

Post-Polio Syndrome Related Pain Pain Study Proposal

for the Post-Polio Health International
Medical Advisory Committee
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Objectives

- Present the template for a national or international survey of 250-300 individuals with Post-Polio Syndrome related pain and its relationship with functioning and quality of life, based on results from our pilot study conducted in California (N=57).
- Facilitate a discussion of the “ideal” methodology of such as survey
- Gauge the interest of clinic directors in this study.

Thank You...

- San Francisco Bay Area Polio Survivors
- Provost's Seed Grant provided for this research by Alliant International University
- Institute on Disability & Health Psychology, Alliant International University
- Lauro S. Halstead, MD
- Carol Vandennaker-Albanese, MD



Limited Research on Polio Related Pain

- Makes broad generalizations such as “muscle pain” versus “joint pain.”
- Part of larger quality of life or symptom studies
- Few resources providing clinical advice
- Almost nothing descriptive from a sample of people with PPS from their point of view

Summary of findings from the Pilot Study, Part 1

Participants

- 57 adults with pain related to polio from California survivors support organizations.
- 80% female, 89.1% Caucasian
- Mean age 65.96 ($SD=10.29$)
- % with formal physician diagnosis of PPS:
%83.6

Summary of findings from the Pilot Study, Part 2

Measures

- Demographic information, polio and PPS history
- Utilization of health care and costs related to PPS
- Hospital Anxiety and Depression Scale (HADS, Bjelland et al., 2005) [2]
- Index of Post-Polio Sequelae (IPPS, Kalpakjian et al., 2005) [3]
- Brief Pain Inventory (BPI, Cleeland et al, 1989) [4]
- continued....

Summary of findings from the Pilot Study, Part 3

Measures , continued

- Four separate pain site questionnaires for up to 4 of the “most severe or disturbing” pain sites:
 - Pain description and drawing for each site
 - Screen for neuropathic pain contribution
 - ID Pain (Portenoy et al, 2006)
 - Neuropathic Pain Questionnaire (NPQ, Krause & Backonja, 2003)
 - History and course of pain for each site
 - Pain management strategy for that pain site
- Post-survey interview regarding life experience with pain related to polio and PPS (20 participants)

Summary of findings from the Pilot Study, Part 3

Mean number of pain sites reported = 6.05 ($SD = 3.99$, range 1-25)

Pain Severity (Brief Pain Inventory, past 24 hours)

- BPI Worst Pain mean = 5.21, $SD = 2.35$
- BPI Average Pain mean = 3.95, $SD = 2.00$

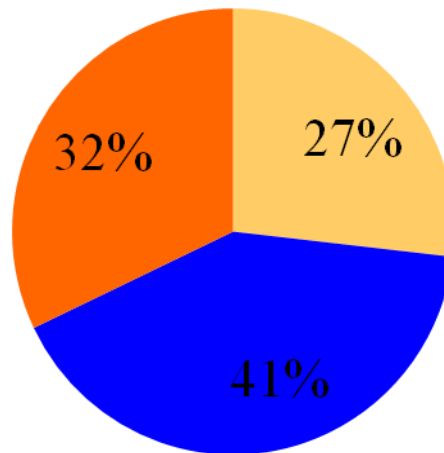
Each individual rated 4 “most disturbing” pain sites

- 1/3 of these sites met criteria as “neuropathic” pain sites based on the ID Pain or the Neuropathic Pain Questionnaire
- (The International Conference on the Mechanisms and Treatment of Neuropathic Pain, November 2007)

Summary of findings from the Pilot Study, Part 3

Brief Pain Inventory Worst Pain Ratings 57 individuals with PPS-related pain

■ Mild (0-3) ■ Moderate (4-6) ■ Severe (7-10)



Summary of findings from the Pilot Study, Part 3

Participants reported:

- Significant loss of daily productivity due to pain
- Fairly *low* levels of depression and anxiety relative to similar samples with pain syndromes
 - Moderate or severe anxiety: 21.8%
 - Moderate or severe depression: 7.3%
- High use of complementary medicine and physical therapy, low overall medical utilization related to PPS related pain
- Key aspects of pain narrative were identified

Recommendations for Phase II

- Better identification/confirmation of PPS status
- Etiology and type of pain at different sites (muscle, nerve, bone, etc.)
- Evaluation of substance use/abuse as pain coping strategy
- Use of other psychological and spiritual coping
- Less emphasis on distinction between neuropathic and nociceptive or inflammatory pain, more on detection of neuropathic pain

Recommendations for Phase II

- More on relationship with quality of life
 - Relationship with function
 - Unique aspects of quality of life
- Larger sample
- More nationally and ethnically representative
- Not only from support groups
- Utilize current polio clinics in a collaborative study

Proposed study template

Objectives

Consultation questions:

1. What needs to be known about pain related to Post-Polio Syndrome?
2. What kind of reference materials for patients and practitioners are needed?
 - What kind of practitioners need to be educated?

Proposed study template

Participants (N=300)

Consultation questions:

1. Is a formal diagnosis of PPS necessary? Or anyone with history of polio and current pain?
2. How should we identify individuals with PPS.
 - Self report
 - Medical record
 - Formal exam

Proposed study template

Additional Measures:

1. Clearer information about polio affected areas and use of assistive devices that may cause pain syndromes
2. Pain Diagram more descriptive (deep/surface, burning/aching)
3. Measure of substance use/abuse with question about use/abuse of substances for coping with pain

Proposed study template

Additional Measures:

1. More systematic evaluation of medication use, interventions used, assistive devices and how much they are actually used.
 - Use checklists instead of open-ended questions
2. Your input?

Proposed study template

- Quality of life and PPS
- Rhoda will discuss this material

Proposed study template

Intended audience for the research:

Consultation question:

What are some of the intended audiences for the data from this study?

physicians (specialties?)

OT/PT/RN/NP

patients?

Proposed study template

Role of Polio Clinic Directors group:

Consultation question:

What role would the group or individuals like to have in this study.

Recommendations for members who are not present today.

Other comments?



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Post-Polio Clinics Directors Network
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Disclaimer: The following are unofficial notes that have not been read by or approved by the speaker.

- Drs. Zelman and Olkin recently completed a study on sleep disturbances with neuropathic pain.
- This presentation is a report on a study to determine how pain related to PPS has been characterized.
- They surveyed 56 adults with pain related to polio from survivors support organizations in California.
- People were not excluded because they had pain related to other problems as long as they had pain related to post-polio in one area.
- Drs. Zelman and Olkin feel a larger national study is needed.
- When a larger study is planned, they want to include what the physicians need to know – what needs to be known about post-polio related pain? What types of resources do you need?
- Polio and PPS patients deal with a very complex pain phenomenon.
- PPS-related pain is very heterogeneous and has numerous sources. This could be due to a number of factors.
- Dr. Maynard commented on the issue of PPS vs. polio-related pain. Looking at Dr. Lauro Halsted's criteria, it does not appear that pain is an issue. You can have pain and no PPS or have PPS and no pain. You have to include it but don't put too much importance on it. Come up with another objective – change in function, new weakness, etc.
- An understanding about muscle pain is needed. We do not have a lot of medical understanding about why having polio would leave you subject to neuropathic pain. It seems that is relatively rare.
- Dr. DeMayo - Individuals with post-polio are not going to post-polio clinics or see physicians who see a lot of patients with post-polio. You take a detailed history and exam and most of the pain that you see has a specific cause you can treat. There is a sense of mystery that some healthcare professionals say they do not know about PPS. It takes a lot of persistence as to what is causing the pain and you can generally find something to treat. A lot of it is simply a matter of taking away the mystic.
- Slide on Average Out of Pocket Costs – suggested slide should reflect this is the average for a year.
- Slide on Number of Days per month I accomplish less.... Suggestion to distinguish between weekdays and weekends. Some patients cannot do anything because they are exhausted from the week. What do you expect of yourself?

- When interviewed, the post-polio patients say that pain in their lives is like music always playing. Sometimes they feel they have, throughout their lives, adapted to a constant level of pain.
- There will be a different profile of pain for those who walk and those who do not. Wheelchair bound patients who have not walked will see little lower extremity pain.
- We ask them to tell us why they thought they had pain. It is hard to get reliable information in a mail-in survey.
- Suggestion: If you put some type of rough correlation with ambulatory and non it could be correlated later on.
- People may not talk about pain unless asked; may not want to get treatment for it and may have a different sense of how much pain is affecting their function.
- People who had pain when they were young said very few people asked about their pain. You live with it and work through it. People got used to having pain and having it as part of their life. May have a higher pain tolerance than their friends.
- A larger survey for a national sample is needed.
- Funding – tried to push for using PPS as a model for complex pain. How do you evaluate pain in people with many forms of pain each with their own history? Try to make this into a broader issue.
- Question: Interested in earlier comments about the sleep study as well. Dr. DeMayo sees a big relationship between sleep and pain and pain and sleep. Do you have any questions about that in the PP population?
 - Not aware of sleep hygiene as an issue. The problems seen are sleep onset, sleep maintenance. In PPS, it would be interesting to look at sleep apnea.
- Any questions about alcohol use?
 - No
- In their work across disabilities, other than spasticity issues there isn't much difference. Think it would be interesting to do a study to see if it's as unique as one might think. Not just aging with disability. It is what we see all the time if you have a disability, everything gets blamed on that. Our patients tend to see that as well.
- Dr. Vallbona – I think this would be an example of a truly collaborative study with all the PPS centers. If you can get the funds, give us an opportunity to review the protocol and your research questions.
- To what extent are some of the problems expressed by our patients common with fibromyalgia patients? If we could get some of the fibromyalgia group to collaborate with us the results would be very interesting to compare across the conditions especially with the soft tissue. Maybe someone with fibromyalgia could help us to formulate the questions.
- Dr. Olkin – we could spend a meeting preparing a collaborative study and the needed funding.