

Physical Therapy—Tips for Successful Treatment of Clients with PPS

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I have worked with many patients with Post-Polio Syndrome (PPS) who have come to me after having a bad experience with Physical Therapy and often in worse shape than before they started therapy.

Treating a client with PPS can be quite a challenge, especially in communities where most practitioners are not familiar with this disorder. Most of the published resources are written by professionals who work in PPS clinics. But while these resources are of great value, the reality is that most therapists (and polio survivors) don't live near these clinics. Many polio survivors travel to PPS centers for a comprehensive evaluation and formal diagnosis, and then return home. They may return to the specialty clinic every year or so for a follow-up evaluation, but they are generally expected to follow the clinic's recommendations once they return home. This often includes a referral for Physical Therapy services. While many therapy practices take a wide variety of patients, most Physical Therapists are not acutely familiar with PPS treatment principles. Here are a few things I have learned through my experience working with PPS clients in an environment where professional knowledge of PPS is limited:

Basic PPS Treatment Guidelines:

1. *If you are experienced in treating neurological disorders such as Multiple Sclerosis (MS), then you already know the basic principles for treating PPS.*

Although the pathology of MS and PPS are very different, the Physical Therapy treatment principles are the same for both conditions. MS is an upper motor neuron disease. PPS refers to the late effects of poliomyelitis, resulting from years of overusing damaged motor units. Poliomyelitis and PPS are traditionally classified as lower motor neuron diseases. However, the pathology research shows that the initial onset of polio actually involves encephalitis, and that every polio survivor has some damage in the reticular formation (the “gatekeeper” between the brain and the spinal cord). Although rare, there have been instances of upper motor neuron damage in polio survivors, with positive clinical upper motor neuron signs (such as spasticity).

- If you have a good understanding of MS, then you already know the basic treatment principles for PPS. Energy conservation and activity pacing are the core principles of treatment for both conditions.
- It is essential to evaluate the client's current use of assistive devices. Many of these clients may need to “upgrade” (i.e. if they are using a cane, they need a walker). You also need to look into the future. When treating an MS patient, you try to maximize their function, but you also have to look at what additional assistance they will likely need, such as powered mobility. The same applies to PPS. Often the addition of extra mobility aids (i.e., power scooters for community mobility) will help the PPS client maintain or increase their independence and more successfully adhere to the principles of energy conservation and activity pacing.
- If a client's function has declined to the point that he has difficulty leaving his home, he may qualify for home health therapy services. Many times PPS clients are referred to outpatient therapy clinics because their decline in function is not associated with an acute hospitalization. However, if you find that your client is getting so worn out coming to your appointments that it is actually interfering with the energy conservation principles

you are trying to implement, you may need to help him get a referral from the physician for home health care.

- One specific difference to keep in mind with the use of modalities is that PPS patients typically cannot tolerate cold, unlike MS patients, who typically cannot tolerate heat.

2. *Keep in mind that PPS affects everything.*

- Whether they have a diagnosis of PPS or not, any person with a history of polio is at risk for developing PPS.
- Most of my clients with PPS are referred to Physical Therapy for other reasons, such as a shoulder injury, chronic back pain, or post-operative rehab.
- Even if your client is getting Physical Therapy treatment for some other reason, PPS will influence your treatment plan and affect your client's recovery. Be sure to obtain any PPS-related information from your client.

3. *Real world challenges*

- While most of the literature and guidelines for PPS treatment stress the importance of a multidisciplinary approach, this is not always possible. Most polio survivors do not live in an area where there is a post-polio clinic or an abundant supply of healthcare practitioners familiar with PPS. Most of the polio survivors I have worked with report that they are only advised to ask their primary care Physician for a referral (this is also what many of the published guidelines state). But many are (rightly) advised to try to find therapists with neurological backgrounds versus those with sports backgrounds. I have always recommended that polio survivors look for therapists who are experienced in treating MS if they cannot find someone who is familiar with PPS. I also have suggested that these clients start by calling hospital-based outpatient clinics, as these settings are more likely to offer appropriate care. Most free standing Physical Therapy clinics are focused on orthopedics, although there are some exceptions.
- You have to be willing to go the extra mile in communicating with your client's other practitioners, because they may not understand the unique needs of this population. You may have to be more of an advocate for your PPS clients than for your other clients.

Preparing for Your Physical Therapy Evaluation and Treatment Program:

1. *Instructions to give your client when they schedule the appointment.*

Many PPS clients have thick notebooks full of information. While this can be helpful, it can be TOO much information! Here are the highlights of what you initially need from your client:

- General medical history: Diagnoses, with dates of onset; Allergies; Previous Surgeries, with dates
- Date/age of original polio onset; original effects of polio; any devices/braces used during initial recovery; level of function after initial polio recovery
- History of PPS; approximate date of symptom onset; formal medical evaluation & diagnosis; previous treatments for PPS symptoms
- Medication list

Many of my clients have typed up a list which can be easily photocopied at the time of their therapy evaluation, which I have always found to be very helpful. You might consider discussing with the clients over the phone what information you will need from them, or offer to mail them a copy of the medical history questionnaires that your office uses.

2. Keep the focus on the initial evaluation visit.

Most PPS clients are very outgoing and talkative, when offered a chance to be heard. Often, they want to tell you their whole life's story at their first appointment. You must understand that it is likely they have spent a great deal of their time "fighting" to have their symptoms taken seriously. We all know that in this day and age in healthcare, you must be adept at advocating for yourself in order to get what you need. They want you to understand their background and why they are so concerned about their current status, but it is typically very easy to get off topic. Because your time for an initial evaluation will likely be limited (most outpatient clinics have 45 minute time slots), you may have to re-direct the client to stay focused on the task at hand. Remember, they've hired you to help them regain the function they have lost. In order to do that, you will need to conduct a focused interview and a thorough physical evaluation. This will include specific questions regarding functional mobility status/changes, assessing range of motion and strength in all of the extremities and trunk, balance, coordination, transfers and gait (or wheelchair mobility if non-ambulatory). If all of your time is spent on talking, you won't be able to look at everything THEY NEED you to look at. Remember, there will be plenty of time to get to know your clients and hear their story. Kindly and sensitively pointing these things out is often a good method of re-direction. However, the reality is that for some polio survivors with complicated histories, it may take longer to obtain the relevant information that you need. If possible, you should schedule extra time for your initial appointment with a PPS client.

3. It is important to work WITH your client.

Ask your client to give you an honest report about his body's response to changes in activities or exercises. There may be times when a therapeutic intervention doesn't work the way you and the client hoped it would. Maybe it caused him to be too fatigued, or caused a significant increase in muscle soreness. You need to know his physical responses in order to adjust the treatment appropriately. Ask the client to be as specific as he can be. Physical therapy can be tricky in the beginning, as each person responds to physical interventions differently. Medicine has always been more of an art than a science, and sometimes a little "trial and error" must occur in order to find just the right intervention.

Have you ever tried a new medication that didn't work and had to get a prescription for a different one? The same thing can occur with therapy. However, if you are *not listening* to your client's feedback and not adjusting your treatment program (just pushing the client to do the same thing regardless of his response), you need to refer him to a different therapist. Not listening to a PPS client's feedback often leads to harm, even though that is not your intention. I have seen many PPS clients who come to me after having aggressive Physical Therapy treatment where they were pushed to do certain activities regardless of their responses, and they were in much worse shape than before they started therapy. Why is this so important? *Every time a PPS client loses strength, it is an indication of further motor neuron loss.* As therapists, we must be acutely aware of this, and adjust treatments appropriately so as not to cause further harm.

Best Case Scenario:

With successful completion of their therapy program, most PPS clients will have a decrease in their symptoms, and be able to manage their PPS appropriately. Some individuals actually experience complete resolution of their symptoms, and regain the functional independence that

they were hoping to regain. This is ideal! However, it is important to keep in mind the principles of energy conservation and activity pacing. Your clients will *always* want to avoid exacerbation of PPS symptoms. They need to continue to be careful not to start “over doing it” because they feel great now. One patient of mine just recently had an exacerbation, after years of staying symptom-free, because he started to ignore the “rules” and overwork himself at the gym. PPS is a life-changing condition. If your clients have been able to resolve their symptoms, they need to continue with whatever program or modifications to their lifestyles that helped them achieve these results.

Worst Case Scenario:

Sometimes, no matter what we do (or don't do), a client with PPS will continue to have functional decline. This may be in spite of 100% appropriate participation in treatment. In this case, the focus of Physical Therapy intervention must shift to helping the client adapt to the new level of disability with appropriate equipment and/or assistance, in order to maximize independence. Like many other chronic conditions, PPS ranges from very mild to very severe. Those who develop very severe PPS will likely continue to decline whether they participate in therapy or not. The problem is that there is no way to tell if this will be the outcome until it happens. But a well-designed and highly individualized treatment program won't harm these clients, and may help them.

“LOCKER ROOM” TALK:

In my experience, there is a widely held perception in the therapy community that PPS patients are “high-maintenance, needy, emotionally draining, and never satisfied.” In fact, many of the therapists I have worked with and educated about PPS treatment actually dread seeing that diagnosis come across their desks. Some have even refused to treat PPS patients. How could this be? Generally speaking, polio survivors have overcome huge obstacles in their lives, and they are very educated, knowledgeable people. They should be an exciting group of people to work with, right?

There is a trend in the complaints I've heard from therapists. Basically, they report that their clients become argumentative and noncompliant. They are not willing to try following the therapist's recommendations, and don't want to take any responsibility for the therapy “not working.” For example, let's say that a gentleman with PPS has started physical therapy. He is having increased loss of balance, has had a few falls, his transfers are more difficult, and he doesn't have the energy to go to his weekly investment group anymore. His therapist tries using a walker with him, and this greatly improves his balance and stability with movement. She recommends that he use his walker at this time to help safely increase his mobility. He, however, is very resistant to the idea, and refuses.

The therapist and patient then have lengthy discussions about the seriousness of potential injury related to falling, and the likely continued decline of function related to overuse and inappropriate activity pacing. She suggests the idea of utilizing the walker as a tool to safely increase his mobility and independence, while continuing therapy to see if he can regain enough endurance, strength and balance to resume some of his normal activities without a walker. Despite the safety concerns and benefits that the therapist outlines, the patient continues to refuse. Could this be related to the stigmas associated with disability and assistive devices from

the time of the polio epidemics? Is this attitude from this gentleman's denial regarding his current functional status? Is it just because the situation he now finds himself in is completely, inarguably unfair?

Regardless of diagnosis, many clients who seek physical therapy treatment are looking for their therapist to “fix” them, and they already have a specific outcome in mind. PPS clients tend to assume that therapy will enable them to overcome their symptoms, and resume life *exactly* the way it was before their symptoms started. This is where having a general understanding of the psychosocial aspects of polio and PPS is very important. Polio patients were taught to work twice as hard as others, and fight as hard as they could to be normal. They were encouraged to do everything they could to get rid of leg braces and crutches, whether that was actually the right thing to do for their bodies or not. They overcame death, disability and social stigmas. When they come to see you, the therapist, they are often dealing with much more than having a hard time going up and down the stairs. They are facing the loss of everything they gained decades before, waging the fight of their lives.

So how can we approach these clients? First of all, we have to acknowledge their struggle and our inability to relate to it directly. It is patronizing to have someone tell you they understand what you’re going through when you know they have not suffered in the same way that you have. That’s not to say you can’t relate to these clients at all. On the contrary, I usually get along very well with polio survivors because I tend to be a “type A” person. I can definitely relate to that drive to get things done, and the frustration that comes when something is preventing you from accomplishing what you would like to. I have found it helpful to explain my role as a therapist and discuss the expectations at the beginning of the treatment program. I explain that, when they walk into the clinic, I work *for* them and *with* them. They are hiring me for my professional expertise, and it is my job to make appropriate clinical recommendations. But at the end of the day, it is their decision whether or not to follow my advice. They are expected to take an active role in their treatment plan. We have to work together in order for therapy to be successful.