

LIVING WELL WITH POST-POLIO AS WE AGE

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I. Introduction

At the Ohio Polio Network 30th Anniversary and 2023 Conference, I was asked, as a mental health professional and member of the OPN Advisory Board, to write an article for OPN. I am an aging 77-year-old who has lived 38 years with Post-Polio Syndrome, so I decided to selectively explore evidence-based literature on both polio and aging to ultimately address living well with Post-Polio as we age. This article provides what I hope is relevant information for any reader about polio and its impacts; physiological changes that come with normal aging; challenges of aging with Post-Polio; suggested adaptations to aging and Post-Polio; and a few reflections derived from this exploration.

II. Poliomyelitis

Poliomyelitis is the virus that causes the disease called polio. The virus is capable of attacking nerves in the spinal cord or brain stem, paralyzing muscles related to breathing, speaking, swallowing, and moving one's limbs. The virus attacks nerves with a shotgun scatter effect, such that the resulting physical symptoms manifest unevenly: One leg might be capable of climbing stairs, the other not. Vaccination against polio since 1955 has eradicated the disease in the United States and in virtually much of the world.

III. Late Effects of Polio and Post-Polio Syndrome: Definitions, Causation, Diagnosis

The Late Effects of Polio (LEoP) is the term for symptoms related to a person having had polio. These symptoms include fatigue; decreased muscle strength and endurance; pain; breathing or swallowing or speech problems; sleep problems; and physical symptoms, such as joint problems and scoliosis. [1]

The LEoP are not associated with re-infection by the polio virus, but rather, with a greater loss of motor neurons than is typical in the normal aging process. Loss of motor neurons leads to increased muscle weakness. Reduced muscle tissue leads to muscle fatigue and pain. Weakened limbs can lead to reduced weight-bearing activity and reduced bone density. Postural abnormalities resulting from polio can lead to pain, and/or sleep or breathing problems. Increased stress on joints can lead to arthritis and pain. [1]

Post-Polio Syndrome (PPS) is a sub-category of LEoP and is a diagnosable neurological condition for those who have had polio, with or without paralysis. PPS is diagnosed 1) when new pain and/or weakness occurs following recovery from the acute illness and 10+ years without new symptoms; 2) when these new symptoms continue for at least one year; and 3) when there is no other clinical explanation for the new symptoms. [1] Nerve Conduction Studies and EMG tests, which measure muscle electrical activity, are sometimes useful in identifying the bases for new symptoms. [6]

The symptoms of Post-Polio Syndrome typically appear 15 to 30 years after recovery from the acute illness. [9] PPS symptoms have been "associated with the degree of residual weakness immediately following [patient] polio infections." [11] However, PPS symptoms usually are not as severe as those experienced following the acute illness. [6] Along with the symptoms of LEoP noted above, other reported symptoms of PPS include cold intolerance and restless leg syndrome. [9]

The prevalence of PPS among polio survivors is estimated to be 25% - 40%, according to the CDC. [2] Risk factors for PPS include female sex, permanent disability caused by motor neuron damage, respiratory symptoms, muscle overuse and underuse, aging, and "immunologic mechanisms." [9] The severity of, and degree of recovery from, symptoms caused by the acute illness determine the risk of developing PPS. [9] "As deficits at the end of the disease increase, the probability of experiencing post-polio symptoms increases." [11]

There are three major theories for the cause of PPS. [8] The prevailing theory for the origin of PPS is based on the fact that recovery from polio involves the body creating new connections between surviving nerve cells and muscles, this to compensate for nerves damaged by the virus. [6] Over time, these compensatory nerve cells or extra nerve branches breakdown due to inflammation, injury, illness, one's immune system, periods of inactivity, and normal aging. [6] This breakdown can occur anytime [11]

A second theory for the existence of PPS is the persistence of polio infection in the brain and spinal cord. [6] Several studies have shown the existence of polio virus genome fragments in the cerebrospinal fluid of PPS patients. [8]

A third theory for the cause of PPS is delayed immune response to the polio virus, leading to chronic inflammation and, thus, persistent symptoms of polio. [8] One study explicitly states that PPS symptoms were attributed to neuronal loss over time with inflammatory mechanisms, but “without any convincing evidence of viral reactivation.” [9]

IV. Normal Physiological Changes with Aging

With the increased experience of increased age comes wisdom. At the same time, normal aging also poses physiologic limitations apart from those experienced due to PPS. [5]

The Washington Post on October 15, 2023 included an online article by Judith Graham, “What’s normal for the body and brain as we age? An expert weighs in.” The information Graham provides is based on an evidence-based new book by Rosanne Leipzig, “Honest Aging: An Insider’s Guide to the Second Half of Life.” Leipzig is a physician and vice chair for education at the Brookdale Department of Geriatrics and Palliative Medicine at the Ichan School of Medicine at Mount Sinai in New York. Graham describes Leipzig’s book as “the most comprehensive examination of what to expect in later life I’ve come across in a dozen years covering aging.” [3]

In her article, Graham notes that explaining how we change with aging is difficult, because the aging process is gradual, decades-long, and influenced by one’s behaviors, as well as one’s economic and social circumstances, and the like. There are common and predictable physiological changes, but the sequence and timing of these changes vary from one person to the next. [3]

Graham delineates some of the age-related issues that Leipzig describes in her book. Importantly, she includes why these changes occur, not covered here due to space constraints. Older people often present with different symptoms than do younger people when they have the same illness, and they often react differently to the same medication. Indeed, due to physiologic changes with aging, older people often require lower doses of medications which they have taken for years. Older people more frequently experience cognitive changes related to medications and illness than do younger people. These cognitive changes are normal and not a sign of dementia. Also, due to physiologic changes with aging, older people experience less musculoskeletal flexibility; weakened tendons and ligaments; reduced joint range-of-motion; reduced height; decreased muscle mass, strength, and energy; and reduced sense of hunger, thirst, taste, smell, and appetite. Older people require more energy for daily tasks and more protein for maintaining and building muscle. [3]

With aging, balance is compromised due to changes in the inner ear, the brain, and the vestibular system. Compromised balance, along with reduced bone density, leads to more frequent falls and fractures among the aging. Older people require more light to read, and more time to adjust to changes in available light. They experience difficulty in hearing, especially higher-frequency sounds and rapid speech. They find it more difficult to fall or stay asleep. Finally, people’s information-processing and reaction times slow with aging, while new learning, multitasking, and word-finding become more difficult. [3]

V. Aging with Post-Polio

In general, conditions which impact the aging population, including age-related chronic diseases, such as high blood pressure, diabetes, heart disease, COPD, and osteoporosis, may occur “more frequently, and at younger ages” among those who are physically disabled. [10] This is because health issues and barriers to maintaining health are often increased in the physically disabled population. Thus, those who are aging as well as physically disabled “need preventive services and at younger ages.” [10]

New symptoms in aging polio survivors might include pain at rest; cold intolerance; issues related to standing, walking, and climbing stairs, which increase both fall risk and accessibility issues. [4] PPS patients lament the lack of accessible public spaces, new lack of accessibility to friends’ homes, and the cost of purchasing assistive technology and services. [2] In one study, research participants were surprised at the nature of their fatigue, as it seemed unrelated to their physical effort. Some expressed surprise that they could no longer rely on parts of their body which they had previously relied upon. [4] All of these new symptoms and issues can lead to greater social isolation.

Psychological features might include reliving original polio trauma; recognition that former coping behaviors, such as “blending in,” no longer work; shame; lack of motivation; and fear of injury. [4] Fatigue due to PPS must be distinguished from fatigue due depression. Risk factors for depression include one’s previous illness experience, attitude towards disability, previous coping style, nature of physical changes, and degree of increased impairment, as well as the quality of one’s support. [12]

Interestingly, one study of aging post-polios found “modest increased weakness which may be commensurate with normal age.” These researchers found a discrepancy between patient experience with growing weakness and actual measurements of strength and neuronal loss, the measurements indicating “modest declines.” This discrepancy was considered likely due to “increased sensitivity due to their disease experiences... they lost so much strength at the time of their illness that any change is very noticeable to them.” [11]

VI. Adaptations to Aging and Post-Polio Syndrome

According to Graham, Rosanne Leipzig, in her evidence-based new book, recommends the following for adapting to age-related changes: Seek medical attention for sudden changes in functioning. Regularly ask your physician what each of your medications is for, and whether or not continued usage and dosages are currently appropriate. Engage in physical activity and in balance and resistance exercises. Stay well-hydrated – “Drink liquids even when you aren’t thirsty” - and eat sufficient protein. Have your eyes checked annually. Use hearing aids, if you find keeping up with conversation difficult. Two to 3 hours before bedtime, avoid exercise, alcohol, and heavy meals. Reduce multitasking and pace yourself. [3]

Post-Polio Syndrome management includes energy conservation; pacing of physical activities to avoid overuse; frequent rest periods; avoidance of stress; avoidance of cold temperatures; avoidance of pain with exercise; use of assistive devices; surgeries for joint repair; respiratory, occupational, and/or speech therapies; exercise physiology; podiatric care; dietetic consultation for weight management; use of mental health specialists and support groups to meet emotional needs; and planning ahead for one’s every move. [1] [2] [4]

The theory of PPS causation as an immune response to the polio virus leading to chronic inflammation proposes “treatment with immune modulators as means of combating the chronic inflammation.” [8] Management might include immunoglobulin to reduce “proinflammatory cytokines present in the cerebrospinal fluid of the spinal cord.” [9]

Aging is “often seen through the lens of the biomedical model of health, which focuses on preventing and curing medical problems causing disability.” Disability is often seen through the lens of the “social model of health, which focuses on building inclusive environments and eliminating systemic barriers.” [2] Both lenses are needed for clear vision towards patient quality of life. Living well with Post-Polio as we age requires an individualized, goal-oriented, comprehensive, interdisciplinary approach, with focus on empowerment and positive self-evaluation. [4]

VII. A Few Reflections

Undoubtedly, there is overlap in symptoms of PPS and aging. Either may aggravate the other. Both PPS and aging populations may experience an increased sense of vulnerability and difficulty accepting help. We aging Post-Polios must trust and honor what our bodies tell us about our need to make adaptations, regardless of how others perceive or judge our capabilities, or what tests might indicate about our strength.

Likewise, there is overlap in adaptations to PPS and aging. The good news is that those with PPS likely have already devised ways to adapt to changes in their physical function prior to experiencing the effects of advanced aging. In fact, they might consider themselves expert at adaptation.

As a polio survivor, I used to be able to conceal my left arm paralysis, the only polio residual I had for years. I was encouraged to find ways to do physically most everything that my peers could do. I was fortunate, for the most part, to be able to “blend in.” Then, at the age of 39, about 35 years after I had polio, I began having trouble climbing stairs. An orthopedic specialist described my legs as “misaligned,” in that polio had impacted muscular function in each leg differently. I had not known my legs were impacted at all.

I was informed that I had Post-Polio Syndrome. I gradually made adjustments. While I had to make adaptations that my non-polio peers did not have to make, I was exceedingly fortunate in having much remaining physical ability, adequate supports, and the financial means to hire help or buy equipment as needed.

Now I use a railing and climb stairs one at a time, since only one particular leg can lift me up each stair. I use a sling to support my limp arm. I’ve had to ask for assistance like never before. The difference for me now is that as I look around, I see that I have company among my aging non-polio friends in the use of assistive devices and asking for assistance. I “blend in,” but in a different way now. Aging has become a common leveler.

If age makes common bedfellows of us all, then I am in good company. Perhaps I can let go of past capacities with a bit more grace, if I view my increasing limitations from that perspective.

Living well with Post-Polio as we age requires that each of us find our own unique way to capitalize on our strengths and move forward, just as we always have. We need to take seriously suggested adaptations to PPS and aging, such as those noted above. That said, I rest my case and will adjourn for my regularly scheduled nap.

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