improve the ability of patients to self-manage their pain and thus benefit health related quality of life post SCI.

Acknowledgements

The authors thank Spinal Injuries Ireland for their support in conducting this study. The authors also thank Dr. Amanda Carty and Dr. Catriona Cunningham for their advice in the preparation of the questionnaire. An unrestricted educational grant from Pfizer Healthcare Ireland supported the study.

The authors declare no conflict of interest with relation to this manuscript.

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Table 1. Demographics of Respondents

Variable	All (n=643)	No Pain (n=185)	Nociceptive Pain (n=206)	Neuropathic Pain (n=236)
Age [^]				
Mean (SD)	52.11 (14.3)	52.32 (15.5)	53.07 (14.7)	50.64 (12.5)
Not reported N (%)	25 (4%)	5 (3%)	5 (2%)	10 (4%)
Time post SCI [^]				
Mean (SD)	16.71 (12.4)	18.00 (12.4)	18.00 (12.7)	14.00 (11.5)
Not reported N (%)	43 (7%)	13 (7%)	13 (6%)	12 (5%)
Variable N (%)				
Gender ⁺				
Male	447 (70)	145 (78)	149 (72)	145 (61)
Female	175 (27)	36(20)	51 (25)	83 (35)
Not reported	21 (3)	4 (2)	6 (3)	8 (3)
Employment Status ^x				
Working/ In education	211 (33)	71 (38)	75 (36)	59 (25)
Not working	394 (61)	104 (56)	124 (60)	160 (68)
Other	22 (3)	6 (3)	5 (2)	9 (4)
Not reported	16 (3)	4 (2)	2 (1)	8 (3)
Cause of SCI [#]				
<u>Traumatic</u>	456 (71)	140 (76)	148 (72)	155 (66)
Road traffic accident	181 (28)	59 (32)	59 (29)	57 (24)
Fall	168 (26)	58 (31)	41 (20)	63 (27)
Other traumatic SCI	107 (17)	23 (13)	48 (24)	35 (15)
<u>Non-Traumatic</u>	165 (26)	41 (22)	53 (26)	69 (29)
Not reported	22 (3)	4 (2)	5 (2)	12 (5)
Level of SCI [#]				
Paraplegia	295 (46)	78 (42)	92 (45)	119 (50)
Tetraplegia	220 (34)	60 (32)	76 (37)	79 (34)

Cervical SCI	218 (34)	59 (33)	75 (38)	79 (34)
Thoracic SCI	219 (34)	57 (31)	70 (37)	81 (34)
Lumbar SCI	78 (12)	22 (12)	17 (8)	38 (16)
Unsure	78 (12)	26 (14)	27 (13)	23 (10)
Not Reported	50 (8)	21 (11)	11 (5)	15 (6)
Completeness of SCI #				
Complete	172 (27)	52 (28)	59 (29)	57 (24)
Incomplete	321 (50)	90 (49)	102 (50)	123 (52)
Unsure	110 (17)	30 (16)	39 (19)	39 (17)
Not reported	40 (6)	13 (7)	6 (3)	17 (7)
Mobility Status #				
Walks independently	128 (20)	43 (23)	36 (18)	46 (20)
Walks with aid	134 (21)	29 (16)	41 (20)	61 (26)
Wheelchair user	378 (59)	112 (61)	129 (63)	128 (54)
Not reported	3 (1)	1 (0)	0 (0)	1 (0)

^= no moderate to strong relationship with this variable was noted for pain presence or pain type when present by point biserial correlation. += higher proportion of females ($\chi^2= 8.6$; $p=0.03$) report pain and neuropathic pain ($\chi^2 13.1$; $p=0.001$). x= higher proportion of those unemployed presenting with neuropathic pain ($\chi^2=10.1$; $p=0.006$). #= no significant difference in proportions reporting presence of pain or pain type.

Table 2. Pain Characteristics and Healthcare Utilisation

Variable N (%)	Any pain in last 7 days (n=458)	Nociceptive pain (n=206)	Neuropathic Pain (n=236)
Number of pain presentations*			
Mean (SD)	2.73 (1.3)	2.29 (1.1)	3.16 (1.3)
Not reported	64 (14)	23 (11)	32 (14)
Pain locations*			
Head	26 (6)	8 (4),	18 (8)
Neck / shoulders/ arms/ hands	367 (80)	115 (56)	167 (71)
Torso(chest, abdomen, pelvis, genitals)	79 (17)	28 (14)	51 (22)
Back (upper and/or lower back)	231 (50)	89 (43)	137 (58)
Upper legs/ thighs/ hips/ buttocks/ anus	234 (51)	66 (32)	163 (69)
Lower legs/ feet	181 (40)	51 (25)	127 (54)
Not reported	5 (1)	0 (0)	1 (0)
Numeric Rating Scale*			
Mean (SD)	6.28 (2.2)	5.57 (2.2)	6.91 (2.1)
Not reported	15 (3)	5 (2)	4 (2)
Location of pain in relation to SCI			
Above the level of injury	78 (17)	37 (18)	38 (16)
At the level of injury	100 (22)	43 (21)	53 (23)
Below the level of injury	277 (61)	121 (59)	148 (63)
Can't say	34 (7)	15 (7)	19 (8)
Not reported	9 (2)	5 (2)	1 (0)
Top 3 Pain Descriptors			
Aching 183 (40)	Aching 87 (42)	Burning 128 (54)	
Burning 174 (38)	Exhausting 54 (26)	Electric shocks 107 (45)	
Exhausting 162 (35)	Cramping 54 (26)	Exhausting 107 (45)	
Not reported 5 (1)	Not reported 2 (1)	Not reported 1 (0)	
DN4 Score			
Three or more	236 (52)	0 (0)	236 (100)
Less than three	206 (45)	206 (100)	0 (0)
Item not reported	16 (4)	0 (0)	0 (0)
Mean (SD)	2.79 (1.7)	1.31 (0.8)	4.08 (1.2)
Pain Interference (Mean (SD))*			
LSF Interference	3.21 (2.13)	2.82 (2.65)	3.21 (2.13)
AMS Interference	3.47 (1.48)	3.02 (1.45)	3.47 (1.48)

Total Interference	3.38 (1.83)	2.94 (1.81)	3.79 (1.79)
Item not reported (N (%))	15 (3)	7 (3)	2 (1)
Pain Medications in last 6 months			
Yes	347 (76)	149 (72)	188 (80)
No	99 (22)	52 (25)	47 (20)
Not reported	11 (2)	5 (2)	1 (0)
Anti-convulsants	198 (43)	69 (34)	129 (55)
Anti-depressants	25 (6)	4 (2)	21 (9)
Opioids	123 (27)	41 (20)	81 (34)
Benzodiazepines	9 (2)	2 (1)	7 (3)
NSAIDs	146 (32)	51 (25)	91 (39)
Acetaminophen	203 (44)	80 (39)	116 (49)
Topical agents	35 (8)	11 (5)	22 (9)
Total number used (Mean (SD))	2.01 (1.8)	1.56 (1.5)	2.43 (1.9)
Pain Treatments			
Yes	237 (52)	97 (47)	133 (56)
No	205 (45)	102 (50)	99 (42)
Not reported	15 (3)	7 (3)	4 (2)
Massage	133 (29)	51 (25)	153 (65)
CBT	14 (3)	2 (1)	12 (5)
Spinal cord stimulator	12 (3)	3 (2)	9 (4)
NMES	17 (4)	7 (3)	10 (4)
TENS	43 (9)	9 (4)	33 (14)
Cold packs	34 (7)	11 (5)	23 (10)
Hot packs	115 (25)	49 (24)	63 (27)
Pain Management Programme	77 (17)	21 (10)	56 (24)
Visual imagery	18 (4)	1 (1)	17 (7)
Acupuncture	41 (9)	13 (6)	27 (11)
Hypnosis	4 (1)	7 (3)	4 (2)
Relaxation	75 (16)	23 (11)	53 (23)
Total number used (Mean (SD))	1.22 (1.5)	0.91 (1.2)	1.50 (1.7)
Top Three Choices of Physical Activity for Pain Management			
	Stretching 224 (49) Standing 179 (39) Walking 145 (32)	Stretching 89 (43) Standing 57 (28) Cycling 53 (26)	Stretching 132 (60) Standing 116 (49) Walking 89 (38)
Not reported	8 (2)	3 (2)	2 (1)
Total number used (Mean (SD))	1.85 (1.5)	1.51 (1.3)	2.15 (1.6)
HCP visited in last 6 months			
Yes	268 (59)	108 (52)	153 (65)

No	178 (29)	94 (46)	80 (40)
Not reported	11 (2)	4 (2)	3 (1)
Top Three HCPs Seen for Pain			
1. General Practitioner	201 (44)	71 (35)	125 (53)
2. Physiotherapist	118 (26)	48 (23)	69 (29)
3. Hospital Doctor	98 (21)	36 (18)	60 (25)
Total HCPs seen (Mean (SD))	1.24 (1.3)	0.99 (1.1)	1.46 (1.4)
Attendance at a pain clinic			
Yes	128 (28)	44 (21)	84 (36)
No	320 (70)	160 (78)	149 (63)
Not reported	9 (2)	2 (1)	3 (1)

AMS; interference with activities, mood and sleep, DN4; Douleur Neuropathique en 4 Questions.

LSF; Limits in activity and changes in social and recreational activity and family related activity, SCI; spinal cord injury. *Items from the International Spinal Cord Injury Pain Basic Data Set (version 1).

Table 3 Comparison of Nociceptive Pain and Neuropathic Pain Presentations

Category		Nociceptive Pain		Neuropathic pain		
Parametric Test	N	Mean (SD)	N	Mean (SD)	t statistic	P value
Numeric Rating Scale	201	5.57 (2.2)	232	6.91 (2.1)	6.538	<0.001
No. of pain presentations	183	2.29 (1.1)	204	3.16 (1.3)	6.924	0.002
Days with pain past week.	196	4.44 (2.4)	225	5.12 (2.1)	3.03	<0.001
No. of treatments used in the past 6 months.						
Medications	201	1.56 (1.5)	235	2.43 (1.9)	5.21	<0.001
Non-pharmacological Rx	199	0.91 (1.2)	232	1.50 (1.7)	4.094	<0.001
Exercise therapies	203	1.51 (1.3)	234	2.15 (1.6)	4.524	0.003
No. of HCPs seen in past 6 months.	202	0.99 (1.1)	233	1.46 (1.4)	3.738	<0.001
Non-Parametric Test	N	Median (Range)	N	Median (Range)	U statistic	P value
Pain Interference						
LSF Interference	197	2.33 (1-33)	234	3.67 (0-6)	15547	<0.001
AMS Interference	234	3.00 (1-6)	232	4.00 (1-6)	15115	<0.001
Total Interference	199	2.67 (1-19)	234	3.83 (0-21.2)	15451	<0.001

AMS; interference with activities, mood and sleep, HCPs; healthcare professionals, LSF; Limits in activity and changes in social and recreational activity and family related activity, No; number, N; number, t; Independent t-test, Rx; treatments, U; Mann Whitney U test.