

Polio and Post-Polio Sequelae: The Lived Experience
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I first became aware that my recovery from polio might not be permanent when I read a brief article in a 1984 issue of Newsweek (April 23) which stated that the disease was "returning" to people who had recovered thirty or more years ago, and that some people who had walked since rehabilitation were now experiencing such severe pain and weakness that they again needed to use wheelchairs. My reaction to this, as a polio survivor who had struggled to walk again, then to discard my braces, was to stick the article in a drawer and not read it again for nearly six months. I had believed that becoming a nurse, wife, and mother proved that the most disabling aspects of the polio experience were over. As a nurse, my response was to decide that the article represented a sensational but inaccurate story which could and should be corrected, which I set out to do by researching the medical, nursing and allied health literature. This signified the start of a journey for me, in which I would not only gather and disseminate knowledge about post-polio sequelae, but uncover long-suppressed polio-related issues and emotions.

Acute Poliomyelitis

Known to the world since ancient Egypt, poliomyelitis (polio) appeared periodically in epidemics throughout the world. For years it was known as infantile paralysis, feared as a major cause of crippling in infants. Polio is an enterically communicated disease, during which the polio virus invades the anterior horn cells damaging motor neurons, which results in weakness or paralysis of the associated muscle groups. In the fifty years prior to 1955, when the polio vaccine became available, there were over 500,000 victims of polio in the United States (Bruno, 1985). From 1940 on, the disease affected an older population than when it first appeared in epidemic form in this country in 1910 (Laurie, 1984, pp. xiii-xiv).

In 1950 I was an eighth grader, the oldest of four daughters living in the small Maine town where my family had lived for three generations. I was home from school with the flu in November when I fell, my legs suddenly crumpling, dropping me to the floor. I was taken to a nearby hospital where I was diagnosed with acute spinal poliomyelitis, put into isolation and separated from my sisters who were quarantined at home. My life had suddenly, and irreversibly, changed. My memories of the first two weeks are sketchy: the smell of boiling wool as hot packs were laid over my paralyzed legs, visits from my masked parents, music from my green metal radio brought from home.... I remember overhearing two nurses talking outside my door, saying, "What a shame; she's only twelve," and looking forward to having Jessie be my nurse because she told me about her goldfish and brought moments of fun into a place that was mostly scary and somber. Before Christmas, I was brought home from the hospital by ambulance. I remember being carried to the second floor, where my parents'

bedroom, which was on the same floor as our one bathroom, had been rearranged to accommodate me. A sturdy stroller was there to take me to the bathroom; a heavy, straight-backed chair was there for carrying me downstairs and out to the car for my frequent trips to the rehabilitation center. The routines of the family were rearranged around my needs, with a tutor coming to the house twice a week, helping me complete my eighth grade education with my class, and daily physical therapy at home, several times a day, thanks to my mother.

I have since learned that in many ways I was typical of people who had polio in the 40s and 50s: a white child between the ages of 4 and 12, diagnosed with spinal paralytic poliomyelitis, with the major site of the paralysis in the extremities (Davis, 1963, p. 182). My treatment was state-of-the-art, based on the work of Sister Kenney of Australia who advocated moist heat to reduce spasms and prevent contractures. Rehabilitation typically progressed over a period of months, frequently extending to two or three years, involving active and passive range of motion exercises in very warm water in Hubbard tanks, exercising in heated pools where the effects of gravity on weakened limbs could be at least partially offset, and intensive stretching and exercising with physical and occupational therapists once signs of function reappeared. People who had bulbar polio underwent similarly long periods of rehabilitation for breathing and swallowing, many spending months in iron lungs, while others struggled to learn again how to eat and drink. Rehabilitation for most polio survivors took place in rehabilitation centers, which for many children and some adults meant being away from their own homes; for many who needed respiratory aids, this meant being sent out of state to a national center.

Poster children for Easter Seals and the March of Dimes grew up. Some of us worked our way out of braces and appeared fully recovered, while others adapted to using wheelchairs, respirator assistance, or iron lungs. Most reached maximum recovery within three years following the acute infection, and have remained on an apparent plateau of function since then. For me, that meant essentially normal functioning, with some ongoing discomfort which exacerbated to pain when I was physically overtired, occasional physical therapy and some minor adaptations. For example, in high school and college, I was assigned to adaptive physical education classes (bird watching one semester!), received heat treatments for my upper back when I typed too long, and had whirlpool treatments for my back and legs when I walked too far. Pain and muscle spasms became a problem again when I had four young children. I awoke one night, rigid with spasm, unable to lift my head or get out of bed. I suddenly realized that the chest pain I'd been experiencing was a sign of overworked truncal muscles. This initial episode, treated at home with an upper back brace and regularly scheduled cervical traction, marked the beginning of an eight year struggle with spasms, pain, and my self-esteem as a wife and mother. Once the children were all in school, I was gradually able to work out of the brace, and return to nursing in settings that required more cerebral than physical activity. Again, I felt I had overcome the effects of polio, and believed that now I had less physical demands, I could resume a fully active and essentially pain-free life.

Post-Polio Sequelae

Learning that I may not maintain this hard-earned level of functioning was initially devastating, appearing to be an undeservedly cruel trick of fate. Once I was past the stages of shock and denial, however, I decided to combine my personal experiences with polio with my professional nursing knowledge, and to try to use these experiences in a productive way. One of the first things I learned was how new the information is on post-polio phenomena, with most of the journal articles published since 1984.

Late effects of polio is an umbrella term, representing the spectrum of health problems which may occur in polio survivors. Post-polio syndrome or post-polio sequelae (PPS) refers to the new onset of pain, weakness, and fatigue typically occurring thirty or more years after recovery from polio. The pain goes beyond what can be explained by aging, chronic poor posture, joint abuse, or progressive scoliosis, and may be compared to the pain experienced during the acute illness. The weakness manifests as an inability to carry out motor functions one has taken for granted for a number of years, and may affect muscles not known to have been affected by polio as well as previously weakened muscles. The fatigue has been well described by Dr. Lauro Halstead, a polio survivor and physiatrist, who coined the term "polio wall" (Halstead and Rossi, 1985). In Halstead's own case, the fatigue was so sudden and severe that he had to pull his car off the road and nap for 20-30 minutes in order to complete his drive home from work. Cold intolerance, a fourth common finding, manifests as increased weakness and pain with even mild cold temperatures.

At the time of the first published study, an estimated 23% of polio survivors were reporting increased pain, fatigue and/or weakness. Variables associated with the risk of developing PPS primarily relate to the severity of the acute polio episode: having been hospitalized, being over 10 years old, requiring a ventilator, and having all four limbs affected (Halstead & Rossi, 1985).

Although the etiology of PPS is not known, several plausible explanations have been suggested. At the time of the acute episode of polio, all anterior horn cells were infected with the polio virus. During the recovery period, surviving motor neurons sprouted, extending their territory to include orphaned muscle fibers, innervating up to ten times the previous number of muscle groups. It is hypothesized that anterior horn cell death may occur at an earlier age and/or at a more rapid rate when the metabolism of anterior horn cells has been altered through the disease process, or when more frequent firing is required to innervate the increased number of muscles (Wiechers, 1985). Other hypotheses include the possibilities that post-polio sprouts could have an inherent abnormality, or that anterior horn cells are affected by unknown immunological changes, causing accelerated breakage of nerve sprouts, or cell death. Maynard (1988) hypothesizes that the gradual weakness, typically noted when a patient is asked to perform repetitions, may be a function of acetylcholine depletion secondary to sprout deterioration, or an intermittent conduction block prohibiting the nerve impulse from negotiating the nerve branches. Cashman of McGill (1987) has found evidence of old denervation and ongoing axon disruption in muscle biopsies of all people who had polio whether or not they have symptoms of PPS. Dalakis et al's (1986) eight year study of 27 patients describes a slow (less than 1% per year) progression of muscle weakness, with current data

indicating that the loss of muscle function will not progress past the level present immediately following the acute polio infection. An earlier theory, that there was a latent virus lurking in the central nervous system, is described by Owens (1983) as "frequently mentioned but unsubstantiated by viral or other neurodiagnostic studies."

The role of physical and emotional stress as a precipitant of PPS is under investigation, with Bruno and Frick (1987) reporting a survey which indicating high levels of "Type A" behavior in people who survived polio, and suggesting that emotional stress can be a precipitant of PPS. There are additional anecdotal reports of people who can date the onset of PPS to stressful events including surgery, heart attack, fracture, motor vehicle accident, or loss of a family member. In 1988, Maynard described stress-induced PPS in four people at the University of Michigan Medical Center Post-Polio Clinic in Ann Arbor.

Assessment for PPS

PPS is diagnosed by ruling out other causes for the pain, fatigue and loss of function. Ideally, health assessment and management would be available from a team including, but not limited to, a physician, nurse, respiratory specialist, physical therapist, occupational therapist, orthotist, nutritionist, and psychologist or social worker. Following an intake interview, comprehensive history and physical examination, team members would evaluate muscle strength and stamina, posture and gait; respiratory function; work habits and lifestyles, support systems and coping mechanisms. Findings would be shared, when the client was rested, with the client and significant others joining the health team to discuss findings and plan strategies to maximize future well-being. Ideally this team should be under one roof for ease of access, conservation of energy, ongoing communication, and consolidated billing.

My own experience with a post-polio evaluation was in 1985, at which time the closest clinic to my home in Maine was run by Dr. Augusta Alba in New York City. Following the trip, which itself was stressful and tiring, I took part in a full day's testing, then returned another day for OT and recommendations. I was disappointed that the only nurse participation was to take my vital signs prior to the physician's taking my health history. The pulmonary function tests and treadmill were physically tiring, but the muscle test was emotionally draining as well. As I approached the PT department, I overheard one therapist say to another, "I have to get going. There's an old polio coming." I felt depersonalized and invalidated, and as I prepared for the manual muscle test, found myself emotionally back to my early teen years when my future seemed to hang on the results of those frequent tests. Memories flooded back, and I felt frightened and vulnerable, a scared child concealed in the tired body of a woman pretending to be self-assured!

Following the tests, I met with Dr. Alba, a warm, friendly, and encouraging woman who made it clear that there was no easy answer for those of us who had once recovered from polio, and that lifestyle changes would help maintain the function that remained. She suggested that I might benefit from lumbar support, and using an electric scooter when I anticipated long periods of walking and standing. At that point, I viewed all such aids as signs of defeat, of not overcoming polio after all, and as something to be avoided at

all costs. Much to my surprise, the real impact of my post-polio evaluation came the next day when I found that I was extremely weak: my fingers unable to depress the keys of an electric typewriter, my hands too shaky for me to eat without spilling. It was three days before my strength began to return, and I felt reassured that I had not permanently lost function as a result of the energy expended in the testing. It took much longer to regain my emotional equilibrium after discovering how easily my strength and stamina could be exceeded.

Treatment for PPS

My concerns are shared by other polio survivors, and are not unfounded. There is general agreement that the vigorous exercise programs, which once helped polio survivors regain function, are contraindicated when weakness and fatigue recur. Both marked aggravation of weakness and permanent loss of function have been reported by people put on vigorous exercise regimens (Halstead and Rossi, 1985). Swimming in warm water is the most widely recommended exercise to promote comfort and flexibility, since cardio-respiratory function can be maintained while mechanical stresses to the musculoskeletal system are minimized. Gentle stretching exercises may also promote comfort. Fatigue and chilling should be avoided and no exercise should be continued past pain, or resumed while pain is present.

Before attempting to treat pain, it is important to determine its origin. Pain may be associated with years of functional misuse, for example soft tissue problems from weight bearing by the shoulders, and carpal tunnel syndrome from using canes or crutches (Maynard, 1988). This type of pain may be diminished by the use of orthotics and adaptive aids. Inflammatory musculoskeletal pain syndrome will frequently respond well to rest, modified activity, moist or dry heat, or anti-inflammatory drugs. Postwood (1987) reports success treating post-polio musculo-skeletal pain and neuralgias using acupuncture or tricyclic antidepressants to increase the body's serotonin levels. Other pain relief modalities reported to be meeting with some success include TENS units, ultrasound and neuroprobe treatments, acupuncture and acupressure, therapeutic touch and biofeedback.

Drugs should be used by polio survivors with caution. My own experience with Valium, prescribed in the early seventies for muscle spasm, led to a month's hospitalization for unremitting muscle spasm. The drug, increased gradually from 10 to 40 mgm. per day when the spasms continued, acted paradoxically, and created not only increased fatigue and pain but also a concomitant depression. I had somehow blamed myself for allowing this to happen until 1987, when I attended the international polio conference in St. Louis, where I first heard that Valium has been associated with increased weakness and increased spasm in some patients. Narcotics and other drugs which can lead to addiction are contraindicated because of the long-term nature of the needs. There have also been numerous anecdotal reports of respiratory problems associated with the use of curare-type drugs and general anesthesia, and of polio survivors being unable to regain previous levels of muscle strength following surgery.

Support Groups for PPS

Psychologically, the era of polio was a time of courage, bravery, and admiration for anyone who maintained a stiff upper lip. Franklin Delano Roosevelt's attitude of maintaining a facade of physical normalcy despite his post-polio paraplegia, and being seen by others as cheerful and uncomplaining represented the prevailing values of the time, and served as a model for others (Gallagher, 1985). The emotional aspects of this sudden, paralyzing illness were typically not addressed, although survivors of the acute disease were described by Gallagher as "bordering on shell shock" as they arrived for rehabilitation at the polio treatment center in Warm Springs, Georgia. Mee (1983) wrote, "Some moaned. Some cried. Some nurtured cynicism. Some grew detached. Some were swept away by ungovernable cheerfulness. Rarely did anyone scream in rage, however common the feeling (p. 42)." Those of us who survived came to believe that we were "the lucky ones," and to complain would be an act of ingratitude to all those who aided and valued our survival.

People who had polio are facing real or potential second disabilities, typically without having grieved the first, and in many cases have reality-based fears. Referral to a post-polio support group often proves beneficial to both patient and families. In 1985, since there were no support groups for polio survivors in my corner of the country, I sent to the New York City Self-Help Clearing House, and to the International Polio Network in St. Louis for information on starting one. I started by mailing press releases to Maine newspapers. The response to the subsequent feature stories was nearly overwhelming, with over 80 people calling, many sharing their polio stories for the first time in 30 or more years. In Maine, we now have a statewide organization with a mailing list of over 700 people, send out bi-monthly newsletters, and sponsor local support groups and annual statewide conferences.

Our post-polio support network, similar to others throughout the country, has helped many of us change our lifestyles, behaviors, and attitudes. I have learned from others who have tried the new, lightweight braces and found their pain lessened and stamina increased; from those who enjoy a more energetic lifestyle using electric scooters in stores and on trips; and from those who use night-time ventilators so that they can maintain adequate oxygenation to enjoy the days.

Where I once viewed the use of such aids as a sign of defeat, that polio had not been overcome after all, I now view using them as a sign of success in overcoming foolish pride, and developing a mature set of values and priorities. I marvel at the technology that has developed since I had polio, and am coming to see it as a way to continue to lead a meaningful life although my body may function less effectively than before. I have already made many simple but helpful changes, which include using lazy susans on my cupboard shelves and desk; displaying a handicapped parking permit when I am fatigued; and planning rest breaks into my day. These now appear as triumphs of Yankee ingenuity!

Self-help groups also help to address our emotional needs as we struggle with fear of the unknown, changes in our bodies and lifestyles, and pain which affects us both physically and emotionally. We face real or potential loss of hard-earned function and independence; potential loss related to disclosure of

the disability to our employers and loved ones; and potential loss of financial stability through less working hours and more health care expenses.

Where am I now, 39 years after having polio, 17 since wearing a back brace, five since first hearing of PPS? I have changed my style of fighting the effects of polio from pushing past pain to conserving my muscle function for the things that I value most. I am fearful of medications, taking only occasional Tylenol, and am open to new, non-invasive treatment modalities. The treatments which have led to the longest term pain reduction are myofascial release, a new procedure being learned by some physical therapists, and therapeutic touch, developed within nursing by Dr. Dolores Krieger, R.N. The latter is particularly helpful, with treatments providing muscle relaxation, pain reduction, and an overall feeling of physical and emotional well-being. I have help with my housework, dictate to a typist when my shoulders and hands protest too much writing at the computer, and continue to teach nursing. The future is unknown, but much less frightening now that I have become informed about PPS, and have the support of so many people in a similar situation.

What can nurses do to help polio survivors? Become knowledgeable about, and alert for signs of PPS, including with people who seem entirely asymptomatic and are in the health care system with unrelated concerns. Please watch us for possible muscle exhaustion when we are ill. Our lack of muscle reserve can lead to exhaustion of our respiratory muscles when pneumonia occurs, and those muscles may need the rest that provided by temporary ventilator assistance. Be aware of and sensitive to the special needs of people who had polio, both those presently experiencing PPS, and those who are at risk. Validate us by listening and knowing that what we are experiencing is real, and treat us with empathy as we struggle to accept what initially seems unacceptable. We are working to overcome years of conditioning that we are "the lucky ones," and that others need the help more than we do. Help us to find the resources that we need to maintain our function and as much independence as is possible. Our goal, perhaps our dream, is to learn to ask for help, to be heard and believed, to find that the resources we need are available and affordable, and to receive the help that will make it possible for us to maintain productive lives with our sense of worth intact.

A handbook on the Late Effects of Poliomyelitis for physicians and survivors can be purchased for \$6.00 from G.I.N.I., 4502 Maryland Avenue, St. Louis, MO, 63108. Subscriptions to the Polio Network News and copies of the proceedings of the international polio conferences are also available from the same organization. To correspond with the author, please write to Houses of Healing, 25 Wakely Ct., Portland, ME 04103.

About the Author

Dorothy Woods Smith is a native of Maine who had acute paralytic spinal poliomyelitis in November, 1950. Since beginning her study of post-polio syndrome in 1984, she has published articles in Maine and in the American Journal of Nursing, submitted a chapter for a book, Post-Polio Syndrome, and given numerous presentations on the topic, including at international post-polio conferences.

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