

Rancho Los Amigos

Post-Polio Support Group

Newsletter - June 2018

Post-Polio Pain: A Review

Reported by Richard Daggett, Editor

Recent comments at support groups and online suggest that pain might be one of the most discussed topics among polio survivors. Pain ranks second only to increased weakness as the primary coping issue. Most of us can tolerate some degree of pain if we know it will decrease with time. Constant or nagging pain is different. Pain that is present most of the time can be debilitating. It can lesson our ability to function physically, or even think clearly.

A study published in the Archives of Physical Medicine and Rehabilitation (APMR) looked at pain location and intensity in 63 individuals with post-polio. The relatively small number of participants precludes generalizations, but it should provide useful information for polio survivors and might lead to further research.

Fatigue, muscle weakness, and joint and muscle pain are the most common symptoms of PPS. Results from previous studies have found that the prevalence of joint pain ranges from 42% to 80% and the prevalence of muscle pain ranges from 38% to 86%. The most frequent pain sites reported in this study were the shoulders, lower back, legs, and hips. Pain interfered most with sleep and with activities requiring a high level of lifting or repetitive efforts.

Pain is not only common in persons with PPS, but pain in general tends to be rated as moderate to severe, tends to occur in many locations, and is related to disruptions in daily living. Joint pain in persons with PPS tends to be caused by overuse and postural changes due to unbalanced muscle strength. Muscle pain is also caused by overuse, and can produce cramps and fasciculations (involuntary contractions or twitching of muscle fibers).

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The information presented at our meetings and/or contained in this newsletter is solely for information. It is not an endorsement of any product, medication, or individual.

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Research Methods

Participants in this study were asked to indicate if they had experienced persistent, bothersome pain in one or more of seventeen 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 previous week on a zero (no pain) to ten (pain as bad as could be) scale.

Participants were also asked to rate the degree to which pain interfered with twelve different activities during the preceding week, on a scale from zero (does not interfere) to ten (completely interferes).

They used a modified pain interference scale or BPI*. The original BPI pain scale consisted of seven 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, regardless of pain level, the authors 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, they added five items (interference with self-care, recreational activities, social activities, communication with others, and learning new information or skills) to better capture interference in areas that could potentially be affected by pain and that might be highly relevant to persons with physical disabilities.

• The Brief Pain Inventory (BPI), previously known as the Brief Pain Questionnaire, is a self-administered questionnaire that was originally designed to assess cancer pain. It is now also used as a generic pain questionnaire for other chronic pain conditions.



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Pain Treatments and Relief

Participants were asked to indicate if they were currently using, or had ever used, any of twenty-five specific treatments for pain. The numbers after each treatment (below) indicate how many participants tried this specific treatment, and how many were still using this treatment.

- Transcutaneous Electric Nerve Stimulation units (TENS) 26//0
- Physical therapy 70/11
- Nerve blocks 14/0
- Biofeedback/relaxation training 30/2
- Acupuncture 26/4
- Magnets 32/4
- Massage 51/19
- Hypnosis 9/4
- Mexiletine 0/0
- Gabapentin (Neurontin) 16/4
- Tricyclic antidepressants 26/7
- Narcotics or opioids 6/32
- Acetaminophen 77/35

- Aspirin or ibuprofen 74/44
- Diazepam (Valium) 25/7
- Carbamazepine (Tegretol) 2/0
- Baclofen 5/0
- Anticonvulsants 11/2
- Chiropractic adjustments 30/4
- Heat 95/47
- Ice 76/25
- Marijuana 9/4
- Strengthening exercises 70/28
- Range of motion exercises 63/39

It is important to note that this study did not assess two commonly prescribed treatments for pain in PPS. These are rest or energy conservation (e.g., decreasing or pacing activities), and the use of orthotics or mobility aids. Both of these treatments have been helpful to many.

The authors recommended that future research include these treatments when assessing the frequency and relative effectiveness of pain interventions in PPS. They 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 the pain's source or type.

It is striking to note the number of participants who tried various pain treatments and the number of participants who had discontinued those same treatments. It would be interesting to know if the discontinuance was because the treatments were not successful, or if the treatments were not the "magic bullet" that the participants were expecting. We have listened to many polio survivors who expressed disappointment about treatment strategies that were, "O.K., but not what I hoped for." After a trial period they stop the treatment and try another, or give up looking entirely. Is it possible that their expectations were not realistic?

In this survey, oral pain medications ranging from narcotics (opiates) to aspirin had the highest

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percentage of "tried" and "still using". Applying heat and using range of motion exercises were also fairly successful. Twenty-six participants tried transcutaneous electric nerve stimulation units (TENS), but no participant continued to use that treatment.

Vibrators for the Alleviation of Chronic Pain

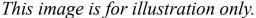
Another study assessed the use of a vibrator for pain relief. This study was printed in the journal of the Scandinavian Physiological Society. This peer-reviewed scientific publication is the official journal of the Federation of European Physiological Societies.

The pain relieving effect of vibratory stimulation was studied in 731 patients suffering from acute pain (135 patients) or chronic pain (596 patients). Most of the patients had previously undergone treatments of various kinds without sufficient pain relief. The effect of vibratory stimulation was assessed before, during, and after stimulation using different rating scales. About 70% of the patients reported reduction of pain during vibratory stimulation. In many patients there was a clear relationship between the degree of reduction of pain and the intensity of pain before the beginning of stimulation.

- In general, relief of pain by more than 50% during stimulation was obtained in the patients who reported light, light to moderate, or moderate pain.
- Patients with moderate to severe, or severe pain before stimulation generally reported a reduction of pain of 50% or less.
- The best pain reducing site was found to be either the area of pain or close to it.

In most patients suffering from musculoskeletal pain, the best pain reducing effect was obtained when the vibratory stimulation was applied with moderate pressure. To obtain a maximal duration of pain relief the stimulation had to be applied for 30-45 minutes. Many of the patients experienced pain relief lasting for more than 3 hours. It may be noticed that in many patients the pain relief lasted for 12 hours or more.

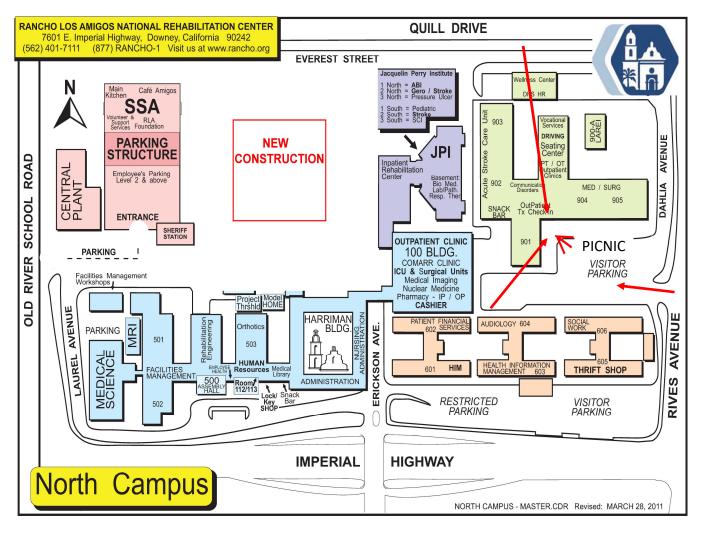
There was a good correlation between the degree of pain relief and its duration. In the patients who experienced a pain reduction of 50% or less the pain relief generally lasted for less than 6 hours, while in the patients who experienced pain relief of more than 50% it lasted for more than 6 hours. A few patients had little or no relief, but at least 82% of patients experienced some degree of pain relief.





Rancho Los Amigos Post-Polio Support Group - Annual Picnic Saturday, June 23, 2018 2:00 p.m. to 4:00 p.m.

At Rancho Los Amigos National Rehabilitation Center, in front of the 900 Building Enter Rancho from Rives Avenue - Please see map below. If you need additional directions or more information, please send an email to: RanchoPolioGroup@gmail.com



Please join us for this fun time.

The Rancho group will supply all the food and beverages.

You bring an appetite and a friendly smile.

You will enjoy yourself, and we will enjoy seeing you.

Bring a family member or friend.

Meeting Reminders

Rancho Los Amigos Post-Polio Support Group

Saturday, June 23, 2018 - 2:00 p.m. to 4:00 p.m. - Annual Picnic

Saturday, July 28, 2018 - 2:00 p.m. to 4:00 p.m. - **We will have a new meeting room**. We will still be at Rancho, just in a different building. Information coming in a special newsletter. Please attend and help us plan exciting meetings.

We also have a new email address: RanchoPolioGroup@gmail.com

Post-Polio Support Group of Orange County

Saturday, July 14, 2018 - 2:00 p.m. to 4:00 p.m. - What are our travel opportunities?

Saturday, September 8, 2018 - 2:00 p.m. to 4:00 p.m. - Sharing ideas and "gadgets" to live well with PPS - also including evacuation "To Go" kits.

Saturday, November 10, 2018 - 2:00 p.m. to 4:00 p.m. - HICAP on Changes in Medicare

The Orange County group will also have a new meeting location:

Newland Street Church of Christ 13852 Newland Street, Garden Grove CA 92844

