



Bruno “Bytes” – August, 2017

(Bits and Tidbits from the Post-Polio Coffee House)

Available through a “link” from www.postpolioinfo.com
 (or) directly through <http://www.papolionetwork.org/bruno-bytes.html>

On the topic of Prescription Drug Prices (8/9/2017)

Dr. Bruno’s Original Post: Here’s a Prescription Reminder...GoodRx

I'm getting e-mails from polio survivors who have had their Medicare Part D plans significantly raise the price for some generic drugs and from others who need to pay less for meds. Just because you have an Rx on file with a Medicare Part D plan doesn't mean that you *must* let the plan fill it. You can get another Rx from your physician and go to a cheaper pharmacy. Check GoodRx, as well as Walmart, Target and your local supermarket pharmacy to look for lower prices. You'll be surprised at the difference! <https://www.goodrx.com/>

On the topic of Trauma or Illness preceding PPS (8/9/2017)

Dr. Bruno’s Original Post:

Trauma and Illness as Precipitants of Post-Polio Sequelae.

Dr. Richard L. Bruno,

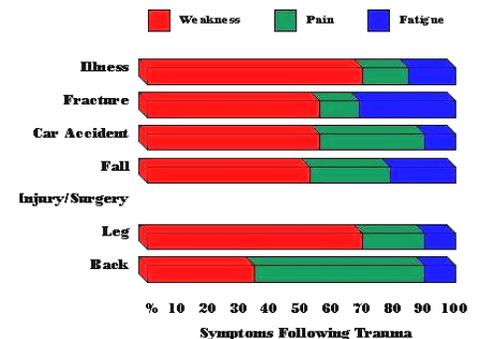
Chairperson, International Post-Polio Task Force
 Director, International Centre for Polio Education

Post-Polio Sequelae Monograph Series. NY: random harvest, 2000.

About once a month, I get a call from an attorney somewhere in these litigious United States. I am asked to be the expert witness for a polio survivor who's been rear-ended in their car, hit by a bus, taken a header down some stairs or simply slipped and fell. Regardless of the type of accident, the lawyer always asks the same question: Can a traumatic event trigger Post-Polio Sequelae, the new and sometimes disabling muscle weakness, fatigue, pain and respiratory problems that occur is as many as 77% of polo survivors? And regardless of the type of accident, my answer is always the same: Yes and no. PPS is not a disease that is just waiting inside polio survivors for a trigger to set it loose to wreak havoc throughout the body. So trauma can't trigger a disease that is not there. . . .

But our 1985 National Survey did show that PPS symptoms are caused by physically or emotionally stressing the poliovirus-damaged motor nerves that remained after survivors' original bout with polio. Many polio survivors have been able to function for 40 years with about half the spinal motor nerves of someone who didn't have polio. So breaking a leg in a fall, having major surgery -- even a whiplash injury -- could sufficiently stress the remaining polio-damaged motor neurons to "blow a fuse" When those fuses blow, neurons function less well and muscle weakness, fatigue, pain may result.

Many polio survivors are terrified about losing function after trauma. One survivor said, "I am afraid if I fall and break something I will never walk again." Fear also causes polio survivors to postpone even necessary



surgery because, as one survivor put it, "I know I'll never survive the anesthetic. I will spend the rest of my days in an iron lung."

Because of the fear that an injury or surgery could cause PPS, we wanted to find out just how many of our patients actually experienced new symptoms after trauma, what those symptoms were, whether they spread throughout the body and whether they were irreversible or treatable.

Surgery, Spills and Other Ills.

We reviewed the histories of 244 consecutive polio survivors evaluated by Kessler Institute's Post-Polio Service who had no other conditions that might cause new fatigue, weakness or pain. Of those patients, 44 (18%) said that their PPS began after a traumatic event. The typical patient was 59 years old and had polio at age 8 in the early 1940's. There were as many men as women reporting these post-traumatic PPS. The traumas that preceded new symptoms included medical illnesses and surgeries (pneumonia, viral infection, hysterectomy, mastectomy with chemotherapy, pregnancy), fractures of the ankle, leg or hip, falls, auto accidents, and injury or surgery to the leg (ankle sprains, knee surgery, hip or knee replacement) or the back (herniated discs, laminectomies, spinal fusions) (see graph). The most common injury was to the leg (71% of patients) while 26% had back injuries. Regardless of the type of trauma or location of the injury, the most common symptom reported was new muscle weakness (55% of patients) followed by pain (34%) and fatigue (11%).

There was no evidence that new symptoms began in an injured area and then "spread" throughout the body. Seventy-one percent of patients had new symptoms only in the body area that had been injured, while 26% had symptoms in the injured area plus one other nearby location. For example, 40% of those who injured one leg developed weakness or pain in the other leg. This is a common problem for polio survivors, who compensate for injury to one part of the body by overusing another part whose nerves were also damaged by the poliovirus.

Only 5% of patients developed symptoms in more than two body areas. One patient who had a hip replacement reported "loss of muscle tone all over," while another who had been in a coma after an auto accident reported weakness in all of his muscles. Two patients who had had fractures, two with back injuries and one with an ankle injury reported new fatigue. However, no patient reported that their trauma "triggered" symptoms unrelated to the injury, such as arm weakness after breaking a leg or difficulty swallowing following a knee replacement.

Can Post-Traumatic PPS be Treated ?

All of the clinical experience and research on treating non-traumatic PPS supports one conclusion: If patients decrease physical and emotional stress their symptoms will at very least stop progressing and typically will get noticeably better. Does this hold true for post-traumatic PPS? There's good news and bad news. The bad news is that the majority (63%) of patients with post-traumatic symptoms refused treatment altogether or refused to complete therapy for their symptoms; more than twice as many posttraumatic PPS patients actually quit therapy. What might cause this?

Seventy-seven percent of those who had a psychiatric diagnosis refused therapy, versus 53% of those without psychological problems. The most frequent psychiatric problem was a major depressive episode; 89% of those who were depressed refused therapy. Depression has been identified before as a significant cause of therapy refusal in polio survivors and highlights how important it is for psychological problems to be identified and treated if therapies for PPS are to even begin. The good news is that 86% of patients regardless of the type of trauma or severity of their injuries had significant reductions in pain, fatigue and muscle weakness after complying with therapies known to be effective in treating PPS: reducing physical and emotional stress, using appropriate assistive devices, energy conservation, adequate rest and the pacing of activities. The remaining patients experienced a reduction in some symptoms, especially pain, but continued to report muscle weakness or fatigue. Two patients who did not stop strenuous work or recreational activities reported

slowly increasing muscle weakness and pain over several years. Another patient who had been thrown to the floor of a van in 1995 reported that muscle strength and endurance in her legs increased only slightly after therapy even though her severe back pain has been eliminated. It is noteworthy that this patient had completely recovered from two previous traumas: a fall early in 1995 that fractured her lower right leg and another auto accident seven years before that herniated a disc. This patient's ability to recover from two previous traumas is also good news. For each of our patients who reported PPS symptoms after a trauma there was at least one other patient who had had the same trauma but did not develop PPS. So while trauma can be sufficient to cause PPS, PPS do not necessarily "cometh after a fall."

The Golden Rule

These findings in our patients should put polio survivors' minds at ease. Neither major surgery nor even a fall that causes a fracture will necessarily push polio survivors down a slippery slope toward total disability. Still, caution must be exercised since damaged motor neurons make polio survivors more susceptible to problems that typically do follow trauma. A leg that has been in a cast for months can become weak, as can the opposite leg that has had to take up the slack for its damaged partner. And bed rest after surgery can more easily cause deconditioning and fatigue in polio survivors.

However, post-traumatic symptoms in polio survivors should not be treated aggressively as they often are in those who didn't have polio. All PPS need to be treated carefully and slowly. Polio survivors and their therapists should not assume that a leg weakened after being in a cast has merely "been resting too long" and will respond to an aggressive program of weight lifting. Polio survivors who have had surgery should not be rushed out of bed to prevent deconditioning, because the lingering effects of anesthetic and post-operative pain are more likely to cause falls than to prevent fatigue.

Regardless of the cause of PPS the "Golden Rule" for polio survivors always applies: If an activity causes fatigue, weakness or pain, don't do it!" Doctors, nurses, and therapists must listen carefully to their patients -- and polio survivors must listen carefully to their own bodies -- to determine how much exercise or therapy causes fatigue, weakness or pain, and to stop before those symptoms appear, so that therapy for PPS does not become just another type of trauma. The experience of our patients is that post traumatic PPS is treatable if polio survivors follow through with therapy.

But even more important is that many traumas can be avoided, like the falls and fractures caused by compulsive overdoing, ignoring new muscle weakness and refusing to use a needed brace, cane or crutch. For polio survivors physical overexertion, like pride, does goeth before a fall.

RESOURCES

The text of articles on the cause and treatment of PPS can be downloaded from the harvest center web site:

<http://members.aol.com/harvestctr/pps/polio.html>

<http://www.postpolioinfo.com/library/trauma.pdf>

[On the topic of Bone Density Studies](#) (8/21/2017)

Original Post: Should I get the same hip side done with each repeat study? Will it show different results between my partially paralyzed Polio side vs my "unaffected" leg?

Dr. Bruno's response: The more affected side (leg, hip, wrist) having less muscle will have lower bone density because the muscle doesn't pull on the bone or there is less weight bearing exercise on that limb. If you have to choose, pick the more affected side for the bone density study. If you have osteoporosis with a high probability of fracture, compared to the side effects from meds, it's probably a good idea to be treated. Talk to your doctor.

[On the topic of Psychological Support for Polio Survivors](#) (8/21/2017)

Dr. Bruno's Original Post: There has been a significant and often painful Coffee House discussion about hospitalization after polio. This paper reflects our published clinical and survey findings and underscores the need for psychological support for polio survivors with PPS.

The Norwegian Polio Study 1994 part II: Early experiences of polio and later psychosocial well-being

Article in Spinal Cord 37(7):515-21 · August 1999

A-K Schanke, et al.

The Norwegian Polio Study 1994 was a nation-wide survey of the medical and psychosocial situation of polio survivors. A questionnaire, consisting of 133 questions with sub-questions, was sent to a total of 2392 polio victims, most of them registered in 'The National Society of Polio Victims' in Norway. 1449 (61%) answered. To investigate the relationship between early polio experiences, such as duration of hospitalization and perceived support, and later psychosocial well-being. Three hundred and ninety-one persons (27%) reported they had been psychologically harmed by the treatment received at the time they contracted polio (Harmed group), while 1053 persons (73%) did not (Non-Harmed group). Persons in the Harmed group were significantly younger at polio onset, were hospitalized for a longer period and had less parental visit and support. Today they use more medication, report more pain, general fatigue, sleep disturbance and concentration problems, more psychosocial distress, less satisfaction with life and less social support than persons in the Non-Harmed group. The results demonstrate that a subgroup of polio survivors has been vulnerable from childhood, with possible consequences for their physical, psychological and social wellbeing later in life. Recommendations for long-life treatment of children with similar diseases should include follow-up not only of their physical disabilities, but also on psychological and psychosocial needs.

[On the topic of Exercise](#) (8/23/2017)

Original Post: I went for my annual health check up today and apart from my weight everything is ok. Both the nurse and my physician were asking me if I could up my exercise a wee bit more. What should I attempt to do? I can change the resistance as much as I want on my exercise bike. My concern is that I don't overdo it. I am fully mobile and walk with a stick.

Dr. Bruno's Response: Based on our years of research at the Post-Polio Institute, I cannot recommend exercise in any form that stresses already damaged motor neurons. Certainly increasing the resistance on your bike could be damaging. If you're doing exercise now that does not cause you symptoms and you've been doing the exercise in this way for a long time, then you should listen to your body...
If you do something and you know it's harming you, stop doing it !

[On the topic of Grants to help pay for Disability Home Modifications](#) (8/24/2017)

Dr. Bruno's Original Post: Here's some information about paying for disability home modifications. (You'll need a sense of humor about the photos. Except for the home with the ramp, none of them make sense).
http://www.homeadvisor.com/r/grants-for-home-modification/?utm_content=buffer12391&utm_medium=social&utm_source=facebook.com&utm_campaign=buffer&fref=gc#.WabQh8iGOU

[On the topic of Physical Activities and PPS Symptoms](#) (8/2017)

Original Post: I had a sudden and dramatic drop in function in a short period of 3-4 months (during which I did not pace myself and allowed myself to get very overtired). The symptoms are typical of PPS (fatigue etc), which I had mildly before, but the neurologists say there's been no drop in nerve function, so it's not PPS.

Dr. Bruno's Response: Whatever the neurologists mean by "no drop in nerve function" (whether measured by an EMG or not) is NOT a predictor of PPS symptoms. But, 3-4 months of not pacing yourself and getting very overtired IS a predictor of fatigue and muscle weakness!

To identify when you're not pacing yourself and you're getting overtired, fatigued and weaker, here is the polio survivors [Daily Log](#). It is a pain to do, I know. However, at The Post-Polio Institute we found it to be the single most effective tool for polio survivors to uncover the relationship between activities and symptoms. For example, the logs uncovered "The 3-Day Lag" for PPS symptoms: You shop till you drop on Monday, feel just fine Tuesday and then can't get out of bed on Wednesday. After 35 years, I still don't know why that happens, but we never would have known about the "lag" without the logs.

One part of the log is measuring your steps with a pedometer or even your smart phone. After compiling data from more than 500 Post-Polio Institute patient logs, we found that 1,500 was the average number of steps that would not cause symptoms. Your number may be higher or lower depending on your activities, abilities and symptoms. But it's only through the log that you'll know how many steps is your limit.

Additional Post: The daily log certainly helped me learn how to manage my PPS. Prior to treatment The Post-Polio Institute, I had been losing 8 to 10 percent of the muscle strength in my legs and arms every year. I haven't had any muscle strength loss in 5 years by using the log to listen to my body and watch my steps. The Post-Polio Institute program taught me that I can lead a productive life and manage my PPS.

The log is available for easy printing, [here](#).

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<http://www.papolionetwork.org/bruno-bytes.html>

Scroll down the page (through the Current Month posts).

Previous months are located there, and are available by "clicking" on them, in easily printable PDF format

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