Published in final edited form as:

Arch Phys Med Rehabil. 2008 October ; 89(10): 1933–1940. doi:10.1016/j.apmr.2008.03.018.

Pain in Persons With Postpolio Syndrome: Frequency, Intensity, and Impact

Brenda L. Stoelb, PhD, Gregory T. Carter, MD, Richard T. Abresch, MS, Sophia Purekal, BA, Craig M. McDonald, MD, and Mark P. Jensen, PhD

From the Department of Rehabilitation Medicine, University of Washington School of Medicine, Seattle, WA (Stoelb, Carter, Purekal, Jensen); and Department of Physical Medicine and Rehabilitation, University of California/Davis, Sacramento, CA (Abresch, McDonald).

Abstract

Objective—To describe the frequency, intensity, and impact of pain in persons with postpoliomyelitis syndrome (PPS).

Design—Retrospective, cross-sectional survey.

Setting—Community-based survey.

Participants—Convenience sample of people with PPS.

Interventions—Not applicable.

Main Outcome Measures—Overall intensity and duration of pain, pain sites, pain interference, pain treatments, and relief provided by pain treatments.

Results—A total of 91% (n=57) of the study participants (N=63) reported pain. The most frequently reported pain sites were the shoulders, lower back, legs, and hips. Participants reported pain intensity to be the greatest in the knees, legs, wrists, lower back, and head. Pain interfered most with sleep and with activities requiring a high level of musculoskeletal involvement. Respondents also reported pain problems that were more severe than those of the general population and than those of a sample of people with multiple sclerosis. Many treatments had been tried previously for pain, but continued use of treatments was reported by relatively few participants at the time of the survey.

Conclusions—The findings indicate that pain is a persistent and common problem in persons with PPS, highlighting the need for effective and accessible pain treatments for this population.

Keywords

Pain; Postpoliomyelitis syndrome; Rehabilitation

Research suggests that chronic pain may be a common problem for people living with progressive NMDs such as PPS.^{1–5} PPS is a disorder characterized by a cluster of neurologic and nonneurologic symptoms that appear decades after a patient has recovered from the initial poliovirus infection.⁶ Classic symptoms of PPS include new and progressive muscle weakness, general fatigue, and muscle and joint pain.^{6–8} Some patients with PPS also exhibit breathing or swallowing problems, sleep-related breathing disorders (eg, sleep apnea), muscle cramping,

Reprint requests to Brenda L. Stoelb, PhD, Dept of Rehabilitation Medicine, University of Washington, Box 356490, Seattle, WA 98195-6490, e-mail: bstoelb@u.washington.edu.

No commercial party having a direct financial interest in the results of the research supporting this article has or will confer a benefit on the authors or on any organization with which the authors are associated.

and decreased tolerance of cold temperatures.⁷ Although late onset of polio-like symptoms in poliomyelitis survivors was documented by the medical community as far back as the late 1800s,^{6,8,9} scientific research on PPS did not begin until the late 1970s and early 1980s when large numbers of polio survivors began presenting to health care providers with symptoms.^{10,11} Studies conducted in the 1990s estimated the occurrence of PPS among polio survivors to range from 29% to 64%.¹² Currently it has been estimated that anywhere from 200,000 to 640,000 people in the United States are dealing with symptoms of PPS.^{6,9,13}

The average interval between acute poliomyelitis infection and onset of PPS is approximately 35 years, with a range of 8 to 71 years.^{7,9} Because no diagnostic test exists, PPS is often considered a diagnosis by exclusion.⁹ Per consensus of the Post-Polio Task Force and the March of Dimes, diagnostic criteria for PPS include the following: (1) a prior episode of paralytic poliomyelitis with residual motor neuron loss, confirmed by history and/or neurologic examination and electromyography; (2) a period of neurologic recovery (usually ≥ 15 y) followed by an interval of neurologic and functional stability; (3) a gradual or abrupt onset of new weakness and/or abnormal muscle fatigability (decreased endurance) with or without generalized fatigue, atrophy, and/or pain; (4) symptoms persist for at least 1 year; and (5) exclusion of other medical conditions that may be causing the above symptoms.⁶⁻⁸ Factors thought to play a role in the development of PPS include attrition of motoneurons, muscle overuse and disuse, the normal aging process, and immunologic mechanisms.^{8,14-20}

Fatigue, muscle weakness, and joint and muscle pain are the most common symptoms of PPS. Results from various studies have found that the prevalence of joint pain ranges from 42%²¹ to 80%²² and the prevalence of muscle pain ranges from 38%²¹ to 86%²² (see Maynard and Gawne²³ for a review). In 1 sample of 150 polio survivors,²⁴ 80% of those surveyed complained of pain. Similarly, pain was the most common complaint in a sample of 875 postpolio patients, occurring in 79% of those surveyed.²⁵ With regard to pain intensity, persons with PPS have reported levels of pain severity significantly higher than national norms on the bodily pain subscale of the SF-36.¹ Other researchers have documented that women with PPS may be more likely to experience pain or may experience more severe pain than men with PPS.^{5,26} Pain is not only common in persons with PPS, but it tends to be rated as moderate to severe, tends to occur in many locations (average, 17.3 body areas), and is related to disruptions in daily living.^{27,28} Joint pain in persons with PPS tends to be caused by overuse and postural changes due to unbalanced muscle strength, whereas muscle cramps, fasciculations, and overuse can lead to muscle pain.⁶

Although research has documented that pain is a significant problem for many people with PPS, much remains unknown about the nature and scope of pain in persons with PPS who are living in the United States. For example, many of the published studies have been conducted in foreign countries,^{5,26,27} and few studies have examined the association between the presence and severity of pain and other important functioning variables (eg, pain interference with daily activities). Also, no studies have examined the frequency and relative efficacy of pain treatment use in samples of people with PPS. Given that (1) the U.S. population is aging at an unprecedented rate and (2) the American health care system is facing numerous logistical and financial challenges, accurate information about pain and its impact in persons with PPS will be of vital importance for health care providers delivering services to those suffering from the disorder.

This study sought to address the need for additional information on the scope of pain in persons with PPS and has 3 major aims: (1) to describe pain interference and the frequency, intensity, and location of pain in a community-drawn, convenience sample of persons living with PPS; (2) to compare pain severity in persons with PPS to national norms and to other groups of

persons living with disabilities; and (3) to describe the frequency of pain treatments used by persons with PPS and their relative effectiveness.

METHODS

Participants

All study protocols and the research methodology were approved by human subjects review committees at the University of Washington Medical Center and at the University of California-Davis. Participants for the present study were recruited from several sources and volunteered to participate after being informed of the study. A total of 85 participants came from a list of patients seen by 1 of the authors (G.T.C.) who is a physician at the University of Washington School of Medicine's Postpolio Syndrome Clinic. An additional 10 participants contacted study personnel themselves, usually having learned about the study through an advertisement. Of the participants included in the study, 1 had completed a previous survey by our team of researchers; 2 were drawn from patients seen at the University of Washington School of Medicine's Limb Viability Clinic; and 4 were recruited through miscellaneous sources. To be included in the survey study, participants had to endorse (via self-report) that they had been diagnosed with PPS. Participants were excluded from the study if they were not 18 years of age or if they could not read or write in English. They were not excluded if they endorsed additional medical or pain problems.

The survey was sent to a total of 102 people. To avoid an overrepresentation of respondents with pain, both a cover letter and the consent form described the survey as a study on quality of life in persons with disabilities rather than only a study about pain. Respondents were paid \$25 for completing and returning the survey. Research assistants contacted respondents by telephone to ask about, and complete, any items on the survey that were left blank or were unclear. Of the 102 surveys mailed, 12 were sent back due to incorrect addresses. One addressee was ineligible for inclusion in the study because he/she did not have PPS. Of the remaining 89 possible participants, 63 returned completed surveys, for a response rate of 71%. Of the 63 study participants, 53 (84%) were referred by the physician mentioned above (G.T.C.) and had a confirmed diagnosis of PPS. A diagnosis of PPS for these patients was made using standard, accepted clinical criteria (eg, Postpolio Task Force diagnostic criteria). We did not confirm the PPS diagnosis of the remaining 10 self-referred participants.

Measures

The survey included questions about demographic information, PPS-related information, pain intensity/severity and duration, pain location, pain interference, and pain treatments as described below.

Demographic characteristics and PPS-related information—Participants responded to questions about their sex, age, race and ethnicity, educational level, and marital and employment status. They were also asked to provide information about their PPS diagnosis including approximate date of onset of poliomyelitis symptoms and approximate date of onset of PPS symptoms (table 1). To assess frequency of pain problems, participants were asked “Are you currently experiencing, or have you in the past 3 months experienced any pain (other than occasional headaches or menstrual cramps)?” Participants who responded affirmatively to this question were then asked to provide additional information about pain intensity/severity, duration, site(s), interference, and treatments.

Pain intensity/severity and duration—An 11-point NRS (range, 0 [no pain] to 10 [pain as bad as could be]) taken from the Graded Chronic Pain Scale²⁹ was used to assess participants' average pain intensity during the past week. Previous research has supported both

the reliability and validity of NRSs of pain intensity. For example, NRSs have demonstrated strong test-retest reliability for average pain intensity over a 2-day period ($r=.78$),³⁰ have correlated highly with other measures of pain intensity,³¹ and have shown sensitivity in detecting changes in pain due to pain treatment.³² Participants who endorsed that they were experiencing pain problems associated with their PPS, either currently or in the past 3 months, were also asked to provide an approximate date for when their pain began. Because pain is a characteristic symptom of PPS, we did not ask participants if they had ever received a separate pain-related diagnosis. Rather, we asked participants to report on their pain in general and on their pain related to their PPS diagnosis.

To compare our study participants' level of pain severity with that of the general population and with other groups of people with disabilities, the 2-item bodily pain subscale of the SF-36³³ was administered. The bodily pain subscale contains 2 categorical items to assess pain intensity and pain interference: (1) How much bodily pain have you had during the past 4 weeks? (6 possible responses, ranging from "none" to "very severe"); and (2) During the past 4 weeks, how much did pain interfere with your normal work (including work both outside the home and housework)? (5 possible responses, ranging from "not at all" to "extremely"). A single score of pain severity is created by combining participants' responses to these 2 items. This score is then transformed to a 0 to 100 scale, with lower scores indicating greater levels of pain severity.

Pain site(s) and intensity at specific site(s)—Participants were asked to indicate if they had experienced persistent, bothersome pain in 1 or more of 17 specific body sites (head, neck, shoulders, upper back, lower back, arms, elbows, wrists, hands, buttocks, hips, chest, abdomen/pelvis, legs, knees, ankles, feet). For each area in which a participant reported pain, he/she was asked to give the approximate date that the pain began and to rate the average pain intensity in that location during the past week on a 0 (no pain) to 10 (pain as bad as could be) scale.

Pain interference—A 12-item scale adapted from the BPI pain interference scale was used to measure pain interference with daily activities.³⁴ Participants were asked to rate the degree to which pain interfered with 12 different activities during the preceding week on a scale from 0 (does not interfere) to 10 (completely interferes). The original BPI pain interference scale consists of 7 items: general activity, mood, walking ability, normal work (including both work outside the home and housework), relations with other people, sleep, and enjoyment of life. Because many people with PPS are unable to walk irrespective of pain level, we altered the original scale by changing item 3 from "walking ability" to "mobility" (ability to get around) to make it more appropriate for persons with disabilities. In addition, we added 5 items (interference with self-care, recreational activities, social activities, communication with others, and learning new information or skills) to better capture interference in domains that could potentially be affected by pain and that might be highly relevant to persons with physical disabilities. A large body of research³⁴ supports the reliability and validity of the original pain interference scale in assessing pain interference in persons with cancer. Recent research also shows that modified versions of the BPI pain interference scale are psychometrically sound in measuring pain interference in persons with MS³⁵ and in persons with SCI.³⁶ In the current sample, the internal consistency (α) of the modified BPI pain interference scale was .94.

Pain treatments and relief provided by pain treatments—Participants were asked to indicate if they were currently using, or had ever used, any of 25 specific treatments for pain (physical therapy, nerve blocks, biofeedback/relaxation training, acupuncture, magnets, massage, hypnosis, counseling or psychotherapy, mexiletine, gabapentin (Neurontin), tricyclic antidepressants, narcotics or opioids, acetaminophen, aspirin or ibuprofen, diazepam (Valium), carbamazepine (Tegretol), baclofen, transcutaneous electric nerve stimulation units, anticonvulsants, chiropractic adjustments, heat, ice, marijuana, strengthening exercises, or

range of motion exercises). For those treatments that participants had tried, they were asked to indicate the amount of relief that each treatment provided on a 0 (no relief) to 10 (complete relief) scale.

Statistical Analysis—Descriptive statistics were used to determine the frequency, intensity, and location of pain reported by our survey participants. Descriptive analyses were also conducted on the pain interference and the pain treatment data. We used Pearson product-moment correlations (r) to explore the relationship between pain intensity and pain interference. Finally, we used t tests to draw comparisons between our participants' reported pain severity with that of the general population and groups of other people with disabilities.

RESULTS

Pain Frequency and Intensity

A total of 91% ($n=57$) of the sample ($N=63$) reported experiencing current pain or pain within the 3 months preceding completion of the survey. Those respondents with pain reported a moderate average pain intensity $\pm$ SD during the past week of 5.32 ± 2.21 on the 0 to 10 NRS, with 20 (35%) of the 63 participants reporting mild pain (ie, 1–4 on the 0 to 10 NRS), 20 (35%) reporting moderate pain (5–6 on the 0 to 10 NRS), and 17 (30%) reporting severe pain (7–10 on the 0 to 10 NRS). No respondents reporting pain endorsed an average pain intensity of 0 during the past week. The majority of respondents with pain (68% [$n=38$]) indicated having intermittent pain in the past 4 weeks, whereas 32% ($n=18$) indicated their pain was constant during that time period. No respondents with pain indicated being pain-free in the last 4 weeks. People with pain reported experiencing PPS-related pain for a mean of 20.22 ± 12.79 years.

Pain Location

Table 2 lists the percent of participants who reported pain at each location. Participants reported an average of 9.54 ± 3.49 different pain sites (range, 3–17 sites). The most frequent pain sites were shoulder(s) (77%), lower back (75%), legs (75%), and hips (67%). Sites with the highest average pain intensity included knees (5.93 ± 2.56), legs (5.47 ± 2.37), wrists (5.35 ± 2.50), lower back (5.33 ± 2.18), and head (5.33 ± 2.24). On average, participants reported experiencing pain at an approximately earlier age in the legs (38.77 ± 19.60) and the chest (39.18 ± 15.33) compared with the other pain locations.

Pain Interference

Table 3 lists the average ratings of pain interference with the 12 activities of the modified BPI pain interference scale. Pain interfered the most with sleep (mean, 4.60 on the 0 to 10 NRS), followed by recreational activities (4.46), mobility (4.42), and normal work (4.42). The correlation between pain interference and average pain intensity for 3 of the BPI items were weak and nonsignificant, probably due to the high number of respondents citing "0" interference in those areas: (1) relations with other people, (2) communication with others, and (3) learning new skills. For the remainder of the BPI items, pain interference was moderately to strongly associated with average pain intensity (correlation coefficient range, .28 – .51; median, .49).

Severity of Pain Relative to National Norms and Other Disability Groups

On the SF-36 bodily pain subscale, the study sample reported pain problems that were significantly more severe (as indicated by a lower score on the bodily pain subscale; mean, 45.94 ± 20.60) than those of a sample drawn from the U.S. population as a whole (mean, 75.15 ± 23.69 ; $t_{2,535}=9.69$, $P<.001$). The effect size for this difference (d , as calculated by the difference in means divided by the SD of the bodily pain subscale in the PPS sample³⁷) is

1.42, representing a very large difference (Cohen's standards³⁷ for small, medium, and large effects are .20, .50, and .80, respectively). Respondents also reported significantly more severe pain problems on the bodily pain subscale than did a sample of research study participants with MS (mean, 59.93 ± 27.49 ; $t_{241} = 3.69$, $P < .001$).³⁸ The effect size for this difference is moderate ($d = .68$). No significant difference was found on the bodily pain subscale, however, between respondents in the current study and a sample of survey respondents with SCI.³⁹

When compared with subjects with other forms of NMD surveyed in a previous study,⁴⁰ respondents in the current study reported significantly higher levels of average pain intensity in the past week than those categorized with "other" NMD diagnoses (eg, spinal muscular atrophy, primary lateral sclerosis, Duchenne muscular dystrophy) ($t_{77} = 2.44$, $P < .05$). A trend was also observed with participants in the current study reporting higher levels of average pain intensity than those with facioscapulohumeral muscular dystrophy ($t_{71} = 1.71$, $P = .09$). No other significant differences were found between the current sample and the other NMD groups in the previous study (limb girdle muscular dystrophy, Charcot-Marie-Tooth disease, amyotrophic lateral sclerosis, myotonic muscular dystrophy), including those with PPS in the previous sample (ie, not overlapping with this sample), with regard to average pain intensity during the past week.

Pain Treatments and Treatment-Related Pain Relief

The percentage of participants with pain who have tried each of the 25 pain treatments listed above at least once previously, the percentage of those who are currently using each treatment, and the average amount of pain relief provided by each treatment are presented in table 4. It is possible that many patients with mild, or even moderate, pain may find their pain manageable and not use pain treatments. Therefore, the percentages of patients with severe pain (average pain, $\geq$ on a 0 to 10 NRS) who have tried and currently use the pain treatments listed are also presented in table 4. Heat is the treatment that participants had tried most often for pain management (95% of all respondents with pain, 94% of those with severe pain), followed by acetaminophen (77%, 71%), ice (76%, 82%), ibuprofen or aspirin (74%, 65%), and physical therapy (70%, 59%). Despite the high frequency with which some of the treatments had been tried, no single treatment was used currently by a majority of the participants with pain.

Also, there was substantial variability in the frequency with which the treatments reported to be most effective had been tried. For example, approximately 56% of the entire sample, and 53% of those participants with severe pain, reported trying narcotics for pain relief, which received the highest average relief rating (8.11 on a 0 to 10 NRS) from patients reporting severe pain. In contrast, carbamazepine (8.00 average relief for all patients, no patients with severe pain reported trying it), marijuana (5.40 average relief for all patients, 8.00 average relief for patients with severe pain), and nerve blocks (7.57, 8.00) were also reported as being relatively effective, but only 2% to 14% of all participants reported ever trying these 3 methods of pain relief.

DISCUSSION

Our aims in the present study were threefold: (1) to describe pain interference and the frequency, intensity, and location of pain in a community-drawn, convenience sample of persons living with PPS; (2) to compare pain severity in persons with PPS to national norms and to other groups of persons living with disabilities; and (3) to describe the frequency of pain treatments used by persons with PPS and their relative effectiveness. Results from our study showed that 91% of this sample with PPS was experiencing pain currently or in the 3 months preceding the study. Although somewhat high, this figure is generally consistent with rates published in other studies^{24,25,40} and indicates that pain is a common problem for many people living with PPS.

Participants with pain in the present study reported a moderate level of pain intensity (5.32) during the past week on a 0 to 10 NRS, on average, which is very consistent with average pain intensity ratings described by persons with PPS in previous studies.^{27,41} Although the percent of patients with PPS reporting moderate average pain intensity was less in the survey by Jensen et al⁴⁰ (15%) than in the present study (36%), the number of respondents with PPS in that sample was also much smaller (n = 13), which limits the reliability of its findings. In general, however, the average pain intensity reported by participants in the current study was comparable to individuals with other forms of NMD, except for those with “other” NMD diagnoses and those with facioscapulohumeral muscular dystrophy. It is likely that the etiology and usual course of PPS and other NMDs account for these noted similarities and differences.

The mean duration of PPS-related pain in our sample was 20 years, and approximately one third of our participants described their pain as constant. Furthermore, no respondents reported an average pain intensity of “0” in the past week, nor did any respondent report being pain-free in the prior 4 weeks. Our findings, combined with findings from previous studies,^{5,42} suggest that the pain experienced by individuals living with PPS is quite chronic in nature. The chronic and severe nature of pain problems in PPS highlights the need for both effective and appropriate pain treatments. Unfortunately, with regard to pharmacologic treatments, results from both large- and small-scale studies have generally proved unpromising,^{6,43–45} or research has focused solely on reducing fatigue and muscle weakness versus ameliorating pain.^{46,47} Furthermore, to our knowledge, no research has investigated how the effectiveness of pain treatments may vary according to demographic characteristics (eg, sex, age, race and ethnicity). These may be important variables to consider in future studies, because women with PPS may be at greater risk for reporting pain²⁶ and/or may report higher levels of pain intensity.⁵ Duration of pain in PPS may also be greater for women than it is for men. In 1 study,⁵ for example, women had pain for an average of 12 years longer than men; in our sample, although not statistically significant, women reported an average pain duration that was 15 years longer than that of men (33y vs 19y).

The most common sites of pain mentioned by respondents in our study (eg, shoulders, lower back, legs, hips) generally reflect findings reported in other studies.^{5,41} Our respondents also reported pain intensity that was greatest in the knees, legs, wrists, head, and lower back. Pain was relatively widespread in our sample, with participants reporting, on average, 10 different pain sites. Although this number is less than the average number of pain sites (17) reported in a previous study,²⁷ different methods of pain assessment between the 2 studies (pain site checklist vs pain drawing) and reliance on self-report data (in both studies) may account for this variation. Both the common pain sites and the level of pain intensity at these sites reported by our participants likely reflect the mechanisms that either cause or contribute to pain syndromes in PPS (eg, joint instability or deterioration, muscle disuse and overuse, abnormal biomechanics). With regard to age, pain began in the different sites, on average, for all participants when they were between 40 and 50 years of age; the exception was pain in the chest and the legs, which began when participants were between 30 and 40 years of age. Only 9 participants, however, cited chest pain, whereas 43 cited leg pain, which may limit the reliability of this finding. Larger, longitudinal studies are recommended to further explore differences in onset of pain problems by site in those persons living with PPS.

Overall, the average pain intensity in our sample was strongly related to interference with life activities (correlation coefficients, >.45 for 8/12 activities), particularly for sleep and those activities requiring a high level of musculoskeletal involvement. Although a large body of evidence^{48–50} supports the use of exercise in reducing fatigue and improving muscle strength in PPS, very few studies have explored exercise as a means of reducing pain or pain-related interference in PPS populations. Future research in this area appears warranted, given that strong relationships have been documented between fatigue, muscle weakness, and pain in

PPS,^{23,26,27} and, as mentioned previously, research investigating the use of pharmacologic agents for the treatment of pain in PPS has been somewhat unfruitful. With regard to pain-related sleep interference in PPS, possible interventions may include sleep hygiene, relaxation techniques, or training in self-hypnosis. It is important to note that persons with PPS may also exhibit sleep-related breathing disorders, such as sleep apnea; therefore, sleep studies are recommended if sleep problems are not alleviated with other techniques.

Consistent with previous findings,¹ participants in the present study reported pain problems that were significantly more severe than those of the general population. Our sample also reported pain problems that were more severe than those of a sample of persons with MS³⁸ but were not more severe than those of a sample of patients with SCI.³⁹ These findings are likely attributable to similarities and differences in the etiology and course among these conditions. For example, the majority of participants (56%) in the study by Ehde et al³⁸ had relapsing-remitting MS, which is characterized by periods of time (sometimes years) when symptoms “settle down” or even disappear.⁵¹ These periods may result in pain “breaks” for patients with MS, whereas patients with PPS may experience pain that is more chronic in nature. These findings emphasize the need for pain assessment and treatment that is comprehensive and individually tailored to patients’ specific medical conditions.

In the present sample, the application of heat was the most commonly tried treatment for pain, followed by acetaminophen, ice, ibuprofen or aspirin, and physical therapy, which reflects findings from a previous study.²⁴ For treatments that provided the most relief from pain, narcotics, nerve blocks, and marijuana were ranked highest among those participants with severe pain, and carbamazepine, nerve blocks, and narcotics were ranked highest among all participants with pain. Many of the treatments that were listed as providing the greatest relief from pain (eg, marijuana, carbamazepine), had either been tried by very few participants or were no longer being used by as many participants (eg, narcotics). It is likely that these treatments are more difficult to obtain or may involve adverse side effects, resulting in their limited use. However, even among those treatments that were frequently tried and rated as relatively effective, current use had dropped noticeably. For example, whereas 95% of the sample reported having tried heat as a treatment for pain, only 47% reported still using it. Similarly, only 35% of participants were currently using acetaminophen for pain, even though 77% of the sample had tried it. This decrease in use may speak to the lack of truly effective treatments for pain in persons with PPS.

It is important to note, however, that our study did not assess 2 commonly prescribed and empirically supported treatments for pain in PPS: rest or energy conservation (eg, decreasing or pacing activities)^{6,52,53} and the use of orthotics.^{54,55} Although we recommend that future research include these treatments when assessing the frequency and relative effectiveness of pain interventions in PPS, we also suggest that alternate treatments be studied because pain in PPS is often exacerbated by lifestyle activities and differs in quality and intensity based on its source or type. Directions for future investigations may include, but are not limited to, exercise, yoga or stretching routines, instruction in self-hypnosis, or acupuncture. Even those treatments that patients rate as highly effective (eg, heat, massage) have not been investigated empirically¹² and deserve further examination.

Study Limitations

The present study has a number of limitations. First, our assessment methods may have contributed in part to the large number of respondents reporting pain. For example, we asked participants if they had experienced any pain (other than occasional headaches or menstrual cramps) in the last 3 months, which may have led to the inclusion of persons with acute as well as chronic pain and/or those with pain problems not directly related to PPS. Furthermore, we did not report rates for joint and muscle pain separately, nor did we ask participants to

distinguish between these 2 types of pain, unlike some previous studies.²³ Future prevalence studies may want to focus on distinguishing chronic from acute pain in PPS, as both may occur, or examine rates of pain in general, as well as presenting rates of pain specific to PPS. Our study is also limited by various factors including the cross-sectional design, small sample size, and reliance on self-report measures. All of these variables impact the generalizability of our findings to other samples of persons with PPS.

CONCLUSIONS

Results from the present study suggest that pain is a common and persistent problem in PPS, with more than 90% of our participants reporting problems with pain. These findings clearly contradict the belief that PPS is a “painless” disease because of lack of sensory nerve fiber involvement. Frequent pain sites included the shoulder(s), lower back, and legs, with participants reporting an average of 10 different pain sites. Participants in the present study also reported pain problems that were more severe than those of the general population and a sample of persons with MS. Pain intensity in our sample was comparable to that of other NMD groups, except for those classified as having “other” NMD diagnoses, who reported significantly lower levels of pain intensity than our patients with PPS. Pain was found to interfere most often with sleep and with physical activities requiring high levels of musculoskeletal involvement. Findings suggest that pain problems in this population are chronic, with participants reporting an average pain duration of 20 years, and women reporting an even longer average duration than men (33y). Many pain treatments are tried by persons living with PPS, but few are highly effective, and the number of those that are discontinued is high.

Acknowledgments

We thank Lindsay Washington, BA, Laura Nishimura, BS, Kevin Gertz, BA, Emily Phelps, BS, Kristin McArthur, BS/BA, Silvia Amtmann, BA, Noel Pereyra-Johnston, BS/BA, Sylvia Wilson, BA, Kerry Madrone, MA, Sarah O'Brien, BS, Eric Weitz, BS, and Tyler Einhauser, Department of Rehabilitation Medicine, for their contributions in data collection and database management.

Supported by the National Institute of Child Health and Human Development (grant no. P01 HD33988) and National Institute of Disability and Rehabilitation Research (grant no. H133B031118).

List of Abbreviations

BPI, Brief Pain Inventory; MS, multiple sclerosis; NMD, neuromuscular disease; NRS, numeric rating scale; PPS, postpoliomyelitis syndrome; SCI, spinal cord injury; SF-36, 36-Item Short-Form Health Survey.

References

1. Abresch RT, Carter GT, Jensen MP, Kilmer DD. Assessment of pain and health-related quality of life in slowly progressive neuromuscular disease. *Am J Hosp Palliat Care* 2002;19:39–48. [PubMed: 12173612]
2. Halstead LS, Rossi CD. Post-polio syndrome: results of a survey of 350 survivors. *Orthopedics* 1995;8:845–859. [PubMed: 3867865]
3. Wekre LL, Stanghelle JK, Lobben B, Oyhaugen S. The Norwegian Polio Study 1994: a nation-wide survey of problems in long-standing poliomyelitis. *Spinal Cord* 1998;36:280–284. [PubMed: 9589529]
4. Widar M, Ahlström G. Experiences and consequences of pain in persons with post-polio syndrome. *J Adv Nurs* 1998;28:606–613. [PubMed: 9756230]
5. Widar M, Ahlström G. Pain in persons with post-polio: the Swedish version of the Multidimensional Pain Inventory (MPI). *Scand J Caring Sci* 1999;13:33–40. [PubMed: 10476192]

6. Bartels MN, Omura A. Aging in polio. *Phys Med Rehabil Clin N Am* 2005;16:197–218. [PubMed: 15561551]
7. Jubelt, B.; Ropka, SL. Poliomyelitis and the postpolio syndrome. In: Younger, DS., editor. *Motor disorders*. Vol. 2nd ed. Philadelphia: Lippincott Williams & Wilkins; 2005. p. 523-537.
8. Trojan DA, Cashman NR. Post-poliomyelitis syndrome. *Muscle Nerve* 2005;31:6–19. [PubMed: 15599928]
9. Halstead, LS. Diagnosing postpolio syndrome: inclusion and exclusion criteria. In: Silver, JK.; Gawne, AC., editors. *Postpolio syndrome*. Hanley & Belfus: Philadelphia; 2004. p. 1-20.
10. Hollingsworth L, Didelot MJ, Levington C. Post-polio syndrome: psychological adjustment to disability. *Issues Ment Health Nurs* 2002;23:135–156. [PubMed: 11901659]
11. Stolwijk-Swüste JM, Beelen A, Lankhorst GJ, Nollet F. CARPA Study Group. The course of functional status and muscle strength in patients with late-onset sequelae of poliomyelitis: a systematic review. *Arch Phys Med Rehabil* 2005;86:1693–1701. [PubMed: 16084828]
12. Jubelt B, Agre JC. Characteristics and management of postpolio syndrome. *JAMA* 2000;284:412–414. [PubMed: 10904484]
13. Gevirtz C. Managing postpolio syndrome pain. *Nursing* 2006;36:17. [PubMed: 17135893]
14. Wiechers DO. New concepts of the reinnervated motor unit revealed by vaccine-associated poliomyelitis. *Muscle Nerve* 1988;11:356–364. [PubMed: 3398882]
15. Wiechers DO, Hubbell SL. Late changes in the motor unit after acute poliomyelitis. *Muscle Nerve* 1981;4:524–528. [PubMed: 6273721]
16. Cashman NR, Maselli R, Wollmann RL, Roos R, Simon R, Antel JP. Late denervation in patients with antecedent paralytic poliomyelitis. *N Engl J Med* 1987;317:7–12. [PubMed: 3587319]
17. Gawne AC, Halstead LS. Post-polio syndrome: pathophysiology and clinical management. *Crit Rev Phys Rehabil Med* 1995;7:147–188.
18. Kaminski HJ, Tresser N, Hogan RE, Martin E. Spinal cord histopathology in long-term survivors of poliomyelitis. *Muscle Nerve* 1995;18:1208–1209. [PubMed: 7659118]
19. Trojan DA, Cashman NR. Pathophysiology and diagnosis of post-polio syndrome. *NeuroRehabilitation* 1997;8:83–92.
20. Trojan DA, Cashman NR, Shapiro S, Tansey CM, Esdaile JM. Predictive factors for post-poliomyelitis syndrome. *Arch Phys Med Rehabil* 1994;75:770–777. [PubMed: 8024423]
21. Ramlow J, Alexander M, LaPorte R, Kaufmann C, Kuller L. Epidemiology of the post-polio syndrome. *Am J Epidemiol* 1992;136:769–786. [PubMed: 1442743]
22. Agre JC, Rodriguez AA, Sperling KB. Symptoms and clinical impressions of patients seen in a postpolio clinic. *Arch Phys Med Rehabil* 1989;70:367–370. [PubMed: 2719539]
23. Maynard, FM.; Gawne, AC. Joint and muscle pain. In: Silver, JK.; Gawne, AC., editors. *Postpolio syndrome*. Hanley & Belfus: Philadelphia; 2004. p. 61-76.
24. Gawne AC, Richards RS, Petroski G. Post-polio muscle pain in polio survivors [abstract]. *Arch Phys Med Rehabil* 2000;81:1621.
25. Yarnell, S. The late effects of polio. In: Sine, R., editor. *Basic rehabilitation techniques: a self-instructional guide*. Vol. 4th ed. New York: Aspen; 2000. p. 60
26. Vasiliadis HM, Collet JP, Shapiro S, Venturini A, Trojan DA. Predictive factors and correlates for pain in postpoliomyelitis syndrome patients. *Arch Phys Med Rehabil* 2002;83:1109–1115. [PubMed: 12161832]
27. Lygren H, Jones K, Grenstad T, Dreyer V, Farbu E, Rekand T. Perceived disability, fatigue, pain and measured isometric muscle strength in patients with post-polio symptoms. *Physiother Res Int* 2007;12:39–49. [PubMed: 17432393]
28. Thorén-Jönsson AL, Grimby G. Ability and perceived difficulty in daily activities in people with poliomyelitis sequelae. *J Rehabil Med* 2001;33:4–11. [PubMed: 11480469]
29. Von Korff M, Ormel J, Keefe FJ, Dworkin SF. Grading of the severity of chronic pain. *Pain* 1992;50:133–149. [PubMed: 1408309]
30. Daut RL, Cleeland CS, Flanery RC. Development of the Wisconsin Brief Pain Questionnaire to assess pain in cancer and other diseases. *Pain* 1983;17:197–210. [PubMed: 6646795]

31. Paice JA, Cohen FL. Validity of a verbally administered numeric rating scale to measure cancer pain intensity. *Cancer Nurs* 1997;20:88–93. [PubMed: 9145556]
32. Jensen, MP.; Karoly, P. Self-report scales and procedures for assessing pain in adults. In: Turk, DC.; Melzack, R., editors. *Handbook of pain assessment*. New York: Guilford Pr; 2001. p. 15-34.
33. Ware, J.; Snow, K.; Kosinski, M. *SF-36 Health Survey: manual and interpretation guide*. Lincoln: QualityMetric; 2000.
34. Cleeland CS, Ryan KM. Pain assessment: global use of the Brief Pain Inventory. *Ann Acad Med Singapore* 1994;23:129–138. [PubMed: 8080219]
35. Osborne TL, Raichle KA, Jensen MP, Ehde DM, Kraft G. The reliability and validity of pain interference measures in persons with multiple sclerosis. *J Pain Symptom Manage* 2006;32:217–229. [PubMed: 16939846]
36. Raichle KA, Osborne TL, Jensen MP, Cardenas D. The reliability and validity of pain interference measures in persons with spinal cord injury. *J Pain* 2006;7:179–186. [PubMed: 16516823]
37. Cohen, J. *Statistical power analysis for the behavioral sciences*. Mahwah: Lawrence Erlbaum Assoc; 1988.
38. Ehde DM, Osborne TL, Hanley MA, Jensen MP, Kraft GH. The scope and nature of pain in persons with multiple sclerosis. *Mult Scler* 2006;12:629–638. [PubMed: 17086910]
39. Jensen MP, Hoffman AJ, Cardenas DD. Chronic pain in individuals with spinal cord injury: a survey and longitudinal study. *Spinal Cord* 2005;43:704–712. [PubMed: 15968299]
40. Jensen MP, Abresch RT, Carter GT, McDonald CM. Chronic pain in persons with neuromuscular disease. *Arch Phys Med Rehabil* 2005;86:1155–1163. [PubMed: 15954054]
41. Willén C, Grimby G. Pain, physical activity and disability in individuals with late effects of polio. *Arch Phys Med Rehabil* 1998;79:915–919. [PubMed: 9710162]
42. Ahlström G, Karlsson U. Disability and quality of life in individuals with postpolio syndrome. *Disabil Rehabil* 2000;22:416–422. [PubMed: 10894205]
43. Farbu E, Rekand T, Vik-Mo E, Lygren H, Gilhus NE, Aarli JA. Post-polio syndrome patients treated with intravenous immunoglobulin: a double-blinded randomized controlled pilot study. *Eur J Neurol* 2007;14:60–65. [PubMed: 17222115]
44. Gonzalez H, Sunnerhagen KS, Sjöberg I, Kaponides G, Olsson T, Borg K. Intravenous immunoglobulin for post-polio syndrome: a randomised controlled trial. *Lancet Neurol* 2006;5:493–500. [PubMed: 16713921]
45. On AY, Oncu J, Uludag B, Ertekin C. Effects of lamotrigine on the symptoms and life qualities of patients with post polio syndrome: a randomized, controlled study. *NeuroRehabilitation* 2005;20:245–251. [PubMed: 16403993]
46. Stein DP, Dambrosia JM, Dalakas MC. A double-blind, placebo-controlled trial of amantadine for the treatment of fatigue in patients with the post-polio syndrome. *Ann N Y Acad Sci* 1995;753:296–302. [PubMed: 7611638]
47. Trojan DA, Cashman NR. Fibromyalgia is common in a post-poliomyelitis clinic. *Arch Neurol* 1995;52:620–624. [PubMed: 7763212]
48. Agre, JC. Exercise in the treatment of postpolio syndrome. In: Silver, JK.; Gawne, AC., editors. *Postpolio syndrome*. Philadelphia: Hanley & Belfus; 2004. p. 117-143.
49. Fillyaw MJ, Badger GJ, Goodwin GD, Bradley WG, Fries TJ, Shukla A. The effects of long-term non-fatiguing resistance exercises in subjects with post-polio syndrome. *Orthopedics* 1991;14:1253–1256. [PubMed: 1758792]
50. Gross MT, Schuch CP. Exercise programs for patients with post-polio syndrome: a case report. *Phys Ther* 1989;69:72–76. [PubMed: 2911619]
51. Multiple Sclerosis Society. What is relapsing remitting MS?. 2008 [Accessed Aug 24]. Available at: http://www.mssociety.org.uk/about_ms/types_of_ms/what_is_rrms.html
52. Agre JC, Rodriguez AA. Neuromuscular function in polio survivors at one-year follow-up. *Arch Phys Med Rehabil* 1991;72:7–10. [PubMed: 1985626]
53. Packer TL, Martins I, Krefting L, Brouwer B. Activity and post-polio fatigue. *Orthopedics* 1991;14:1223–1226. [PubMed: 1758789]

54. Perry J, Fontaine JD, Mulroy S. Findings in post-poliomyelitis syndrome: weakness of the muscles of the calf as a source of late pain and fatigue of muscles of the thigh after poliomyelitis. *J Bone Joint Surg Am* 1995;77:1148–1153. [PubMed: 7642658]
55. Waring WP, Maynard F, Grady W, Grady R, Boyles C. Influence of appropriate lower extremity orthotic management on ambulation, pain, and fatigue in a postpolio population. *Arch Phys Med Rehabil* 1989;70:371–375. [PubMed: 2719540]

Table 1**Study Sample Characteristics (N=63)**

Characteristics	Values
Sex, male/female (%)	38/62
Mean age $\pm$ SD (range), y	63.97 $\pm$ 8.92 (45–85)
Mean years since PPS symptom onset $\pm$ SD (range)	28.80 $\pm$ 16.85 (2.84–60.95)
Mean polio-PPS interval $\pm$ SD (range), y	34.46 $\pm$ 8.97 (9.95–63.00)
Ethnic group (%) [*]	
White	95
Native American	2
Black	0
Hispanic	0
Asian/Pacific Islander	2
Other	3
Marital status (%)	
Married	57
Never married	11
Divorced	16
Living with partner	5
Widowed	11
Separated	0
Education, highest level (%)	
Grade 11 or lower	6
High school/GED	8
Vocational/technical/business school	3
Some college	25
College graduate	22
Graduate/professional school	35
Employment (%) [*]	
Employed full-time	11
Employed part-time	6
School/vocational training	0
Retired	59
Homemaker	10
Unemployed	48

Abbreviation: GED, General Educational Development diploma.

^{*} Total sums to greater than 100% because respondents were allowed to select more than 1 option.

Table 2

Pain Locations, Average Pain Intensity, and Approximate Average Age at Which Pain Began for All Subjects Reporting Pain (n=57)

Pain Location	n	%	Average Pain Intensity $\pm$ SD	Approximate Average Age Pain Began $\pm$ SD (y)
Head	8	14	5.33 $\pm$ 2.24	42.82 $\pm$ 16.14
Neck	35	61	4.57 $\pm$ 2.36	46.59 $\pm$ 19.90
Shoulder	44	77	4.77 $\pm$ 2.36	49.78 $\pm$ 18.64
Upper back	24	42	5.25 $\pm$ 2.19	45.18 $\pm$ 18.89
Lower back	43	75	5.33 $\pm$ 2.18	46.60 $\pm$ 20.44
Arms	27	47	4.33 $\pm$ 2.35	43.44 $\pm$ 19.38
Elbows	16	28	5.19 $\pm$ 2.32	43.61 $\pm$ 21.20
Wrists	21	37	5.35 $\pm$ 2.50	49.16 $\pm$ 19.64
Hands	29	51	4.72 $\pm$ 2.28	49.00 $\pm$ 20.01
Buttocks	13	23	4.23 $\pm$ 2.20	41.56 $\pm$ 17.06
Hips	38	67	4.95 $\pm$ 2.31	46.02 $\pm$ 18.77
Chest	9	16	3.56 $\pm$ 2.65	39.18 $\pm$ 15.33
Abdomen/pelvis	15	26	4.53 $\pm$ 2.62	43.09 $\pm$ 18.90
Legs	43	75	5.47 $\pm$ 2.37	38.77 $\pm$ 19.60
Knees	30	53	5.93 $\pm$ 2.56	43.08 $\pm$ 24.13
Ankles	24	42	5.17 $\pm$ 2.58	44.07 $\pm$ 21.88
Feet	27	47	4.59 $\pm$ 2.87	46.44 $\pm$ 20.45

NOTE. The n value for average age is lower because not all participants could recall date when pain began.

Table 3
Pain Interference for All Subjects Reporting Pain (n=57)

Measure	Mean $\pm$ SD	Correlation With Average Pain Intensity	95% Confidence Interval
General activity	3.96 $\pm$ 2.61	.49 [*]	.26 to .67
Mood	3.49 $\pm$ 2.71	.28 [†]	.02 to .50
Mobility (ability to get around)	4.42 $\pm$ 3.08	.50 [*]	.28 to .67
Normal work (including housework)	4.42 $\pm$ 2.90	.49 [*]	.26 to .67
Relations with other people	2.40 $\pm$ 2.40	.24	-.02 to .47
Sleep	4.60 $\pm$ 2.97	.51 [*]	.29 to .68
Enjoyment of life	4.02 $\pm$ 3.00	.32 [†]	.07 to .54
Self-care	2.05 $\pm$ 2.31	.47 [*]	.24 to .65
Recreational activities	4.46 $\pm$ 3.42	.51 [*]	.29 to .68
Social activities	4.00 $\pm$ 3.01	.46 [*]	.23 to .64
Communication with others	1.95 $\pm$ 2.23	.16	-.10 to .40
Learning new skills	2.36 $\pm$ 2.70	.16	-.11 to .41
Mean BPI score	3.51 $\pm$ 2.17	.50 [*]	.28 to .67

NOTE. Not all participants responded to each BPI item, so the n values differ slightly (range, 55–57).

^{*} $P < .001$

[†] $P < .05$.

Table 4

Percentage of Participants With Pain Who Have Tried Each Treatment, Percentage of Participants Who Still Use the Treatment, and Average Relief Rating Associated With Each Treatment

Pain Treatment	All Subjects With Pain (n=57)		Subjects With Severe Pain (n=17) [*]	
	Percentage Tried/ Percentage Still Use	Average Relief ± SD	Percentage Tried/ Percentage Still Use	Average Relief ± SD
Physical therapy	70/11	5.34±2.86	59/12	4.89±3.55
Nerve blocks	14/0	7.57±1.81	12/0	8.00±2.83
Biofeedback/relaxation training	30/2	3.56±3.20	35/6	4.33±4.41
Acupuncture	26/4	3.73±3.63	29/0	3.60±4.98
Magnets	32/4	2.47±2.67	35/0	2.75±2.99
Massage	51/19	6.68±2.16	53/12	6.63±2.93
Hypnosis	9/4	0.60±1.34	12/6	0.00±0.00
Counseling	16/0	3.00±3.20	18/0	6.00±2.65
Mexiletine	0/0	†	0/0	†
Gabapentin (Neurontin)	16/4	3.22±3.99	13/6	3.50±4.95
Tricyclic antidepressants	26/7	3.85±3.11	24/6	3.33±4.16
Narcotics	56/32	7.13±2.56	53/29	8.11±2.52
Acetaminophen	77/35	4.11±3.17	71/30	4.75±3.55
Aspirin or ibuprofen	74/44	4.88±3.13	65/24	5.45±3.88
Diazepam (Valium)	25/7	7.00±1.81	18/0	6.67±2.08
Carbamazepine (Tegretol)	2/0	8.00±0.00	0/0	†
Baclofen	5/0	1.33±2.31	6/0	0.00±0.00
TENS unit	26/0	3.77±3.44	24/0	2.50±3.32
Phenytoin (Dilantin), anticonvulsants	11/2	3.00±4.69	25/0	2.50±5.00
Chiropractor	30/4	5.25±3.17	47/6	5.88±3.04
Heat	95/47	5.74±2.26	94/47	6.13±1.92
Ice	76/25	5.19±2.75	82/35	5.00±3.01
Marijuana	9/4	5.40±3.29	6/0	8.00±0.00
Strengthening exercises	70/28	3.12±2.83	53/18	3.11±2.98
Range of motion exercises	63/39	4.29±2.90	41/24	3.00±3.00

Abbreviation: TENS, transcutaneous electric nerve stimulation.

^{*} Severe pain is defined as average pain per week ≥ 7 on a 0 to 10 NRS.

† No one reported using the particular pain treatment.