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Treatments for Chronic Pain Associated With Spinal Cord Injuries: Many Are Tried, Few Are Helpful

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Abstract:

Objective: The objective was to investigate, in two community samples of people with spinal cord injuries, the frequency of use of different pain treatments and the perceived helpfulness of these treatments.

Design and Setting: A postal survey was conducted in the community.

Participants: The participants were 471 persons aged 18 years or older who had spinal cord injuries and pain. There were 2 separate samples (n = 308 and n = 163).

Outcome Measures: The pain treatments used, the helpfulness of these treatments, and the Chronic Pain Grade questionnaire answers were assessed.

Results: Respondents reported multiple pain treatments (range of 0–14 and median of 4 in sample 1; range of 0–16 and median of 4 in sample 2). The most commonly reported treatments were oral medications and physical therapy. Medication types most commonly reported were nonsteroidal anti-inflammatory drugs (NSAIDs), acetaminophen, and opioids. The treatments rated as most helpful were opioid medications, physical therapy, and diazepam therapy, and those rated as least helpful were spinal cord stimulation, counseling or psychotherapy, administration of acetaminophen, and administration of amitriptyline. Alternative treatments reported as most helpful were massage therapy and use of marijuana. Acupuncture was tried by many but was rated as only moderately helpful.

Conclusions: This survey of two large samples of community-dwelling individuals with spinal cord injury–related chronic pain indicates that multiple pain treatments are tried but only a few are rated as more than somewhat helpful. Furthermore, the treatments that are most commonly reported are not always those that are rated as most helpful. The findings point to a number of potentially fruitful directions for future research.

Key Words: Pain—Spinal cord injury—Survey—Treatment.

Chronic pain is a common and significant problem occurring after spinal cord injury (SCI). Previous studies have found the prevalence of post-SCI pain to range from 47% to 96%.[1] More recently, in two postal surveys of community-dwelling people with SCI, current problematic pain was reported by 80.5% of a sample of 164 individuals and 79% of a second sample of 384 individuals.[2,3] Numerous studies have also provided evidence that SCI-related pain significantly interferes with daily functioning and ability to participate in life activities.[2–8]

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In short, the problem of pain after SCI is of sufficient magnitude that efforts to identify effective treatment options should be a major research priority.

A variety of therapies have been reported in reviews, but relatively few studies have evaluated specific treatments. Commonly, reviews have grouped treatments according to the type of approach to the pain problem. Such categories include pharmacological approaches, surgical approaches, psychosocial modalities, electrical stimulation procedures, neurolytic injections, and physical modalities.[9–11] In addition, one review names "alternative therapies" as another group of treatment options.[11]

Pharmacologic approaches to SCI-related pain depend upon the type of pain problem. Commonly suggested for neuropathic pain are tricyclic antidepressants, anticonvulsants, and oral anesthetic antiarrhythmic agents. Nonsteroidal anti-inflammatory drugs (NSAIDs) are frequently suggested for musculoskeletal pain, and opioid and nonopioid analgesics are used for both types of pain. There is considerable controversy over the use of opioid maintenance therapy for people with nonmalignant pain.[12,13] One study suggested that morphine and equivalent doses of other opioids were not effective in relieving neuropathic deafferentation pain[14]; however, there were only 12 patients with neuropathic pain in that study, and none of them had SCIs. More recently, a review of scientific data on antidepressants and opioid medications for the treatment of neuropathic pain conditions concluded that administration of antidepressants or anticonvulsants should be first-line therapy, but for refractory cases, chronic opioid therapy is appropriate and safe.[15]

Few pharmacological treatments have been evaluated in controlled trials for efficacy in relieving pain from SCI. The medications that have been systematically tested in clinical trials appear to be of questionable efficacy. For example, a small (n = 18) double-blind, placebo-controlled trial failed to show significant relief of dysesthetic pain by trazodone (an antidepressant medication) but showed significantly more side effects with trazodone than with placebo.[16] A small (n = 20) placebo-controlled crossover trial evaluated the efficacy of valproate (an anticonvulsant medication) for severe chronic central pain after SCI.[17] A trend toward improvement was observed during valproate treatment, but the difference between valproate and placebo did not reach statistical significance. The effect of mexiletine (an anesthetic/antiarrhythmic medication) on dysesthetic pain was evaluated in another small (n = 11) placebo-controlled crossover trial.[18] As with the other medications, mexiletine was not superior to placebo in relieving pain. We identified no other published controlled trials of pharmacological pain treatments for people with SCI.

Initially approved in 1994 for treatment of seizures, gabapentin, an anticonvulsant, has shown efficacy in treatment of postherpetic neuralgia, postpolio neuropathy, painful diabetic neuropathy, and complex regional pain syndrome.[19] In response to published studies of other patient populations with neuropathic pain, case reports,[20] and anecdotal reports, gabapentin has been increasingly used for treatment of SCI-related neuropathic pain. No randomized controlled clinical trials of treatment with gabapentin for people with SCI have been reported, but reviews of gabapentin efficacy for pain management recommend such trials.[19,21,22]

Treatment decisions regarding use of pharmacological modalities are for the most part based on case reports, clinical experience, and reports of success in treating other pain syndromes such as postherpetic neuralgia, complex regional pain syndrome, and diabetic neuropathic pain. Despite multiple pharmacological treatment options, pain associated with SCI appears to be quite refractory. Two decades ago, a survey of 96 individuals with SCI and pain living in the southern United States showed that 38% used medications for pain, but only 22% obtained consistent relief with their use.[6] A recent survey of 146 individuals with SCI in the United Kingdom found that the majority had tried various medications, but 43% of respondents indicated they would like further treatment of pain.[23] The authors interpreted this to mean that current treatments are not always effective. This survey did not ask about the helpfulness of specific medications or other treatments. Recently, another survey in the United States of 88 persons with SCI and pain showed that the majority reported having received some form of pain treatment but that only 19% were satisfied with that treatment.[24]

Nerve stimulation treatments for pain in people with SCI have been evaluated in uncontrolled studies. Transcutaneous electrical nerve stimulation (TENS) was investigated as an adjunct to medications in a group of 31 people with SCI-related pain.[25] Slightly more than one third of study participants had results that were termed "successful" or "partially successful"; of these patients, two thirds had pain at the site of injury. None of the participants with a cervical level of injury had "successful" pain relief. Another uncontrolled study involved a group of 20 patients with acute SCI and pain associated with severe, extensive soft-tissue injury.[26] Stimulation was delivered constantly at the injury site level, and analgesics were provided as needed to all patients. A reduction in pain of 50% or greater was reported by 90% of these individuals on the first day, and 75% reported that this level of relief was maintained for at least 3 days. Because this study was uncontrolled, it is not possible to

determine whether the pain reduction was due to TENS, the analgesics provided, or a placebo effect. Furthermore, it is unknown whether results would be similar for people whose injury is not recent or whether there is any long-term efficacy.

Implanted spinal cord stimulators for treating intractable pain in SCI have been evaluated, but published results have been disappointing.[27–30] Across studies, fewer than 25% of patients who received stimulators had ongoing relief and continued to use them.

A surgical treatment option that has been used for relief of chronic pain in people with SCI is the dorsal root entry zone (DREZ) lesion. Three published clinical case series were identified.[31–33] In these case series, between 50% and 55% of individuals who were treated with DREZ lesions reported ongoing pain relief, but surgical complications (cerebrospinal fluid leaks, new weakness, sexual dysfunction, and new paresthesias) occurred in 9 to 16% of cases. Although DREZ lesions have been reported to relieve pain in some people with SCI in case series, there are potentially serious associated risks. In addition, in the absence of randomized controlled trials, the effects of DREZ versus placebo effects and natural history have not been distinguished.

Another surgical treatment option is the implantation of an intrathecal pump for continuous medication delivery. Intrathecal baclofen delivered via pump infusion is commonly used in people with SCI for treatment of spasticity. Relief of pain as a secondary effect of intrathecal baclofen after a single bolus dose[34] and as a result of continuous delivery via an implanted pump[35] have been reported. Significant reduction of both neurogenic and musculoskeletal pain for 8 to 12 hours after a single bolus dose of 50 μ of baclofen was noted in a blind placebo-controlled trial.[34] Musculoskeletal pain decreased significantly in 5 of 6 patients followed for up to 1 year after implantation of a baclofen pump; however, no pain relief occurred in 9 patients with neuropathic pain.[35] Although use of implantable pumps for continuous intrathecal administration of morphine for chronic intractable pain is common, only a single report evaluating such use in people with SCI could be identified.[36] In a double-blind randomized controlled trial involving 15 patients, the efficacy of intrathecal morphine, clonidine, and a combination of both medications was investigated. The combination of morphine and clonidine produced significantly more pain relief than either drug alone 4 hours after administration. This study did not evaluate the efficacy of ongoing use of the medications.

There are few reports of the use of alternative therapies for pain in SCI. A recent review of acupuncture for pain of neurologic origin focused on pain in SCIs and described two uncontrolled studies published in abstract form only.[37] The first abstract presented a series of 61 patients with myofascial and deafferentation pain.[38] Good to excellent pain relief was reported by 77% of patients. The second abstract[39] reported a significant reduction in pain ratings after acupuncture treatment in an unknown number of patients. Three recent studies suggest that people with disabilities, including those with SCI, do use alternative therapies. In a telephone survey of 401 working-age adults with disabilities, 57.1% reported use of one or more alternative therapies in the past year and 22% said they had consulted providers of those therapies.[40] The authors reported that in a randomly selected national sample of the general population, comparable figures were 34% and 10%. The most common condition treated by alternative therapies in the physically disabled sample was pain. The most commonly used alternative treatments for pain were relaxation, massage, and chiropractic. In a sample of 103 adults referred for rehabilitation care who completed a questionnaire about use of alternative therapies, 29.1% reported they had used one or more for their presenting problem.[41] The most common problems treated by alternative therapies were musculoskeletal pain syndromes, and the most common alternative therapies used were massage, chiropractic, vitamin and mineral supplements, and acupuncture. Most recently, a survey of 77 people with SCI showed that 40.3% had used at least one alternative therapy to manage chronic pain. Acupuncture was used most frequently, followed by massage, chiropractic manipulation, and herbal medicine.[42]

In the current article, we report the findings from two surveys of community-dwelling persons with SCI-related chronic pain regarding the use and helpfulness of treatments for pain. (Other results from the first of the two surveys have been reported elsewhere.[3] After the preparation of that report, four additional questionnaires were received and are included in the results for questionnaire v1 in this article.) We conducted two surveys with different versions of a questionnaire to replicate and extend the findings from an initial sample in a second sample. The primary objective of the current study was to determine the frequency of use of different pain treatments and the perceived helpfulness of specific pain treatments. Additional questions explored in the second sample included the following. (1) What treatments were used specifically for the worst pain in people with more than one pain problem? (2) What treatments are still being used? (3) How common is the use of gabapentin in this population and how helpful is it? (4) What alternative treatments are most common and reported as most helpful?

Although lacking the rigor of a randomized controlled trial, a postal survey used to learn about treatment helpfulness may provide information useful in guiding the selection of therapies for evaluation in future clinical trials.

MATERIALS AND METHODS

To ensure that reporting of treatments received would not simply reflect practice in a single clinical setting, we recruited subjects from the community rather than through a single hospital or clinical setting. Study participants were solicited primarily through the mailing list for the newsletter of the Northwest Regional SCI System (NWRSCIS), a comprehensive interdisciplinary service delivery model system funded in part by the National Institute on Disability and Rehabilitation Research, Department of Education. In addition, notices about the study were placed in Seattle area clinics, facilities serving people with SCI, and the NWRSCIS newsletter. Two different versions of a questionnaire were mailed to 1,100 adults with SCI who were selected randomly from the mailing list or who had called in response to a notice. After 17 months, the questionnaire was revised to differentiate between pain types in people who reported more than one type of pain. Questionnaire version 1 (v1) was mailed to 701 individuals between February 1997 and July 1998, and questionnaire version 2 (v2) was mailed to 399 individuals between August 1998 and June 2000. Each questionnaire was accompanied by a consent form and a cover letter inviting individuals with SCI of at least 6 months' duration who were aged 18 years or older to participate in the study. Each participant was paid $20 for completing the questionnaire. The University of Washington Human Subjects Review Committee approved the study questionnaires and protocol.

All participants were asked to answer questions about their sociodemographic characteristics, injury characteristics, and pain experienced since SCI. Participants were asked whether they had a current pain problem. Participants with a current pain problem were asked to complete the seven-item Chronic Pain Grade questionnaire to assess pain intensity and pain interference with normal daily activity.[43] The Chronic Pain Grade questionnaire has demonstrated validity and high internal consistency and has been used in prior mail survey instruments.[43–46] *Characteristic pain intensity* was calculated by averaging 0 to 10 ratings of current pain and worst and average pain in the past 3 months and then multiplying by 10. Likewise, 0 to 10 ratings of pain interference with daily, social, and work/housework activities in the previous 3 months were averaged and then multiplied by 10 to calculate *pain-related disability scores*.[43]

Questionnaire v1 asked respondents with current pain to indicate whether they had received any of 18 treatments for pain and to rate the helpfulness of each treatment received on a scale of 1 (not at all helpful) to 5 (extremely helpful). The list of 18 treatments was constructed on the basis of our past clinical experience with treatments commonly used for pain in people with SCI and a pilot study testing the questionnaire.[2] In addition, respondents were invited to list any additional treatments received for pain and to rate their helpfulness. Treatments belonging to a single class (e.g., NSAIDs and opioid medications) were listed as a single treatment type; examples of specific medications belonging in the class were listed in parentheses after the class name. Questionnaire v2 asked respondents whether they had more than one pain problem and to answer questions separately about their worst pain and second-worst pain. Because several treatments were commonly written in on questionnaire v1, the list of pain treatments was expanded to 24 treatments for questionnaire v2. Respondents were asked to indicate whether they had received any of the 24 treatments and to rate the helpfulness of those treatments separately for their worst pain and second-worst pain. In addition, for each treatment received, respondents were asked whether they still used that treatment. Statistical analyses were performed comparing respondents to questionnaire v1 with respondents to questionnaire v2 about worst pain. There were no statistically significant differences between responses to the first questionnaire and responses to the second questionnaire about worst pain. Therefore, only questionnaire v2 responses relating to worst pain were analyzed for this article.

Statistical analysis

Means, standard deviations, and percentages were calculated to describe the sociodemographic and SCI characteristics of each sample and their responses to the survey questions. Mann–Whitney U tests, t tests, and χ^2 tests were conducted to determine whether the two samples differed significantly in any sociodemographic, injury, or pain characteristic. We did not conduct statistical tests to compare ratings of helpfulness across treatments, because the same individuals used multiple treatments. To examine whether subjects who were still using a treatment rated it as more helpful than did subjects who had used but were no longer using the treatment, t tests were performed.

RESULTS

Response rate

Of the 701 v1 questionnaires mailed, 522 (74.5%) were returned. Of these, 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 (e.g., was younger than age 18 years or did not have an SCI), and 30 were returned with a note indicating that the addressee declined to participate in the study. Completed questionnaires and consent forms were received from 388 people aged 18 years or older with SCI (accounting for 65% of the mailed questionnaires, excluding those mailed to addressees who were deceased, ineligible for the study, or no longer at that address). Of these respondents, 308 (79.4%) had current pain and therefore answered the questions about pain treatments. Of the 399 v2 questionnaires mailed, 256 (64%) were returned. Of these, 19 were returned because the addressee was no longer at that address, 8 were returned with a note indicating that the addressee was deceased, 14 were returned with information indicating that the addressee was not eligible for the study, and 16 were returned with a note indicating that the addressee declined to participate in the study. Completed questionnaires and consent forms were received from 215 eligible participants (accounting for 60% of the mailed questionnaires, excluding those mailed to addressees who were deceased, ineligible for the study, or no longer at that address). Of these respondents, 163 (75.8%) reported current pain and responded to the questions about treatments. Thus, the participants in this study were 308 people with pain in sample 1 and 163 people with pain in sample 2.

TABLE 1. *Respondent sociodemographic and injury characteristics*

Characteristic	Sample 1 (n = 308) (n)	Sample 1 (n = 308) (%)	Sample 2 (n = 163) (n)	Sample 2 (n = 163) (%)
Ethnic group				
White	259	84.1	138	84.7
Native American	13	4.2	6	3.7
Black	9	2.9	6	3.7
Hispanic	7	2.3	7	4.3
Asian/Pacific Islander	9	2.9	4	2.4
Other	11	3.6	2	1.2
Marital Status				
Married or living with partner	137	44.5	72	44.2
Never married	97	31.5	56	34.3
Separated, divorced or widowed	74	24.0	35	21.5
Education (highest level)				
High school/GED or less	61	19.8	46	28.2
Some college, vocational, technical, business school	144	46.7	63	38.7
College graduate	103	33.5	54	33.1
Employment*				
Employed (FT or PT)	112	36.4	42	25.8
School/vocational training	25	8.1	14	8.6
Retired/homemaker	57	18.5	33	20.2
Unemployed	193	62.7	119	73.0
Level of injury				
C1–C4	49	15.9	32	19.6
C5–C8	105	34.1	53	32.6
T1–T5	34	11.0	10	6.1
T6–T12	85	27.7	52	31.9
L1–S5	26	8.4	14	8.6
Unknown	9	2.9	2	1.2
Cause of SCI				
MVA	144	46.8	80	49.2
Fall	45	14.6	32	19.6
Sports accident	13	4.2	10	6.1
Diving	22	7.1	9	5.5
Gunshot wound	20	6.5	11	6.7
Other	64	20.8	21	12.9

*Percentages total more than 100% because respondents endorsed more than one category.

FT, full time; PT, part time; SCI, spinal cord injury; MVA, motor vehicle accident; GED, general equivalency degree.

Respondents' characteristics

Sociodemographic and injury characteristics of the respondents with current pain are presented in Table 1. Both samples were predominantly male (72.1% in sample 1 and 70.0% in sample 2), as is characteristic of the general SCI population, and white. Average age was similar in the two samples (sample 1 age in years: mean = 43.0, SD = 13.02, and range = 18–84; sample 2 age in years: mean = 41.6, SD = 13.6, and range = 18–77). Approximately two thirds completed at least some college. The most common cause of injury was a motor vehicle accident (46%), and approximately half had injuries at the level of C8 or above (tetraplegia).

The two samples did not differ significantly in sex, age, ethnic group representation, or marital status. However, sample 2 respondents were less educated (19.8% of sample 1 and 28.0% of sample 2 reported high school or less as the highest level of education completed [$\chi^2 = 4.3$, $df = 1$, $p = 0.04$]) and were more likely to be unemployed (62.6% versus 73.0%; $\chi^2 = 5.07$, $df = 1$, $p < 0.05$). Levels, completeness, and causes of injury did not differ across the two samples; however, respondents in sample 1 were injured longer ago (median = 11.2 years, range = 0.65–53.8 years) than those in sample 2 (median = 4.3 years, range = 0.5–39.3 years; Mann–Whitney U = 16420.0, $p = 0.000$). This was most likely related to the fact that although respondents were selected randomly from a mailing list to receive questionnaires, new names were added to the list as people had new SCIs.

The most common sites of pain in both samples were the back (48.5% and 45.6%), legs or feet (46.1% and 46.5%), and hips or buttocks (47.9% and 40.0%), but a variety of other locations were endorsed as well. Characteristic pain intensity and pain-related disability scores derived from the Chronic Pain Grade questionnaire did not differ significantly across the two samples (characteristic pain intensity: mean = 59.35 and SD = 21.02 in

sample 1 and mean = 61.02 and SD = 18.53 in sample 2; pain-related disability: mean = 40.02 and SD = 29.99 in sample 1 and mean = 43.7 and SD = 29.42 in sample 2). Mean number of days with pain in the previous 3 months was 74.68 (SD = 27.72) in sample 1 and 75.02 (SD = 27.03) in sample 2. The average number of days in which pain kept respondents from their usual activities in the previous 3 months was 16.06 (SD = 28.70) in sample 1 and 21.06 (SD = 32.48) in sample 2.

Treatments received and helpfulness

Respondents reported multiple pain treatments received (range = 0–14 and median = 4 in sample 1; range = 0–16 and median = 4 in sample 2). Tables 2 and 3 present the responses to the questions about which pain treatments were tried and their helpfulness. Medications were the most frequently tried treatments, and there were slight differences between the two samples in proportions of subjects who reported use of each medication. Three types of medication were used by more than 50% of both samples—NSAIDs, acetaminophen, and opioids. Additional medications used by at least 25% of respondents, in order from most to least frequently reported, were baclofen, diazepam, and amitriptyline in sample 1 and baclofen, diazepam, and gabapentin in sample 2. In sample 2, fewer than 25% reported the use of amitriptyline. The nonpharmacological treatment most commonly reported in both samples was physical therapy (used by 66.8% of sample 1 and 68.2% of sample 2). Other treatments used by more than 10% of either sample were TENS, biofeedback or relaxation techniques, counseling or psychotherapy, nerve blocks, and spinal cord stimulation.

Ratings of treatment helpfulness were very similar across the two samples. Among the treatments reported by more than 10% of either sample, those rated as most helpful were opioid medications (mean = 3.08 in sample 1 and 3.47 in sample 2), physical therapy (mean = 2.87 in sample 1 and 3.06 in sample 2), and diazepam (mean = 2.78 in sample 1 and 3.18 in sample 2). These three treatments were rated as very or extremely helpful (4 or 5 on the 5-point scale) by substantial proportions of people who reported using them (38.9% and 54.1% for opioid medications; 29.3% and 36.0% for physical therapy; and 32.8% and 49% for diazepam in samples 1 and 2, respectively.)

The least helpful treatments among those reported by at least 10% of either sample were spinal cord stimulation (mean = 1.67 in sample 1 and 1.78 in sample 2), counseling or psychotherapy (mean = 1.92 in sample 1

TABLE 2. *Past treatments for pain and helpfulness*

	Sample 1 (n = 308)		Sample 2 (n = 163)†		
Treatment	Who used it n (%)	Helpfulness* Mean (SD)	Who used it n (%)	Helpfulness* Mean (SD)	Still using proportion (%)
Oral medications					
NSAIDs	202 (65.6)	2.30 (1.23)	89 (54.6)	2.26 (1.46)	47/89 (52.8)
Acetaminophen	178 (57.8)	2.07 (1.12)	86 (52.8)	2.03 (1.21)	41/86 (47.7)
Opioid medications	159 (51.6)	3.08 (1.27)	98 (60.1)	3.47 (1.22)	47/98 (48.0)
Baclofen	136 (44.2)	2.35 (1.41)	68 (41.7)	2.72 (1.46)	45/68 (66.2)
Diazepam	125 (40.6)	2.78 (1.44)	51 (31.3)	3.18 (1.42)	30/51 (58.8)
Amitriptyline	79 (25.6)	2.08 (1.24)	34 (20.9)	2.06 (1.10)	11/34 (32.4)
Carbamazepine	37 (12.0)	2.16 (1.44)	16 (9.8)	2.19 (1.33)	3/16 (18.8)
Gabapentin‡	15 (4.9)	3.21 (1.12)	42 (25.8)	2.90 (1.28)	24/42 (57.1)
Mexiletine	6 (2.0)	2.00 (1.26)	4 (2.4)	2.75 (1.71)	2/4 (50.0)
Other Modalities					
Physical therapy	205 (66.6)	2.87 (1.27)	111 (68.1)	3.06 (1.36)	47/111 (42.3)
Biofeedback/relaxation training	69 (22.4)	2.23 (1.26)	30 (18.4)	2.17 (1.18)	11/30 (36.7)
Counseling/psychotherapy	66 (21.4)	1.92 (1.17)	37 (22.7)	2.14 (1.36)	11/37 (29.7)
Nerve blocks	53 (17.2)	2.34 (1.43)	23 (14.1)	2.43 (1.59)	3/23 (13.0)
Spinal cord stimulator	36 (11.7)	1.67 (0.99)	9 (5.5)	1.78 (1.30)	2/9 (22.2)
Intrathecal infusion pump	9 (2.9)	4.00 (1.50)	8 (4.9)	4.13 (1.46)	0/8 (00.0)
DREZ lesion	2 (0.6)	2.50 (2.12)	1 (0.6)	1.00 (0.00)	NA
Cordectomy	1 (0.3)	4.00 (0.00)	1 (0.6)	3.00 (0.00)	NA
Cordotomy	1 (0.3)	1.00 (0.00)	1 (0.6)	2.00 (0.00)	NA
Rhizotomy	1 (0.3)	4.00 (0.00)	3 (1.8)	3.00 (2.00)	NA
TENS‡	9 (2.9)	2.56 (1.59)	38 (23.3)	1.89 (1.06)	8/38 (21.1)
Regular activity or exercise§	5 (1.6)	3.80 (1.39)	4 (2.5)	4.75 (0.50)	4/4 (100.0)

*1 = not at all helpful, 5 = extremely helpful.
†Treatments received for worst pain only.
‡Not asked directly in sample 1; write-in responses only.
§Not asked directly in either sample; write-in responses only.
NSAID, nonsteroidal anti-inflammatory drug; DREZ, dorsal root entry zone; TENS, transcutaneous electrical nerve stimulation.

TABLE 3. *Alternative treatments for pain and helpfulness*

	Sample 1 (n = 308)		Sample 2 (n = 163)†		
Treatment	Who used it n (%)	Helpfulness* Mean (SD)	Who used it n (%)	Helpfulness* Mean (SD)	Still using proportion (%)
Acupuncture‡	11 (3.6)	3.09 (1.51)	23 (14.1)	2.57 (1.47)	7/23 (30.4)
Acupressure‡	1 (0.0)	5.00 (0.00)	12 (7.4)	2.83 (1.40)	6/12 (50.0)
Massage therapy‡	16 (6.2)	3.63 (1.02)	62 (38.0)	3.40 (1.15)	34/62 (54.8)
Chiropractic§	4 (1.3)	4.00 (0.00)	4 (2.4)	3.75 (0.50)	3/4 (75.0)
Hypnosis‡	0 (0.0)	NA	9 (5.5)	2.22 (0.83)	1/9 (11.1)
Marijuana§	8 (2.6)	4.38 (0.74)	4 (2.5)	4.00 (0.82)	4/49 (100.0)

*1 = not at all helpful, 5 = extremely helpful.
†For "worst pain" only.
‡Not asked directly in sample 1; write-in responses only.
§Not asked directly in either sample; write-in responses only.

and 2.14 in sample 2), acetaminophen (mean = 2.07 in sample 1 and 2.03 in sample 2), and amitriptyline (mean = 2.08 in sample 1 and 2.06 in sample 2).

It appears that the use of gabapentin may have increased over the time span of the study: only 3.9% of individuals responding in the first 2 years reported using it, compared with 19.5% of those responding during the second 2 years. However, because gabapentin was not listed on questionnaire v1, responses were write-ins only; it was listed on questionnaire v2 and thus may have been acknowledged more frequently for that reason. Although use of gabapentin was reported by very few individuals in sample 1 (n = 15), 46.7% of these respondents rated gabapentin as very or extremely helpful. In sample 2, however, a larger number reported use of gabapentin (n = 42). Although only 28.6% rated it as very or extremely helpful, 38.1% rated it as moderately helpful. Mean helpfulness ratings for gabapentin were 3.21 in sample 1 and 2.90 in sample 2. Similarly, use of a TENS unit was not asked directly of sample 1, but for those individuals writing it in (2.9%), the mean helpfulness rating was somewhat to moderate (2.56), and 2.2% reported it to be very or extremely helpful. On questionnaire v2, which specifically listed TENS, 23.3% of respondents reported its use, but the mean helpfulness rating was only 1.89 and only 10.5% rated it as very or extremely helpful.

Only questionnaire v2 assessed whether treatments were still being used. Physical therapy, opioid medications, and NSAIDs were the most frequent ongoing treatments: continued use of each was reported by 28.8% of the sample. Those who reported ongoing physical therapy rated it as significantly more helpful, on average (mean = 3.51), than did those who were no longer receiving it (mean = 2.73, $t = 3.09$, $p = 0.003$). Similarly, those who reported continuing to use opioid medications and NSAIDs rated the medications as significantly more helpful than did those who no longer used them (still using versus not using opioids: mean = 3.85 versus 3.14, $t = 3.04$, $p = 0.003$; still using versus not using NSAIDs: mean = 2.77 versus 1.69, $t = 4.52$, $p = 0.000$). Other medications still being used by at least 10% of the sample were baclofen, acetaminophen, diazepam, and gabapentin. Physical activity or exercise was written in by four respondents, of whom all four were still using it for pain relief.

Although the use of alternative treatments was not commonly reported in either sample (proportions endorsing specific therapies ranged from 0 to 38.0%), on questionnaire v2, which listed specific alternative therapies, two were endorsed by more than 10% of respondents. These were massage therapy (38.0%; mean helpfulness = 3.40) and acupuncture (14.1%; mean helpfulness = 2.57). Although reported by only a small number of individuals, marijuana and regular exercise or physical activity were rated as very helpful on average (means ranging from 3.80 to 4.75). Neither of these therapies was listed on either of the two questionnaire versions.

DISCUSSION

The results of these two surveys of community-dwelling individuals with SCI indicate that most people with SCI have chronic bothersome pain, that most of these individuals have tried numerous treatments for pain, and that the treatments used tended, on average, to be only somewhat helpful. Other surveys have shown similar pain prevalence and number of treatments tried in smaller samples (n = 88–200)[2,3,6,23,24]; however, this is the largest sample surveyed to date about treatments for pain associated with SCI. Furthermore, helpfulness of specific treatments has not been explored in surveys by other investigators.[6,23,24] In sum, this study supports the findings of other surveys in substantiating that chronic pain is a serious problem for people with SCI and that pain treatments are frequently ineffective. It extends these findings by linking specific treatments with their perceived helpfulness, thus indicating potentially fruitful directions for future research.

In this survey, the most commonly reported treatments for pain were physical therapy and medications. Although rated as only somewhat to moderately helpful on average, physical therapy was the nonpharmacological treatment most likely to still be used. We did not gather information on the specific type of physical therapy received (e.g., ultrasound, exercise, or other modalities) and whether therapeutic activities were carried out in a home-based program as well as with a therapist. Furthermore, although we did ask respondents to rate only treatments used for pain, we cannot be certain that respondents differentiated between physical therapy received specifically for pain and therapy received for some other purpose. Indeed, in many cases, it may not be possible to make such a distinction, because physical therapy is commonly used for more than one problem at a time. Research is needed to identify the specific physical therapies most effective for different types of pain problems (e.g., musculoskeletal versus neuropathic) in people with SCI.

Although endorsed by only a small number of individuals, regular physical activity or exercise was rated as very helpful on average. Among the nine individuals who listed this as a pain treatment, seven (78%) rated it as very or extremely helpful. In addition, of the four individuals in sample 2 who reported the use of activity/exercise as a pain treatment, all four reported its ongoing use. Because regular physical activity or exercise was not listed specifically on either questionnaire, no information is available about the amounts and types of activity viewed as having a beneficial effect on pain. Further research on the effects of physical activity on pain in people with SCI is needed.

In both samples, nonsteroidal anti-inflammatory drugs, acetaminophen, and opioid medications were the three types of medications most commonly reported as used for pain. This finding is consistent with the results of a recent survey of individuals with SCI in the United Kingdom that showed the same three medication classes to be used most frequently.[23] We found that 55% of the two samples (combined) reported use of opioid medications (compared with 57% using "weak" opioids and 14% using "strong" opioids in the United Kingdom sample) and 56% reported use of acetaminophen (compared with 51% in the United Kingdom sample). In both of our samples, of the three medications most commonly reported, only opioid medications were rated as more than somewhat helpful. In addition, similar to the United Kingdom survey finding that 23% reported ongoing use of "weak opiates," 28.8% of sample 2 reported continued use. The fact that such a substantial number continue to use opioid medications, with fairly highly perceived helpfulness, suggests a need for randomized controlled trials of the efficacy of these medications for treatment of chronic pain related to SCI.

The use of nonsteroidal anti-inflammatory drugs and acetaminophen was very common in our samples: 54–66% (62% of the combined sample) reported use of these medications. This relatively frequent use may reflect both their availability over the counter and their recommendation/prescription by health care providers. Despite the frequency of their use, these medications were rated as only somewhat helpful. Use of NSAIDs was reported by twice as many (62%) in our combined sample as in the United Kingdom sample (30%).[23] In contrast to the United Kingdom sample, of which only 7% reported ongoing use of NSAIDs, 28.8% of our sample reported continuing use of them. Given the known risks associated with prolonged use of NSAID medications, it may be advisable for clinicians who provide care for this population to ask about the use of such medications and monitor their continued use.

The frequency of use of gabapentin appeared to increase over the course of the study. Only 4.9% of sample 1 reported using it, in contrast to 25.8% of sample 2. The extent to which this difference was due to the fact that gabapentin was included only in the list of specific treatments to be rated in questionnaire v2—or, alternatively, to an increasing tendency of health care providers to prescribe it for pain—is unknown. The reported helpfulness of gabapentin for SCI-related pain in our samples was second only to that of opioid medications. Further research is indicated to evaluate the efficacy of this medication for different types of pain problems in people with SCI.

Although baclofen and diazepam are usually prescribed for spasticity rather than for pain, our respondents reported frequent use of these two medications for pain and rated them as somewhat to moderately helpful. It is interesting that Loubser and Akman[35] reported significant decreases in musculoskeletal pain, but not in neuropathic pain, after administration of intrathecal baclofen to 12 people with SCI and pain. On the basis of our results, it seems that controlling spasticity with oral medications may also decrease pain. Further research is needed to evaluate the effects of oral medications for spasticity on different types of pain and the extent to which diazepam may decrease the affective component of pain or decrease anxiety. Research on the relationship between pain and spasticity may also prove fruitful.

Although only a few people in each sample reported having received an intrathecal pump, those who did rated it as very helpful on average (mean = 4.00 in sample 1 and 4.13 in sample 2). In contrast, as found in previous

studies,[27,28] those who reported trying spinal cord stimulation (n = 45) did not rate it as very helpful, on average (mean = 1.67 in sample 1 and 1.78 in sample 2).

As in two previous studies of people with disabilities[40,41] and the recent United Kingdom survey of people with SCI about pain treatments,[23] our respondents reported use of alternative treatments for their pain. The most commonly reported was massage therapy. On questionnaire v2, which specifically asked about massage therapy, 38% of respondents reported having tried it and 20.9% reported its ongoing use. Helpfulness was rated as moderate to very good on average. Although no previous studies of the efficacy of massage therapy for pain in people with SCI were identified, massage has been found to be beneficial for other pain problems, including back pain.[47] Research is needed to evaluate the efficacy of massage therapy for pain in people with SCI.

Although its use was reported by only a small number of respondents, those who mentioned it rated marijuana as very helpful. This supports the findings of a survey more than 2 decades ago of the effects of marijuana on people with SCI.[48] Of 10 respondents reporting marijuana use in that survey, 50% reported an increase in pleasant sensations, 44% reported decreased pain, and 22% reported being distracted from their pain. A second survey on marijuana use in this population found that 88% of 24 respondents who reported current marijuana use reported a significant reduction in spasticity.[49] Effect on pain was not directly explored in this survey. We could identify no other studies on the effects of marijuana on people with SCI; however, the recent United Kingdom survey[23] similarly found that a small number of individuals reported current use of marijuana for pain. Our findings suggest that a controlled trial of cannabinoids for treatment of pain in people with SCI may be warranted.

Several limitations of this study should be noted. First, most respondents resided in the northwestern United States; it is possible that study findings may reflect regional differences in prescribing practices or standards of care. A second limitation is the 60 to 65% response rate. It is possible that respondents differed from nonrespondents in terms of pain or other characteristics. However, this rate is comparable to response rates (53–67%) in other surveys concerning pain in people with SCI in which similar methods were used[6,23] and is much greater than the 33% rate in one recent survey.[24] The findings of this study need to be replicated in other samples to determine their generalizability.

Third, participants' responses were not compared with other sources of information, such as medical records. Respondents may not have recalled or may not have recalled accurately some treatments received, and they may not have recalled accurately how helpful a treatment was. In particular, the ratings of treatments that were written in should be interpreted with caution. Written-in treatments may have been rated as more helpful because respondents may have remembered and/or reported the most helpful treatments. Fourth, it is unknown whether respondents took adequate doses or received treatment for an adequate length of time. Finally, we did not ask respondents to distinguish the specific pain problem for which a treatment was used; therefore, treatment response cannot be linked to type of pain treated. However, given the complexity of diagnosing SCI-related pain and the finding that the majority of people with SCI pain report more than one pain site and more than one pain problem,[3,6] matching pain type to treatment may not be possible with the use of survey methods.

Despite these limitations, this descriptive cross-sectional study is the first to systematically assess frequency of use of specific treatments for pain and their perceived helpfulness in two large samples of community-dwelling adults with SCI. Within the limitations of this method, opioid medications emerged as worthy of consideration for treating chronic pain in this population. The findings also point to a number of directions for further research that may prove seminal in identifying which treatments are most effective for which patients and for which specific pain problems.

CONCLUSIONS

This survey of the use and helpfulness of treatments for pain in two large samples of community-dwelling individuals with SCI-related chronic pain indicates that multiple pain treatments are tried but few are rated as more than somewhat helpful. Furthermore, the treatments that are most commonly reported are not always those that are rated as most helpful. Of treatments tried by at least 5% of respondents, those that were rated as most helpful were opioid medications, physical therapy, and diazepam. Those rated as least helpful were spinal cord stimulation, counseling or psychotherapy, and two medications, acetaminophen and amitriptyline. The use of alternative treatments for pain in this population is not common, but two, massage therapy and marijuana, were rated as very helpful. This study illuminates the need for further research to evaluate specific pain treatments in this population in randomized controlled trials. Treatments that warrant further evaluation include opioid medications, gabapentin, marijuana, massage, and physical activity/exercise. Furthermore, the relation between spasticity and pain warrants further investigation. This study also provides additional evidence supporting the

finding in previous studies that current treatment options are seldom effective for chronic pain related to SCI.

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