



Polio Survivors' Page

POST-POLIO RESEARCH UPDATE

With Dr. Jacquelin Perry

Reported by Mary Clarke Atwood

World renowned polio specialist, Dr. Jacquelin Perry, was the featured speaker at the Rancho Los Amigos Post-Polio Support Group meeting in Downey, California on December 10, 1995.

In her annual talk to this support group, Dr. Perry gave an overview of some current research approaches to managing Post-Polio Syndrome (PPS) including reports of studies on nerve axon overuse, medications used for treating PPS fatigue and pain and myoneural junction overuse. She cautioned people to look at the volume of data, not just the numbers, when looking at results of studies.

Dr. Perry advised survivors to avoid overuse by cutting back and realistically managing the demands of home, family, work and play.

DIAGNOSIS OF PPS

PPS is one of the disabilities that is diagnosed only through clinical findings. Often muscle studies such as EMG, Macro EMG or biopsy are performed on weakened muscles; but these studies can only reveal prior motor unit lesion, i.e., the reports may say that a person has had something like polio at one time, but not polio definitively.

[A motor unit is composed of the nerve cell, its attached nerve axons, and the supplied muscle fibers. Even if enlarged motor units are detected on an EMG, that single finding cannot confirm PPS.]

In a previous talk Dr. Perry said she bases a diagnosis of PPS on three things:

1. a history of polio.
2. a period of some recovery followed by new loss of function.
3. a physical examination that reveals:
 - a. scattered muscle weakness (observed during an extensive manual muscle test from head to toe)
 - b. normal sensations
 - c. reflexes that are normal (2+) for strong muscles and depressed for weak muscles.

NERVE AXON OVERUSE

During the acute phase of polio, 95% of the patient's anterior horn cells were either injured or destroyed by the polio virus. (These are the nerve cells that ultimately control muscles.) Then as recovery began, new nerve axon sprouts formed to adopt orphaned muscle fibers that no longer had a nerve supply. Within a month, 12% to 91% of these cells began to recover.

Although many people seemed to "recover", the majority do not have as many motor nerve cells as normal. (The average person had only 47% recovery.) Therefore, their motor system is not as strong as normal. So with fewer motor units, the muscles have been working harder than normal trying to meet regular demands. This results in overuse of the system and weakness develops.

Dr. Perry cited a study by Pachter with rats (B. Pachter, Ph.D., "A Rat Model of the Post-Polio Motor Unit," Orthopedics Vol. 14 Dec. 1991). This study demonstrated that when a muscle loses its nerve supply (as in polio) there is less muscle strength and less muscle fiber; when the nerve supply is increased there is an increase in muscle fibers and muscle strength. But, in the later life cycle of the rat, those muscle fibers again decrease and the muscle strength decreases also.

Dr. Perry said, "This is not good news but at least it gives you facts." (There has been speculation about the cause of PPS being due to the failure in the muscle, the myoneural junction or the nerve cell body.) "This study indicates that the secondary [nerve] sprouts:

1. are not that good,
2. cannot take strain,
3. can fail when challenged.

Pachter's conclusion is that the sprouts are degenerating from overuse."

MANUAL MUSCLE TESTING

Determining what is significant muscle weakness can be a problem because it depends on the strength of the examiner and how much pressure is exerted on a muscle. The examiner can create a great variable in manual muscle testing. Since some examiners cannot identify differences between muscle grades 3+ and 5 (normal), Dr. Perry's current research is defining the guidelines to differentiate muscle strength within that range.

Dr. Perry advises that muscles that are less than grade 3 must be protected; grade 3+ muscles can be used gently; grade 4 and 4+ muscles can be used moderately and grade 5 muscles can be used freely. Be aware that even a grade 5 (normal) muscle for a polio survivor is still only 50% of normal.

FATIGUE SEVERITY

Dr. Perry cited a Fatigue Severity Scale that shows:

- Normal fatigue varies between 1 - 6 and averages 3.
- Fatigue in people with other neurological diseases was slightly higher, reportedly between 2 - 7 and averaging 4.
- People with PPS have the most fatigue; it was reported between 3 and 7 and averaged 5. Note that the least fatigue reported for PPS is greater than that in the other two categories.

MEDICATIONS FOR FATIGUE

Since fatigue is a major complaint of many people with PPS and other doctors sometimes prescribe medications to counteract that fatigue, Dr. Perry investigated reports on their use and effects.

1. Amantadine

According to reports, the use of amantadine to decrease PPS fatigue was almost equal to the use of a placebo: 6 out of 10 people with PPS reported less fatigue with amantadine while 6 out of 13 reported less fatigue when taking a placebo.

2. Growth Hormone

Studies have revealed that in 1/3 of normal elderly people growth hormone level was reduced and activity

level was also decreased. If a person has physical reasons to reduce activity, then growth hormone level might be low, but it cannot be increased by taking this medication.

When growth hormone was prescribed for PPS, about 1/3 of these people reported a decrease in fatigue. Those who improved were mostly older, obese men who had difficulties with Activities of Daily Living (ADL). For those who reported less fatigue the results were not significant. Therefore, the level of growth hormone was not significant as a causative or a curative factor in treating PPS fatigue.

3. *Prednisone*

Cortisone-type drugs have been used for many years at minimal levels to control the symptoms of arthritis. Nothing specific has been reported beneficial for PPS.

4. *Mestinon*

For many years Mestinon has been prescribed for myasthenia gravis patients. It functions at the nerve and muscle (myoneural) junction to improve the transmission between the nerve and the muscle. Studies of its use for PPS fatigue show that about 64% of those who used the drug felt some reduction in fatigue but no change in muscle strength.

Mestinon helps myoneural junction overuse. According to Grimsby, a muscle that is grade 4+ (or basically normal) activates its muscle fibers 20 times per second, i.e., essentially pushes the button 20 times to make that muscle work. A weaker grade 3+ muscle must activate its muscle fibers 40 times per second or twice as fast (double-timing) to get more work out of less. The duration of activation for the normal muscle would be 100 milliseconds; but for the weaker 3+ muscle it would have to be activated for 500 milliseconds.

Dr. Perry concluded that:

- if these "borderline inadequate" muscles are all being overworked, and
- if Mestinon is working at the myoneural junction, and
- if the junction could be overused, maybe that is why Mestinon helps some polio survivors.

There is no controlled study on who benefits from Mestinon, but Dr. Perry has observed that people with muscle grades between 2 and 3+ seem to find Mestinon helpful; but people with stronger muscles seem to get little benefit from this drug. Thus, myoneural junction overuse is one situation that can be helped medically.

MEDICATION FOR PAIN

In general, Dr. Perry's philosophy is not to use pain medication for PPS because it acts as a mask and a person might continue overusing a weak neuro-motor system. To reduce inflammation, nonsteroidal anti-inflammatory drugs (NSAIDs) are acceptable because they act at the first level of injury.

COPING

- We need to protect ourselves from overuse and its consequences. Dr. Perry says, "Don't dream of what was. That is past."
- Weigh your demands to make sure they do not exceed what you can do -- at home with your family, at work, and at play.
- How do you control PPS? The only way to control it is to remove the strain by cutting back.
- The key symptom of PPS is weakness. When the nerve supply to the muscle is reduced, the result is a decrease in muscle strength.

- When a person is not coping and facing things, anxiety and depression can be secondary effects.

In summary, since all polio survivors have less strength, they also have less work capacity. So it is necessary to plan how to make less demands on your body by lifestyle modification.

LIFESTYLE MODIFICATION

Dr. Perry again cautioned that those people who had severe polio followed by good recovery are most at risk for neuromuscular overuse injury. Even when polio muscles appear normal on the outside, those muscles are less efficient and their motor units are most likely to decompensate. These muscles must be protected from overuse both by cutting back demands and possibly by bracing.

It is necessary to learn how to control lifestyles in order to continue enjoying the pleasures of life. If a person currently has no symptoms, there is no problem. But if or when problems do appear, then a person may need to adjust his lifestyle. For those people whose lifestyle currently exceeds their neuromuscular physiology, they may "bankrupt" that system unless lifestyle is modified and strain is removed. For people with joint degeneration and mechanical problems, orthoses may help protect those muscles and joints.

Dr. Perry advises overweight patients to try to get rid of their "spare tire" by losing weight, thus reducing the strain on weakened muscles.

EXERCISE

Here in Southern California winter weather is different from many other parts of the country where it freezes, forcing people to stay indoors and get lots of rest. With the mild winters here, people remain active outdoors and muscles do not get the same amount of rest compared to muscles of people living in places that have long hard winters. Thus Dr. Perry believes that exercise is not very useful for PPS patients in Southern California because our lifestyles are very active already -- leaving no extra muscle to use.

In a Canadian study of exercise, there was a gain of 3% - 26% in strength. But the raw data showed that only one person had a gain of 26% while the other four people showed 3% - 5% gain or a slight loss. (A 26% gain in a grade 2 or 3 muscle is still not a large gain of muscle strength.)

Rx: REDUCE STRAIN

1. Lifestyle modification is by far the most important.
2. Orthoses and aids (braces, canes, crutches, power wheelchairs) can help support weak muscles.
3. Exercise is not too effective -- sometimes muscle strength is increased only 5%.
4. Surgery is occasionally helpful.

HOW TO CUT BACK

1. First of all, polio survivors need to sense what is happening to their bodies and become aware of which muscles are getting tired and which muscles are not.
2. Break up activities into pieces by working a little, rest a little, work a little, rest, etc. Sit whenever possible.

Dr. Perry does not advise patients to stop everything because then muscles will atrophy from disuse.

HOW TO EDUCATE YOUR DOCTOR

Dr. Perry suggests that a polio survivor provide their personal physician with the briefest literature that is pertinent to their own PPS problem. Remember that you are a small portion of that doctor's practice. If your physician does not respond, Dr. Perry advises looking for another doctor.

CONCLUSION

This report has focused on some of the current research approaches to managing PPS. Dr. Perry still feels that lifestyle modification is one of the most effective ways of managing PPS. Her guidelines for a safe activity level are that "polio survivors can do anything as long as it results in no pain and fatigue that lasts more than ten minutes."

[\[Return to Post-Polio Information Packet\]](#)



This site is now maintained by Chris Salter, linpolioweb@loncps.demon.co.uk, of the [Lincolnshire Post-Polio Network](#).

Original Document Preparation: [Tom Dempsey](#).

Document Reference: <URL:<http://www.eskimo.com/~dempt/perryup.htm>>

Last modification: 23rd December 1997