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Utilization and Patients' Perceptions of the Effectiveness of Pain Treatments in Multiple Sclerosis: A Cross-sectional Survey

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Abstract

Background—Although chronic pain is common among persons with multiple sclerosis (MS), little is known about the utilization and patients' perception of the effectiveness of pain treatments in MS.

Objectives—The objectives were to: (1) identify specific treatments currently used for pain relief by adults with MS; (2) examine patients' perceptions of the effectiveness of each of these treatments; and (3) examine rates of health care utilization, specifically provider and emergency department visits, for pain.

Design—Cross-sectional survey

Methods—One hundred twenty-five community dwelling participants with MS and pain completed a postal survey that measured demographics, MS disease, pain, pain treatments, perceived effectiveness of treatments, and healthcare utilization.

Results—The majority (89.6%) of the sample reported use of a variety of and multiple pain treatments (range = 1-19, median = 9.0, mean = 9.0, SD = 4.2); few were rated as providing pain relief. Non-prescription pain relievers were the most commonly reported treatment. Physical treatment modalities were also common. The treatments that were reported by patients to provide the greatest pain relief, such as hypnosis, nerve blocks, and marijuana, were not those that were the most frequently used. Overall, 75% reported at least one visit to a provider for pain in the past six months; participants made, on average, 9.7 visits for pain during this same time period. Emergency department visits explicitly for pain were reported by 11% of respondents.

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Conclusions—These findings suggest that pain is inadequately treated from the perspective of persons with MS and results in a high level of health care utilization.

Keywords

multiple sclerosis; chronic pain; healthcare delivery; pain

Introduction

Multiple sclerosis (MS) is the most common cause of acquired neurologic disability in young adults,¹ with the typical individual with MS facing many decades of managing this chronic disease. The economic burden of MS in the United States is immense and includes high direct (e.g., medical care) and indirect (e.g., reduced productivity) costs to both individuals and society.² Among the many factors contributing to MS's burden is chronic pain. Over 50% of people with MS experience moderate or severe chronic pain and its associated negative consequences,³⁻⁷ despite the number and range of available treatment options.^{4,5}

Very little is known about the utilization and perceived helpfulness of treatments and health services for chronic pain in MS.⁵ One study of an MS clinic sample reported specifically on utilization, with 64% of those with pain using pain medications, and, of these, 28% using behavioral techniques such as stress avoidance and rest.⁸ In the only study to examine MS patients' perceived effectiveness of pain treatments,⁹ medications were described as effective by 45% of the sample, followed by physical/mechanical/temperature manipulation (21%), exercise (13%), "psychosocial" techniques (12%), and rest/sleep (9%). Interestingly, 48% of the participants listed medication use as an *ineffective* technique. This study was limited by the use of patient-derived lists and the broad categorization of many nonpharmacologic treatments as "psychosocial treatments." Lastly, one study evaluated the specific healthcare providers patients with MS visited for pain, with participants most commonly visiting neurologists, followed by primary care physicians.¹⁰ This study did not assess the utilization of emergency departments for pain relief, however, nor was the use of specific psychosocial pain interventions assessed.

The present study's aim was to extend the literature on MS pain treatments by describing in detail self-reported use and perceived helpfulness of a variety of specific treatment modalities for pain in a community-based sample with MS and pain. We identified three important points to explore: (1) the specific types of treatments used (as opposed to broadly categorizing treatments as medication or psychosocial treatments, as in previous studies); (2) patients' perceptions of the effectiveness of each treatment, to increase understanding about treatments from the patients' perspectives; and (3) which healthcare providers patients visit for pain management, including emergency departments.

Methods

Participants

Participants were recruited from a pool of participants with MS who had previously completed a research survey on quality of life in MS conducted in the Pacific Northwest region of the United States^{11,12} and indicated a willingness to participate in future research. To be eligible, participants needed to have a diagnosis of MS and be able to complete the survey in English; these criteria were required for the initial study. The survey was mailed to 300 randomly selected individuals; of these, 25 were undeliverable. Of the 275 surveys delivered, 187 were returned for a response rate of 68%. Given this study's aims, only participants who indicated a current or recent pain problem were included in the analyses (n = 125). Respondents were paid \$25 for returning the consent forms and survey. Study procedures were approved by the University of [removed for blinded review] Human Subjects Committee. Data from this survey have been previously used to describe pain^{6,13} and associated psychosocial factors.¹⁴ A previously published study¹⁵ reported on the association between depression and pain treatments but did not present the data used in this study.

Measures

Demographics—Demographic questions assessed age, gender, race/ethnicity, employment status, education level, and marital status.

MS-Related Factors—Participants provided information on MS disease course, progression, and duration. Respondents selected a pictorial graph (with accompanying written description) corresponding to their disease course over time, based on an international survey of disease patterns.¹⁶ Respondents also completed the self-report version¹⁷ of the Expanded Disability Status Scale (EDSS),¹⁸ the standard measure of disease severity and impairment in MS clinical practice and research. EDSS scores were categorized as mild (0–4.0), moderate (4.5–6.0), and severe (6.5–9.5) to reflect milestones in progressive loss of functioning. Date of MS diagnosis was used as a proxy for disease duration.

Pain—Participants rated their average pain intensity during the past week on a 0-10 Numerical Rating Scale (NRS), with 0 = “no pain” and 10 = “pain as bad as could be.” The 0–10 numeric rating scale has demonstrated validity.¹⁹ Participants provided the date of pain onset in order to estimate pain duration.

Pain treatments and healthcare utilization—Participants indicated whether they had ever used or were currently using any of 25 specific treatments for pain and an “other” category for any not listed. For each treatment that had been tried, respondents indicated the amount of perceived relief that treatment had provided on a 0 (no relief) to 10 (complete relief) scale. The frequency of healthcare visits for pain (to primary care providers, other physicians, physical/occupational therapists, chiropractor, emergency department, and other) during the previous six months was also assessed.

Data Analysis

Descriptive analyses described the frequency and severity of pain in this sample as well as utilization, amount of relief obtained, and duration of pain relief for each pain treatment. Rates, percent, means, and standard deviations were computed for the healthcare utilization questions to describe healthcare utilization for pain in this sample. Correlational analyses examined the association between pain duration and treatment utilization.

Results

Participants

Participants ($n = 125$) were predominantly female (75.2%), white (96.8%), and an average of 50.8 years old ($SD = 10.8$ yrs). Most (68.0%) were married or living with a partner and had completed at least some education beyond high school (88.0%), with 25.6% employed full or part-time. Participants reported a range of MS disease courses: 53.3% relapsing/remitting, 23.8% secondary progressive, 13.1% primary progressive, and 9.8% progressive relapsing. Half of the sample (50.0%) had severe disease on the EDSS, with the remainder reporting mild (27.9%) or moderate (22.1%) disease severity. The mean number of years since MS diagnosis was 12.9 ($SD = 10.0$). Participants reported having pain for an average of 8.8 years ($SD = 8.9$). Fewer than 2% reported no pain (0 on NRS), 46.4% reported mild pain (1-4 on NRS), 27.2% reported moderate pain (5-6 on NRS), and 24.8% reported severe pain (7-10) for the week preceding survey completion.

Pain Treatments

All participants reported trying 1 treatment for pain at some point in the past; 89.6% reported current use of 1 pain treatment at the time of this survey. The majority (89.6%) reported use of multiple treatments (range = 1-19, median = 9.0, mean = 9.0, $SD = 4.2$). Pain duration was positively associated with the number of treatments ever tried ($p < .01$).

Table 1 lists the percent of participants with pain who had tried each pain treatment at least once previously, the percent who reported current use of each treatment, and the perceived amount of pain relief provided by each treatment. Medications were the most frequently tried treatments: two non-prescription medications, NSAIDs and acetaminophen, had been tried for pain by >75% of the sample and were also currently being used by a large proportion of persons who had tried them. Baclofen and opioid medications had also been tried by a large number of participants. Only 23.2% reported using gabapentin, and of these, 62.1% were still using it at the time of the survey. Of those who reported use of marijuana for pain, over half reported continued use (54.5%).

Several physical modalities were also commonly reported: >64% reported trying strengthening exercises or physical therapy for pain, with >50% reporting the use of massage, heat, or ice. Chiropractic care was also common (40.8%). Regarding psychological interventions, 27.2% reported trying counseling/psychotherapy for pain, with fewer reporting biofeedback/relaxation training (19.2%) or hypnosis (3.2%). In addition to the 25 treatment choices on the survey, patients wrote-in 21 treatments in the "other" category. Examples included acupressure, prayer, diet, topical medications, and feldenchrist exercises.

As seen in Table 1, the treatments that were reported to provide the greatest pain relief were not those that were the most frequently used. Among the treatments reportedly tried by >25% of the sample, those rated as most helpful were opioid medications (mean = 6.6), benzodiazepines (mean = 6.4), and massage (mean = 5.6). Hypnosis was the most highly rated (mean = 7.3) for the few (N=4, 3.2%) who had tried it. Two other highly rated but infrequently tried treatments were nerve blocks (mean = 6.7, N=11) and marijuana (mean = 6.1, N=22). Other treatments that provided some pain relief (relief rating ≥ 5.0 on the 0–10 scale) were NSAIDs, gabapentin, mexiletine, and heat. Treatments that reportedly provided relatively little relief (relief rating < 4.0) were tricyclic antidepressants, dilantin, physical therapy, chiropractic care, acupuncture, counseling/psychotherapy, biofeedback/relaxation training, and magnets.

Healthcare Utilization

Table 2 reports on the proportion of the sample who reported visiting a healthcare provider for pain in the six months prior to the survey. Overall, 75% reported at least one visit to a provider for pain in the past six months, and participants made, on average, 9.7 visits (SD = 14.4; mode = 4.0) for pain during this same time period. Primary care providers were the most frequently visited, followed by specialty physicians. Approximately 1 in 10 participants reported seeking care from an Emergency Department for pain in the six months preceding the survey. In addition, 23% of the sample reported seeking care for pain in the past six months from any of a variety of healthcare providers written in under the “other category”, including dentists, acupuncturists, massage therapists, naturopathic providers, and nurses.

Discussion

The current study extends prior research by detailing the specific pain treatments utilized by individuals with MS and pain, patients’ perceptions of the effectiveness of these treatments, and the frequency of visits to specific healthcare providers for pain. Participants with MS and pain sought pain relief via a broad range of pain treatments and a surprisingly high number of visits to healthcare providers (average of 9.7 visits in the last 6 months). Most (75%) participants visited a provider for pain management in the preceding six months, with many seeking assistance from multiple providers. An alarming 11% presented to an emergency department for pain management, one of the most costly and ineffective ways to manage pain in a chronic condition. The frequency of ER visits may also reflect the intensity and/or intractability of pain episodes, as well as the timing of flare-ups at night or on weekends when other options for pain care are not available.

In terms of specific treatments, an overwhelming majority (89.6%) reported current use of 1 treatment. Of the broad range of pain treatments tried, nonprescription medications and physical modalities (strengthening exercises, physical therapy, massage) were the most commonly reported treatments. However, these treatments were perceived to be only moderately effective. Similarly, the treatments that provided the greatest self-reported pain relief were *not* the most frequently used. The treatments that were rated as providing the most pain relief (benzodiazepines, nerve blocks, hypnosis, marijuana) had been tried by

<25% of the sample. It is possible that side effects, costs, access, or other factors may contribute to choice of pain treatments, although such factors were not assessed in this study. Regardless of the reasons, this mismatch between treatment utilization and perceived effectiveness may increase healthcare costs unnecessarily.

We were particularly interested in the utilization of psychological interventions for pain, as evidence shows that psychological interventions for pain (e.g., cognitive-behavioral therapy, hypnosis) are effective in decreasing pain severity and the negative impact of pain on peoples' lives in other pain populations.^{20,21} Similar to studies in spinal cord injury,^{22,23} neuromuscular disease,²⁴ and limb loss,²⁵ our results suggest that psychological interventions for pain are infrequently utilized by persons with MS, despite the fact that a psychological intervention, self-hypnosis training, garnered the highest rating of pain relief of *all* of the treatments studied. Hypnosis is currently the psychosocial intervention with the most evidence supporting its efficacy for decreasing pain in MS.²⁶⁻²⁸ In contrast, both psychotherapy and biofeedback/relaxation training provided little self-reported pain relief. Although this may be surprising given the efficacy of such interventions in the pain literature, the present study asked only about pain relief and did not assess other core outcomes²⁹ such as pain-related interference with functioning or depression, both of which may be more affected by psychological interventions. Moreover, while our list of treatments was more comprehensive than previously published studies, the quality, dose, and ingredients of psychotherapy was not assessed. It is unknown whether or not the treatments used were empirically supported interventions for pain (e.g, cognitive-behavioral therapy).

This study has several limitations. The sample was drawn from community-dwelling participants who had previously participated in a quality of life survey. Although this allowed us to obtain the perspective of people living with pain in the community as opposed to a clinic population with its own inherent biases, the sample may not be representative of the general MS population. The sample size precluded us from conducting subgroup analyses to see if there were differences in utilization or perceived effectiveness for demographic or disease-related subgroups. This study used retrospective self-report data, which allowed us to examine the perceived effectiveness of pain treatments from the patients' perspectives. Future studies should consider examining pain care utilization prospectively and from other sources, such as medical records and telephone surveys. However, the patient's perspective is increasingly being recognized as critical to improved healthcare outcomes, as evidenced by the focus on patient-centered outcomes research and the Patient Centered Outcomes Research Institute (<http://www.pcori.org/>).³⁰ Another limitation is that there is overlap between treatment modalities (e.g, physical therapy, strengthening exercises, and range of motion), so some of the survey's treatment categories may overlap; additionally, other treatments are constantly changing (e.g., introduction of new pharmacologic interventions). While the present study is more comprehensive than prior studies of the breadth of pain treatments in MS, it is difficult to perfectly capture all available options. Lastly, we recommend that future research should clarify the nature of treatments as well as examine reasons for discontinuation of pain interventions.

Despite these limitations, our study's findings suggest that pain in MS is inadequately treated from the perspective of persons with MS and may result in a high level of healthcare

utilization. These results highlight the need for additional research identifying, developing, and testing pain interventions in MS. Nonpharmacological treatments, in addition to medications, warrant investigation given the frequency with which they were used in this study. Identifying effective treatments will likely not suffice, however: we found that the treatments being utilized were *not* the treatments that participants identified as most effective for pain relief or that have the most support in the literature. For example, hypnosis, marijuana, and nerve blocks were three of the highest-rated interventions for perceived effectiveness, but were used by very few people with MS and pain. Research is needed which examines and rectifies dissemination and implementation gaps. Systems approaches, such as collaborative care, may represent a promising way to address these translation concerns.^{31,32} Conducting research in partnership with relevant stakeholders, including patients with MS and pain and their providers, may facilitate the identification and utilization of effective treatments through increased social validity and patient-centeredness.³³

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Table 1

Proportion of Participants Who Used and the Average Pain Relief Ratings for Each Treatment

Treatment	% Ever Used	% Still Using*	Pain Relief Rating** Mean (SD)
<u>Medications</u>			
Nonsteroidal anti-inflammatory drugs	82.4	69.9 (72/103)	5.1 (2.7)
Acetaminophen	78.4	58.2 (57/98)	4.8 (2.6)
Baclofen	46.4	55.2 (32/58)	4.8 (3.5)
Opioid medications	42.4	37.7 (20/53)	6.6 (2.9)
Tricyclic antidepressants	27.2	38.2 (13/34)	3.9 (2.9)
Benzodiazepines	25.6	43.8 (14/32)	6.4 (2.5)
Gabapentin	23.2	62.1(18/29)	5.1 (2.8)
Carbamazepine	17.6	40.9 (9/22)	4.2 (4.2)
Dilantin	6.4	12.5 (1/8)	2.9 (3.6)
Mexiletine	2.4	66.7 (2/3)	5.7 (5.1)
<u>Other Physical Modalities</u>			
Strengthening exercises	68.0	62.3 (53/85)	4.5 (2.8)
Physical therapy	64.8	16.0 (13/81)	3.8 (2.9)
Massage	54.4	35.3 (24/68)	5.6 (2.4)
Heat	53.6	49.2 (33/67)	5.0 (2.5)
Ice	52.8	43.9 (29/66)	4.4 (2.4)
Mobility or range of motion exercises	48.0	66.7 (40/60)	4.2 (3.1)
Chiropractic care	40.8	19.6 (10/51)	3.9 (3.3)
Acupuncture	27.2	5.9 (2/34)	3.9 (2.9)
TENS ⁺	12.8	12.5 (2/16)	4.7 (2.8)
Nerve blocks	8.8	0 (0/11)	6.7 (3.0)
<u>Psychological Interventions</u>			
Counseling or Psychotherapy	27.2	41.1 (14/34)	3.7 (3.2)
Biofeedback or Relaxation Training	19.2	20.8 (5/24)	3.9 (2.5)
Hypnosis	3.2	25.0 (1/4)	7.3 (2.5)
<u>Other interventions</u>			
Magnets	22.4	10.7 (3/28)	2.0 (2.9)
Marijuana	17.6	54.5 (12/22)	6.1 (2.7)

* the % currently using it is the proportion of those report current use/ the number reporting ever trying the treatment

** 0 = no pain relief to 10 = complete pain relief

⁺TENS: transcutaneous electrical nerve stimulation

Table 2

Healthcare Utilization for Pain During Past Six Months

Type of Provider	% Visiting	Mean (SD) # of visits	Range of Visits
Primary care provider	62%	2.1 (3.2)	0-24
Specialty physician	47%	1.8 (4.3)	0-30
Physical or occupational therapist	33%	3.5 (9.1)	0-48
Emergency Department	11%	0.3 (0.9)	0-6
Chiropractor	9%	0.5 (9.1)	0-20
Other Providers	23%	1.7 (5.7)	0-52
Overall Totals	75%	9.7 (14.4)	0-81

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