

POLIO: AN AMERICAN STORY

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The following excerpt begins on page 282:

Sometimes forgotten amidst these triumphs and controversies are the lives that were affected most by this devastating disease. Today the word “polio” describes a vaccine to be taken, not a disease to be feared. “It’s interesting”, a polio survivor observed, “but even with my limp and all my braces I’ve worn over all the years, people usually don’t have any idea what’s wrong with my legs.” Another survivor recalled a young neighbor asking him whether his parents practiced “a strange sort of religion” that didn’t permit vaccination. “To her, and to most others her age,” the man added, “there had always been a polio vaccine.”

By conservative estimates, there are at least 400,000* survivors of paralytic polio in the United States. Some recovered much of their muscle function through a process of muscle regeneration whereby surviving nerve cells developed extra branches, known as axonal sprouts, which reattached themselves to orphaned muscle fibers. Others endured multiple surgeries to reconstruct a “dropped foot,” realign a shortened leg, or straighten a badly curved spine – surgeries that required stapling of bones, the lengthening of tendons, and the fusing of joints. Many still walk with the aid of canes and crutches, wear a built-up shoe to compensate for a shorter leg, use motorized wheelchairs to move about, or need a respirator to help them breathe. What polio survivors have always had in common, however, is a drive to excel in the face of physical disability. Studies have compared them to the hard-driving over-achieving individuals associated with Type A personality. In the words of one survivor: “We were [taught] to be tough and gritty. I did what was expected...I needed to have a disciplined life with a no-quit attitude. That was what worked.”

According to Dr. Lauro Halstead, director of the post-polio program at the National Rehabilitation Hospital in Washington, D.C., most survivors developed “a special relation to their bodies unknown to able-bodied persons. They experienced a new mastery over their muscles and movements, an element of control...that carried over into other aspects of their lives and probably accounts for why so many...excelled at school and work.” Surveys have shown polio survivors to be better educated than the general population, with higher incomes and marriage rates as well. “Don’t let any [of us] tell you they just want to be ‘normal’ like everyone else,” a survivor wrote in a questionnaire, “We have to be better than anyone else just to break even...and that may not be enough.”

Following years of surgery, rehabilitation and exercise, polio survivors came to regard their condition as stable. They saw polio as a static disease, unlikely to return or worsen with age. But this comforting assumption was challenged in the 1980’s, as polio survivors began to experience health problems eerily reminiscent of their earlier ordeal. *(400,000 to 1,000,000 is another figure often used)

The symptoms were alarming: joint pain, sensitivity to cold, difficulties with breathing

and swallowing, progressive muscle weakness, and extreme fatigue. There were so many cases that polio survivors formed support groups to pool information and alert the medical community to their plight. Most American doctors of the post-Salk, post-Sabin era had never treated a case of polio. Their ignorance of the disease, beyond the importance of immunization, was distressing.

In 1984, Dr. Halstead and others organized the first international conference on the delayed effects of polio. The idea was to increase public awareness and spur medical research. The organizers attached a handle to these multiple symptoms – Post-Polio Syndrome (PPS). “Without a name there was, in essence, no disease,” Halstead recalled. “Having a name -even if imprecise and misleading as to causation – at least confers an element of credibility.”

In the past two decades, researchers have studied PPS at some length. Most believe that the fatigue and muscle weakness experienced by so many polio survivors are due to wear and tear on existing nerve cells – a theory bolstered by the three to four decades it took for these complaints to be voiced. According to researchers, the motor neurons that survived the initial polio attack and sprouted extra branches have degenerated over time. Part of this is due to the normal aging process, but a larger part, it appears, is caused by the heavy demand put on these remaining motor neurons. “It’s as if you had a ten-cylinder car

before you had polio and have a four-cylinder car afterward – a car that has driven just fine for forty years or more,” a researcher explained. “At some point, the engine is going to break down.”

Though no conclusive diagnostic test yet exists for PPS, the percentage of polio survivors suffering from progressive muscle weakness and extreme fatigue is estimated to be as high as 50 percent. Moreover, those who endured the severest cases of polio and made the greatest functional recovery are the most likely to be affected. Dr Halstead presents himself as an example. Contracting polio as a college student in 1954, he moved, “from iron lung to wheelchair to foot brace and then to no assistive device at all.” Though his right arm remained paralyzed, he sped through medical school, took up competitive squash and mountain climbing, and convinced himself that “polio is behind me. I have finally conquered it.” But in the early 1990’s, Halstead wrote, “I had begun developing new weakness in my legs. As the weakness progressed over a period of month, I went from being a full-time walker who jogged up six flights of stairs for exercise to having to use a motorized scooter full-time at work.” Halstead had no doubts about his condition. It was the same one he had been diagnosing in other polio survivors for a decade.

The recognition of PPS has had a powerful bonding effect on a group that showed great trouble acknowledging its past. “Until recently,” a polio survivor noted, “most of us tended to avoid [each] other and polio help groups. We knew we weren’t physically normal, but if we thought about it at all, we considered ourselves as inconvenienced, not disabled.” Brought together by common fears and concerns, polio survivors began to relive the memories they had long suppressed: the splitting headaches and widening paralysis that signaled the disease, the excruciating spinal tap that confirmed it, the terror of the isolation ward, the grief-stricken parents, the long separation from family, the multiple surgeries, the months spend in a body cast, the feeling of helplessness, humiliation, and loss. Dr. Richard Owen, a polio survivor who founded the Post-Polio Clinic at the Sister Kenny Institute in Minneapolis, recalled that he and other victims were often treated at teaching hospitals, where, “clad only in little cloth things that hardly covered us and our embarrassment,” they became perfect subjects for clinical demonstration. “For many of us,” Owen added, “the acute illness and convalescence was during adolescence with the impact of polio superimposed on all the usual stresses and strains of growing up. Barriers to building, activities, opportunities, and associations added to frustration and, in some cases, social isolation of young people with the residuals of poliomyelitis. Many barriers...were self-imposed. Various coping mechanisms often covered true feelings of loss. Denial often led to distorted reality.”

Those days are over. The concerns over PPS created a powerful network to deal with physical and psychological issues facing polio survivors, which in turn fueled a growing disability-rights movement across the United States. Polio survivors played a key role in lobbying for the passage of the Americans with Disabilities Act of 1990, which prohibits discrimination against the disabled and requires physical access to most public spaces. More symbolically, they joined with disability-rights activists to protest a new memorial for Franklin Delano Roosevelt in Washington, opened by the National Park Service in 1997, which largely ignored the president’s struggle with polio. The park service insisted it was only reflecting FDR’s own desire to portray himself as able-bodied. “With the country ravaged by the Great Depression and yearning for strong leadership,” it said, “Roosevelt realized the need to continue this façade.” But polio survivors wanted Americans to remember him “as both heroic and disabled,” arguing that his disability had been integral to his character, and an essential part of who he was and what he accomplished. In the end, the park service reluctantly added a ten-foot statue of Roosevelt seated in his wheelchair. The concession spoke volumes to those who best understood the late president’s dilemma. “Our national disability politics has come a long way since the 1930’s,” an activist explained. “Shouldn’t our national aesthetics now take up the challenge to transform the meaning of disability?”

For information about the world-wide campaign to eradicate polio, please visit the Rotary International website <http://www.rotary.org/>

For information about Polio Survivors and Associates (a Rotary Fellowship) visit our website www.rotarypoliosurvivors.org

For more information about post-polio syndrome, please visit Post-Polio Health International (PHI) at <http://www.post-polio.org/>.

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