

Chronic Pain Associated With Spinal Cord Injuries: A Community Survey

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ABSTRACT. Turner JA, Cardenas DD, Warme CA, McClellan CB. Chronic pain associated with spinal cord injuries: a community survey. *Arch Phys Med Rehabil* 2001;82:501-8.

Objective: To investigate, in a community sample of people with spinal cord injuries (SCIs), chronic pain prevalence, associated factors, sites, characteristics, interference with daily functioning, treatments received, and treatment helpfulness.

Design: Postal survey.

Setting: Community.

Participants: Three hundred eighty-four individuals aged over 17 years with SCIs.

Main Outcome Measures: Chronic Pain Grade questionnaire, Short-Form McGill Pain Questionnaire, pain sites, and treatments.

Results: Current pain was reported by 79% of respondents and was significantly more common in less highly educated persons, and individuals not employed or in school. Most common locations of current pain were the back (61%), hips and buttocks (61%), and legs and feet (58%). Upper extremity pain was experienced by 76% after the injury and by 69% currently. Individuals with tetraplegia were significantly more likely to have neck and shoulder pain than were those with paraplegia. On average, respondents reported a high level of pain intensity and a moderate level of pain interference with activities, and rated treatments received for pain as being only somewhat helpful.

Conclusion: Most individuals with SCI experience chronic pain that is refractory to medical treatment. Further research is needed to delineate the causes of, and optimal treatments for, the various pain problems in this population.

Key Words: Chronic pain; Rehabilitation; Spinal cord injuries.

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THERE IS EVIDENCE that pain is a significant problem among people who have experienced a spinal cord injury (SCI), often starting within the first 6 months¹⁻⁴ after injury and

continuing throughout life.⁵ These pain conditions are notoriously unresponsive to treatment.⁶ In a needs assessment survey of members of the Paralyzed Veterans of America, chronic pain was among the most frequently identified medical concerns, with 45% of the sample indicating that they needed help with this problem.⁷ Respondents to the survey also reported that chronic pain interfered significantly with activities of daily living (ADLs) (20% indicated it interfered a great deal, 30% indicated it interfered "a fair amount"). Interference with ADLs caused by chronic pain was comparable to that caused by spasticity. Other studies have also documented high rates of pain interference with daily function among patients with SCI.^{2,3,5,8,9} For example, in a recent study, 67% of patients with SCI and chronic pain reported that pain had some effect on their daily life, and 23% indicated that their daily routines were markedly or almost completely limited by pain.²

Although chronic pain is an important problem, the literature on its clinical and functional significance among SCI patients is limited⁵ and there is surprisingly little certainty about its prevalence, causes, characteristics, and optimal treatments. For example, estimates of the prevalence of chronic pain in people with SCI have ranged from 11% to 94%^{9,10} (18%–63% for severe, disabling pain^{5,10,11}). Only a few studies have examined the prevalence of pain in specific body sites among SCI individuals.^{1,12}

Information about factors associated with pain and SCI may point to possible causes and treatments. Unfortunately, the literature yields few consistent findings, other than that there do not appear to be gender differences in pain prevalence among individuals with SCI.^{1,13-15} Three studies¹³⁻¹⁵ found pain to be associated with older age, but in a previous investigation¹ we found no significant association between pain and age or time since injury. Most studies have not found significant differences in pain between people with tetraplegia versus paraplegia, or incomplete versus complete SCIs.^{1,2,4,14-17} However, a study¹³ in Turkey found that pain was more common in persons with paraplegia than with tetraplegia and among patients with incomplete versus complete lesions.

Findings about associations between pain and the neurologic level of the SCI have also been contradictory. In an early study,³ pain seemed to be more severe and to interfere more with ADLs among patients with lumbosacral lesions. A later study¹⁵ reported that chronic pain was more frequent among patients with cervical and lumbar (compared with thoracic) injuries, but failed to report whether these differences were statistically significant. In contrast, several studies¹⁸⁻²⁰ observed lower rates of pain among patients with cervical injuries, compared with thoracic and cauda equina injuries, and 2 studies^{14,16} found no relation between pain and level of injury.

There is evidence that pain may be more common among persons whose SCIs were caused by gunshot wounds. Patients with SCI who were classified as having disabling dysesthetic pain (also called central or spinal cord pain, defined as diffuse pain below the level of injury) were more likely than other SCI patients to have been injured by gunshot.⁹ A subsequent study²¹ found that patients with SCI resulting from gunshots reported more pain than did patients whose injuries were from other

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causes. Similarly, we found in a previous study¹ that community residents with SCI from gunshot wounds were significantly more likely to report current pain than were those with SCI from other causes.

Information on qualitative characteristics of pain in individuals with SCI may also point to possible causes and categories of pain. Several investigations have assessed pain descriptors in this population, again with disparate findings. In a small study⁹ of patients with SCI classified as having disabling dysesthetic pain, the McGill Pain Questionnaire (MPQ)²² words chosen most frequently to describe pain were cutting (63%), burning (58%), piercing (47%), radiating (47%), tight (37%), cruel (37%), and nagging (37%). No association was found between MPQ scores and the clinical characteristics that were assessed (paraplegia, injury completeness, spasticity, gunshot wound cause, surgical spinal stabilization). In a study³ of SCI outpatients, more than half of those with pain described it as burning and/or stinging, and 25% described it as pulling or pressing. The words cramping, stabbing, and tingling/numbness were each chosen by 20% of persons reporting pain. Patients in rehabilitation after SCI most commonly chose the words burning (28%), aching (21%), cramping (14%), throbbing (14%), and shooting (13%) to describe their pain.¹¹ We previously found aching, hot-burning, and sharp to be the words most frequently chosen by community residents with SCI to describe their pain.¹ In sum, burning, cramping, and aching appear to be the words most consistently used by substantial minorities of individuals with SCI to describe their pain, but there is substantial variation across studies.

Individuals with chronic pain who have an SCI may be less likely than those who do not to use affective words to describe the pain. Compared with patients at a chronic pain clinic, patients with SCI and chronic pain rarely endorsed affective words (eg, terrifying, sickening) on the MPQ.¹⁷ In our previous study,¹ we found that the descriptors most frequently chosen on the Short-Form MPQ (SF-MPQ) to describe pain were all sensory subscale words. A large study² in Germany found that the words most commonly used by patients with SCI to describe pain were also sensory rather than affective (eg, burning, tingling, stabbing, tight/tense).

It is clear that there are substantial gaps in the literature and that many basic questions about chronic pain problems in individuals with SCI remain unanswered. This study surveyed community residents with SCI to investigate: (1) the prevalence of chronic pain problems; (2) characteristics associated with the presence and intensity of chronic pain; (3) chronic pain sites and association with level of injury; (4) pain intensity and interference with daily functioning; (5) qualitative aspects of pain; and (6) treatments received for pain and their perceived helpfulness. Because previous studies have reported conflicting findings, we had no specific hypotheses, but rather conducted exploratory analyses to test for differences on the pain measures in different levels of injury groups. We also examined the associations between pain measures and respondent demographic and injury-related characteristics. To obtain a sample representative of the population of Pacific Northwest community residents with SCI, study participants were recruited primarily from the community, rather than from a particular clinic or hospital.

METHODS

To obtain a sample representative of Pacific Northwest adults with SCI, study participants were solicited primarily through the mailing list of the newsletter of the Northwest Regional Spinal Cord Injury System (NWRSCIS). The NWRSCIS is a comprehensive, interdisciplinary service delivery model system

funded in part by the National Institute on Disability and Rehabilitation Research.²³ In addition, notices about the study were placed in Seattle-area clinics serving patients with SCI and in the NWRSCIS newsletter. Questionnaires were mailed to 701 individuals who were selected randomly from the newsletter's mailing list, or who had called in response to a notice. Each questionnaire was accompanied by a consent form and a cover letter inviting adults with SCI (age 18 and older) to participate in the study and informing them that they would be paid \$20 for completing and returning the consent form and questionnaire. The study questionnaire and protocol were approved by the University of Washington Human Subjects Review Committee.

Study participants were asked questions about their sociodemographic characteristics and the pain experienced since the injury. Respondents with current pain were asked to indicate whether they had received each of 14 treatments for pain, and to rate the helpfulness of each treatment they received on a scale from 1 to 5, with 1 being "not all helpful" and 5 being "extremely helpful." Respondents with current pain were also asked to indicate the sites of their pain.

The survey questionnaire also included the 7-item Chronic Pain Grade questionnaire, which assesses pain intensity and interference with normal daily activities.²⁴ The questionnaire has shown validity and high internal consistency, and was used in previous mail survey instruments.²⁴⁻²⁷ Characteristic pain intensity was calculated by averaging 0 to 10 ratings of current pain, worst pain in the past 3 months, and average pain in the past 3 months, then multiplying by 10. Pain-related disability scores were calculated by averaging 0 to 10 ratings of pain interference with daily, social, and work/housework activities in the past 3 months, then multiplying by 10.^{24,28} The Chronic Pain Grade questionnaire classifies individuals with pain into 4 categories: I = low pain intensity and low pain-related disability; II = high pain intensity and low pain-related disability; III = moderate pain-related disability; and IV = severe pain-related disability. We added 2 items to the questionnaire to assess least pain in the past 3 months on a 0 to 10 scale and number of days that pain was experienced in the past 3 months.

The questionnaire also included the SF-MPQ,²⁹ which consists of 15 pain descriptors rated by the respondent on a scale ranging from 0 (none) to 3 (severe). The SF-MPQ correlates highly with the sensory, affective, and total scores of the original MPQ, and is sensitive to the effects of treatments for pain.²⁹ We added 8 descriptors (stinging, cutting, piercing, radiating, tight, nagging, squeezing, tingling) from the original MPQ that were found previously to be used frequently to describe pain associated with SCI,⁹ and 1 additional descriptor, "shocking." These words were included for descriptive purposes and were not used in the scoring of the SF-MPQ.

RESULTS

Response Rate

Of the 701 questionnaires mailed, 518 (74%) were returned. Of that number, 59 were returned because the addressee was no longer at that address, 27 were returned with a note indicating that the addressee was deceased, 18 were returned with information indicating that the addressee was not eligible for the study (eg, under the age of 18, did not have a SCI), and 30 were returned with a note indicating that the addressee declined to participate. Completed questionnaires and consent forms were received from 384 people with SCI age 18 and older (64% of the mailed questionnaires, excluding those mailed to addressees who were deceased, ineligible for the study, or were no longer at that address).

Respondent Characteristics

Sociodemographic and other characteristics of the 384 respondents are shown in table 1. To assess the extent to which this sample is representative of the Pacific Northwest population of persons with SCI, comparisons were made with the 961 people registered in the NWRSCIS database. In our sample, there was a lower proportion of men (73.7% vs 79%); comparable proportions of whites (84.4% vs 83%), Hispanics (2.9% vs 3.2%), and Asians and Pacific Islanders (2.9% vs 2.8%); a slightly higher proportion of Native Americans/Alaskan Natives (4.2% vs 2.1%); and a slightly lower proportion of African Americans (2.3% vs 4.9%).

The mean age of the survey respondents was 42.5 years. There was a wide range in number of years since SCI (range, 0.7–53.8yr; mean, 12.2yr). A minority were married (36.7%) or living with a partner (8.3%). Most had completed high school. Thirty-eight percent were employed and 9.9% were in school

Table 1: Respondent Characteristics (n = 384)

Gender (%) (M/F)	73.7/26.3
Age (yr) (mean \pm SD)	42.5 \pm 13.8 (range, 18–84)
Years since SCI (mean \pm SD)	12.2 \pm 9.67 (range, 0.7–53.8)
Ethnic group (%)	
White	84.4
Native American	4.2
Black	2.3
Hispanic	2.9
Asian/Pacific Islander	2.9
Marital status (%)	
Married	36.7
Never married	32.6
Divorced	18.2
Living with partner	8.3
Widowed	2.9
Separated	1.3
Education (%) (highest level)	
Grade 11 or lower	6.8
High school/GED	12.8
Vocational/technical/business school	9.8
Some college	34.6
College graduate	22.7
Graduate/professional school	13.3
Employment (%)	
Employed full-time	24.2
Employed part-time	13.8
School/vocational training	9.9
Retired	14.8
Homemaker	4.4
Unemployed	55
Cause of SCI (%)	
Motor vehicle crash	46.6
Fall	15.4
Sports injury	4.9
Diving	7.8
Gunshot wound	5.5
Other	19.8
Level of injury (%)	
C1–4 (high tetraplegia)	15.3
C5–8 (low tetraplegia)	35.8
T1–5 (high paraplegia)	11.0
T6–12 (paraplegia)	29.0
L1–S4/5 (low paraplegia)	8.9

or vocational training. The most common cause of the SCI was a motor vehicle crash (46.6%). Approximately half were tetraplegics and half were paraplegics. The SCI was reported to be complete in 37.2% and incomplete in 48.2%; 14.6% indicated that they did not know whether their injury was complete or incomplete.

Pain Prevalence and Associated Respondent Characteristics

Among the 384 respondents, 315 (82%) indicated that they had persistent, bothersome pain at some time after discharge from initial inpatient rehabilitation and 304 (79.2%) indicated that they were currently experiencing pain. Respondents who had current pain were compared with those who did not, by using *t* tests and chi-square tests on age, gender, education, employment status, racial group (white vs nonwhite), marital status (married or living with partner vs other), years since injury, cause of injury (gunshot wound vs other), level of injury, and complete versus incomplete injury. Significant differences were found only on education and employment status. Respondents who completed college, as compared with less educated respondents, were significantly less likely to have a current pain problem (71.7% vs 83.8%; $\chi^2 = 7.21, p = .007$). Respondents who were employed or in school or vocational training were also significantly less likely to have a current pain problem, compared with those who were not working or in school (74.3% vs 83.7%; $\chi^2 = 5.10, p = .02$). There was a trend for the 21 respondents with SCI caused by gunshot wounds to be more likely to have a current pain problem compared with those whose injury was from other causes (95.2% vs 78.2%; $\chi^2 = 3.48, p = .06$). The next sections describe the findings for the 304 respondents who reported a current pain problem.

Sites of Pain

Pain location relative to level of injury. Most (83.2%) respondents with current pain experienced pain below the level of injury, and only 22% of these indicated that this pain was unilateral. Pain above the level of injury was reported by 41% (24% unilateral). Approximately 50% experienced pain at the level of injury (24% unilateral). (Percentages sum to more than 100% because most respondents reported pain in more than 1 area.) Table 2 shows the number of respondents who reported pain above, below, and at their level of injury, grouped by level of injury. There was a significant difference in proportions of respondents with pain at their level of injury across the different categories of levels of injury. Rates of pain at the level of injury were significantly lower ($p < .05$) in those with C1–4 injuries than in those with L1–S4/5 injuries, and in those with C5–8 injuries as compared with those with upper cervical, thoracic, and lumbosacral injuries.

Pain locations in the body. Table 2 also shows the number of respondents, grouped by injury level, who reported pain in specific body locations. The most common sites of pain in the body were the back, hips, and buttocks (61% each), and then the legs and feet (58%). Among respondents with back pain, 67% indicated that it was made worse by activity and 72% by position. Upper extremity (shoulder, arm, hand) pain problems were also common. Among respondents with current pain, 75.6% reported that they had experienced upper extremity pain after their SCI, and 69.1% reported that they were currently experiencing such pain.

Location of pain by level of injury. There were significant ($p < .05$) differences in rates of neck, shoulder, arm or hand, and hip or buttock pain across different level of injury groups

Table 2: Differences in Pain Sites Among Respondents With Different Injury Levels

Site of Pain	Level of Injury					Total sample (n = 294)	χ^2
	C1-4 (n = 48)	C5-8 (n = 102)	T1-5 (n = 34)	T6-12 (n = 85)	L1-S4/5 (n = 25)		
Pain Location Relative to Injury Level							
Above	16	37	16	37	8	114	3.14
Below	40	89	27	66	23	245	4.84
At	23	31	21	45	18	138	21.77*
Pain location in Body							
Neck	25	40	12	15	5	97	20.74*
Shoulder	32	55	14	25	6	132	25.40*
Arm/hand	22	55	13	19	5	114	24.24*
Back	25	57	24	53	19	178	6.42
Hip/buttock	21	61	22	54	21	179	12.04†
Abdomen	20	35	9	29	9	102	2.08
Leg/foot	22	63	20	47	18	170	5.78

NOTE. Frequencies shown reflect number of respondents who reported pain in each location. Most respondents reported pain in more than 1 site. Value $n = 294$ because 10 respondents did not know their level of injury.

* $p < .001$.

† $p < .05$.

(table 2). For the pain locations in which a significant overall difference was found, additional analyses were performed to determine which level of injury groups differed significantly. Neck pain was significantly more frequent in persons with cervical and T1-5 injuries than in those with T6-12 injuries. Neck pain was also significantly more frequent in individuals with C1-4 injuries than in those with L1-S4/5 injuries. Rates of shoulder pain were significantly higher in the C1-4 group than in the thoracic and lumbosacral groups, and significantly higher in the C5-8 group than in the T6-12 and L1-S4/5 groups. Arm or hand pain was significantly more frequent in persons with C1-4 than in those with T6-12 and L1-S4/5 injuries; it was also significantly more frequent in those with C5-8 injuries than in those with T6-12 and L1-S4/5 injuries. Hip or buttock pain was significantly more common in the T6-12 and L1-S4/5 groups than in the C1-4 group, and more common in the L1-S4/5 than in the C5-8 group.

Pain Intensity and Interference With Activities

Table 3 shows the Chronic Pain Grade questionnaire²⁴ ratings of pain intensity and interference with activities made by the respondents reporting a current pain problem. On average, these respondents reported a high level of pain intensity (mean characteristic pain intensity \pm standard deviation, 59.36 ± 20.96 ; scale range, 0-100) and moderate pain-related disability (average of 3 pain interference with activities ratings, 39.76 ± 29.82 ; scale range, 0-100). However, there was wide variation in pain intensity and activity interference. There were no significant differences in characteristic pain or pain-related disability scores between men and women, between persons with tetraplegia and paraplegia, between individuals with complete versus incomplete injuries, or between persons with injuries from gunshot wounds versus other causes. Respondents reported that in the past 90 days, they had experienced pain an average of 74.68 days and were kept from their usual activities because of that pain an average of 16.06 days.

Von Korff et al²⁴ have suggested that characteristic pain scores of 50 or greater should be considered high intensity pain; they found that scores that high were usually associated with pain interference with activities. In this sample of individuals with SCI and current pain problems, 71.4% had characteristic pain scores ≥ 50 and 35.9% had scores ≥ 70 .

Pain-related disability scores were ≥ 30 in 60.3%, ≥ 50 in 41.1%, and 70+ in 19.9%. On the Chronic Pain Grade scale, 26.3% of respondents with pain were classified as grade I (low pain intensity, low pain-related disability), 34.0% as grade II (high pain intensity, low pain-related disability), 17.7% as grade III (moderate pain-related disability), and 22.0% as grade IV (severe pain-related disability).

Qualitative Aspects of Pain

Table 3 also shows respondents' scores on the SF-MPQ.²⁹ Respondents with SCI from gunshot wounds did not differ significantly on the SF-MPQ from those with injuries from other causes. There was a trend toward higher sensory scale scores in persons with incomplete injuries than in individuals

Table 3: Pain Intensity, Frequency, Interference With Activities, and Descriptors

Measure	Mean \pm SD
Pain Intensity and Frequency	
Current pain (CPG)	5.01 \pm 2.40
Average pain, past 3mo (CPG)	5.33 \pm 2.25
Worst pain, past 3mo (CPG)	7.45 \pm 2.37
Characteristic pain intensity (CPG)	59.36 \pm 20.96
Least pain, past 3mo	3.00 \pm 2.49
Number of days with pain, past 3mo	74.68 \pm 27.72
Pain-Related Activity Interference (CPG)	
Pain interference with daily activities, past 3mo	4.01 \pm 2.99
Pain interference with recreational/social/family activities, past 3mo	3.91 \pm 3.19
Pain interference with work/housework, past 3mo	3.96 \pm 3.31
Pain-related disability score	39.76 \pm 29.82
Number of days kept from usual activities because of pain, past 3mo	16.06 \pm 28.70
Pain Descriptors	
SF-MPQ affective scale	2.77 \pm 3.08
SF-MPQ sensory scale	11.14 \pm 7.73
SF-MPQ total	13.90 \pm 10.14

Abbreviations: CPG, Chronic Pain Grade (questionnaire).

with complete injuries (mean, 11.96 ± 7.64 vs 10.25 ± 7.54 , $t = -1.79$, $p < .08$); these groups, however, did not differ on the affective scale. Figure 1 shows, for each of the SF-MPQ and additional pain descriptors, the mean rating (0–3 scale) of all respondents with pain and the proportion who indicated that the word described their pain (ie, score of 1–3). The SF-MPQ words most frequently used to describe pain (chosen by more than half of respondents) were aching (77.3%), hot-burning (61.2%), tiring-exhausting (59.2%), throbbing (55.0%), and sharp (53.9%). In addition, more than half of the respondents endorsed several words contained in the original MPQ but not the SF-MPQ: nagging (69.1%), tingling (58.6%), and tight (55.8%).

Treatments for Pain

The data for pain treatments are summarized in table 4. The treatments most frequently reported were physical therapy, nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, opioids, baclofen, and diazepam. On average, these treatments were viewed as being only somewhat helpful. The exception was an implanted morphine pump, with a mean helpfulness rating of 4.00, although only 9 respondents had this device. Many respondents wrote in treatments they had used for pain that were not included in the list. Of these, the most frequently mentioned were massage therapy ($n = 16$, mean helpfulness, 3.63), gabapentin ($n = 14$, mean helpfulness, 3.21), acupuncture ($n = 11$, mean helpfulness, 3.09), transcutaneous electric nerve stimulation ($n = 9$, mean helpfulness, 2.56), and marijuana ($n = 8$, mean helpfulness, 4.38).

Table 4: Past Treatments for Pain and Helpfulness

Treatment	% who had it	Helpfulness*
		Mean \pm SD
Physical therapy	66.7	2.88 \pm 1.27
NSAIDs	65.7	2.31 \pm 1.23
Acetaminophen	57.8	2.07 \pm 1.12
Opioid	48.5	3.08 \pm 1.27
Baclofen	44.6	2.35 \pm 1.41
Diazepam	40.6	2.78 \pm 1.45
Amitriptyline	25.4	2.09 \pm 1.25
Biofeedback/relaxation	22.1	2.25 \pm 1.27
Counseling/psychotherapy	21.1	1.94 \pm 1.18
Nerve blocks	16.8	2.33 \pm 1.42
Spinal cord stimulator	11.6	1.69 \pm 0.99
Carbamazepine	11.2	2.21 \pm 1.47
Implanted morphine pump	3.0	4.00 \pm 1.50
Mexiletine	2.0	2.00 \pm 1.26

* 1 = not at all helpful; 5 = extremely helpful.

DISCUSSION

Of the 384 respondents to this survey, 82% reported having persistent, bothersome pain after being discharged from initial inpatient rehabilitation, and 79% reported having current pain. The prevalence of current pain in this sample was similar to that in our earlier survey (81%),¹ to that in another community survey (75%),³⁰ and to that found 2 decades ago in a survey of former inpatients in another regional SCI system (77%).³¹ Differences in prevalence rates in other studies might result from different case definition criteria (eg, thresholds for pain duration or severity) and to differences in study samples (eg, inpatients vs community residents). Among respondents with pain in this sample, 71% reported a high level of pain intensity (as defined by characteristic pain intensity scores ≥ 50 on the Chronic Pain Grade questionnaire) and 36% rated their pain as severe (scores ≥ 70).

The prevalence of pain problems in individuals with SCI raises the question of why some SCI individuals do not have chronic pain after their injury. It could prove informative to study this group in more depth to determine what medical, demographic, and psychosocial factors protect against the development of persistent, bothersome pain. This study failed to find an association between current pain and paraplegia versus tetraplegia, level of injury, gender, age at time of injury, age at time of survey, or length of time since injury. However, pain was significantly less common among respondents who were more highly educated and among those who were working or in school. It is unknown whether pain prevented some respondents from working or attending school, or whether working or being in school may in some way buffer individuals with SCI from a chronic pain problem. Further research is needed to replicate these findings and to explore possible reasons.

Few consistent findings about factors associated with pain have emerged from previous studies. However, 3 studies found pain to be more prevalent in individuals with SCIs resulting from gunshot wounds than from other causes.^{1,9,21} In this study, there was a trend ($p = .06$) toward a higher rate of pain in respondents with SCI from gunshot wounds; all but 1 reported a current pain problem. The reason for the higher prevalence of pain remains speculative.

An important finding in this study is that many individuals with SCI frequently have pain that interferes with daily activities. On average, those with pain experienced it on 75 days in

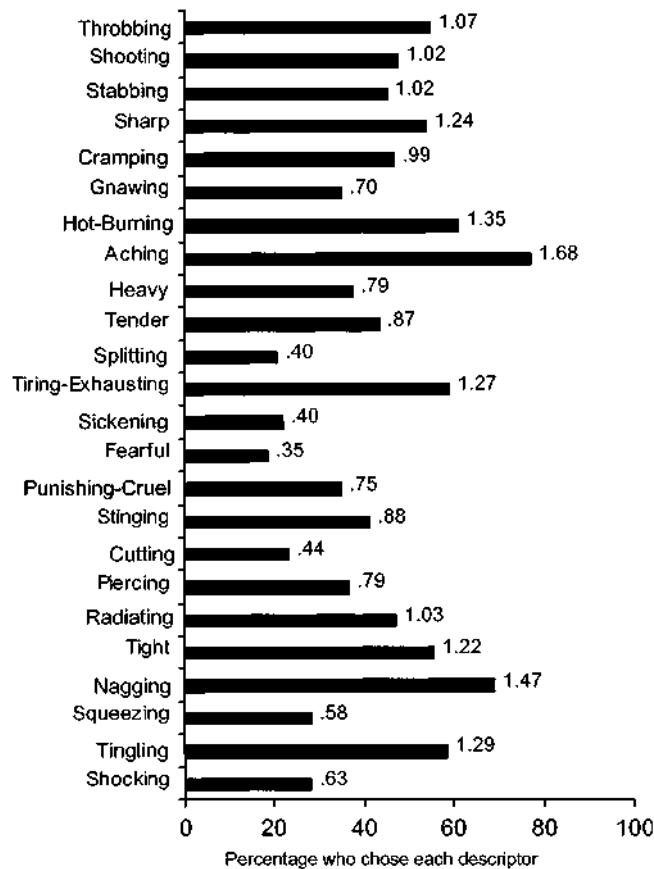


Fig 1. SF-MPQ and other qualitative descriptors of pain: mean ratings (0–3 scale) of respondents with pain.

the past 3 months and were kept from usual activities because of pain on 16 days of the past 3 months. Ratings of pain interference with daily activities; recreational, social, or family activities; and work activities ranged from 3.4 to 4 on 0 to 10 scales, on average. Pain-related disability scores²⁴ were 50 or higher on a 0 to 100 scale in 41%, and 70 or higher in approximately 20%, of respondents with a current pain problem. These findings are consistent with those of previous studies^{1,3,5,8,9} documenting pain's negative impact on activities in this population. For example, 67% of SCI patients with pain in a study² in Germany indicated that their pain had some effect on their daily life, and 23% reported that their daily routine was markedly or almost completely limited by pain. A survey of members of an SCI self-help association found that a significant number of those who were unemployed reported that it was the severity of pain and not paralysis that prevented them from working.⁸ Among those who were employed, 83% indicated that pain interfered with their work.

No published studies have reported data from the Chronic Pain Grade questionnaire with SCI samples. The proportion categorized as grade III in this study (17.7%) was comparable to that reported by Von Korff et al²⁴ for groups of primary care patients with back pain (20%) and headache (20.2%). The proportion categorized as grade IV in our study (22%) was somewhat higher than that for patients with back pain (17.2%) and more than twice as high as that for patients with headache (10%), as reported by Von Korff.²⁴ It is of concern that more than 20% of community residents with SCI and pain were categorized as grade IV, given the evidence of the poor physical and mental health and high level of unemployment, functional limitations, and health care use of patients with this classification.^{24,27}

It was noted previously that pain problems after SCI are often chronic and refractory to treatment.⁶ The individuals surveyed reported receiving different treatments for pain, but the only treatments rated on average as higher than 3 (on a scale from 1 = not at all helpful to 5 = extremely helpful) were opioids and an implanted morphine pump. Nearly two thirds of the respondents had used NSAIDs, but on average these were rated as only minimally helpful. Less than half had used opiates for pain and only 3% had implanted morphine pumps. Physicians may be reluctant to prescribe opiates for chronic pain, and many patients may be reluctant to use them. However, the finding that those who have used them rated them as more effective, on average, than other treatments calls for research to evaluate their benefits and drawbacks in this population. The number and diversity of therapies spontaneously mentioned indicate that alternative treatments may be helpful to some SCI persons. Randomized clinical trials are needed to examine the efficacy of therapies such as massage, acupuncture, and marijuana.

Most respondents reported more than 1 pain problem, as was reported in previous studies.^{1,2,14} Consistent with our clinical experience, most respondents with current pain experienced bilateral pain below the level of injury. However, pain above the level of injury was reported by 41% and pain at the level of injury was reported by about 50% of the respondents. Persons with lumbar and sacral injuries were more than twice as likely to report pain at the level of injury as were individuals with lower cervical injuries. The extent to which pain at the level of injury reflects transitional zone pain could not be determined in this study.

Although most respondents indicated that their pain was bilateral, regardless of location relative to level of SCI, about one quarter of pain problems were unilateral. This raises questions about the causes of these pain problems. Most spinal cord

lesions (with the possible exception of cauda equina injuries) affect both sides of the body; furthermore, associated peripheral nerve and brachial plexus injuries that might cause unilateral pain occur in less than 2% of SCIs.²³ Because our study participants were not examined clinically, the categorization of pain was limited to body location relative to injury level and the cause of pain could not be specified. Additional studies are needed that combine questionnaire data with physical examination and clinical history information to refine the classification of pain problems in people with SCI, and to identify the causes of, and the most effective treatments or combinations of treatments for, specific pain problems.

The most common sites of persistent, bothersome pain were the back (61%), hips or buttocks (61%), and legs or feet (58%). Other studies have also found the back and legs to be the most common sites of pain in individuals with SCI.^{1,12} Further investigation is needed to determine the causes of these pain problems (eg, neurogenic vs musculoskeletal) and whether there are common patterns of multiple pain problems in this population. The finding that most respondents with back pain indicated that it was made worse by activity and by position suggests that mechanical factors may cause or contribute to back pain in this population. Such pain problems may be helped by treatments used for other populations of patients with chronic pain, including activity pacing; avoidance of prolonged activity in 1 position; and regular stretching, range of motion, and exercise regimens, tailored to individuals who use wheelchairs.

Upper extremity pain problems are also common (reported by 69% of those with current pain), especially among people with cervical injuries. Other studies have found fairly comparable rates of shoulder pain in SCI populations, ranging from 30% to 51%.^{1,32-35} Studies have also found that tetraplegic persons were more likely than paraplegic persons to report shoulder pain.^{32,36} Further research is needed into the causes of, and most effective treatments for, shoulder and other upper extremity pain problems in the SCI population. This is particularly important because upper extremity pain can have a profound negative impact on ability to function independently (eg, independent transfers, pressure reliefs, wheelchair locomotion, hand positioning for daily activities). One study³⁷ of shoulder pain in tetraplegic patients found several causes, including instability, capsular contracture and capsulitis, and rotator cuff tears. Both tetraplegic and paraplegic individuals may experience pain associated with overuse related to weight bearing during wheelchair transfers and the demands of wheelchair propulsion. Furthermore, tetraplegic persons might experience more shoulder stress when trying to use arms that are only partially innervated and may also experience pain associated with underuse/immobilization of shoulders. Moderate activity may serve a protective function.³⁸

There were other significant differences in pain site for different levels of injury in this study. Hip or buttock pain was more common in people with low thoracic and lumbosacral injuries than in those with cervical injuries. Strikingly, respondents with cervical injuries were almost twice as likely to report neck pain than were those with other injuries. Further research is needed to see if these differences replicate in other samples, and, if so, to explore possible reasons for these differences. The high rate of neck pain in the C1-4 group (52%) raises the possibility that immobilization is a cause, because such persons are likely to use head supports on their wheelchairs.

The SF-MPQ words most frequently used to describe pain (chosen by > 50% of respondents) were aching, hot-burning, tiring-exhausting, throbbing, and sharp. In addition, more than

half of the respondents endorsed several words contained in the original MPQ but not the SF-MPQ: nagging, tingling, and tight. These findings were similar to those of our previous study¹ of a different sample of community residents with SCI, which found nagging, aching, hot-burning, sharp, and tiring-exhausting to be the most common pain descriptors. The mean sensory subscale score in the current study (11.14) was almost identical to that in our previous study (11.31) and comparable to that reported by Melzack²⁹ for small samples of patients with musculoskeletal pain and postsurgical pain before treatment. The mean affective subscale score in the current study (2.77) was slightly lower than that in our previous study (3.00), and lower in both studies than in the musculoskeletal and postsurgical pain groups described by Melzack.²⁹ Both the sensory and affective subscale scores in our study were lower than those reported for groups of individuals with chronic back pain, rheumatoid arthritis, and headache.³⁹ Another study¹⁷ also found that individuals with SCI used fewer affective words to describe their pain than did other patient populations. Cohen et al¹⁷ suggested that patients with SCI may perceive their pain as less threatening and dangerous than do patients with other chronic pain problems because they face urinary, bowel, and other medical problems that have more potential risk than pain presents. We also hypothesize that many individuals with SCI may view pain as a permanent consequence of the SCI "experience."

This study had several methodologic limitations. First, only 74% of the mailed questionnaires were returned and only 64% of questionnaires mailed to individuals not later determined to be deceased, ineligible for the study, or no longer at that address were completed. However, the response rate was approximately twice that of a recent survey study³⁶ with comparable methods. Second, we have no way of knowing whether individuals with pain problems were more or less likely than those without pain to complete the survey. However, the financial incentive was the same for persons with or without current pain, and the cover letter emphasized the importance of completing and returning the questionnaire whether or not the individual had pain. Third, a number of statistical tests were performed; thus, some significant differences found may have occurred by chance. Finally, though the sample is fairly representative of individuals in the Northwest Regional System, they may differ in sociodemographic and other characteristics from the larger population of individuals in the United States with SCI. For these reasons, additional research is needed to replicate these findings with other samples.

CONCLUSIONS

This literature review and survey of individuals with SCI indicate that most individuals with SCI experience chronic pain, for which treatments are not helpful on average. A substantial number of respondents reported that their pain interferes significantly with their customary work, home, social, and recreational activities. All the evidence suggests that chronic pain is a serious secondary problem in individuals with SCI, and that there is a great need for early and better diagnosis and treatment. In particular, there is a need to focus on the assessment and most effective treatment of upper extremity pain problems. Because individuals with SCI rely on their upper extremities for mobility, their shoulders and arms are subject to increased physical stress and overuse. Upper extremity pain can have a significant, negative impact on a person's functional independence. Further research is needed to delineate the various causes of, and the most effective treatments for, these and

other specific pain problems. Psychosocial and biomedical causes, contributing factors, and treatments need to be examined.

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