SPECIAL COMMUNICATION

A Brief History of Postpolio Syndrome in the United States

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This is an overview of the history of the late effects of polio in this country from 1980 to the present in the context of the broader and much longer history of acute poliomyelitis. Books, articles, conference proceedings, and other relevant historical resources that dealt with polio-related issues from January 1, 1980, through December 31, 2009, were reviewed. The mean number of articles published per year was calculated for 5-year intervals beginning in 1980; the number of postpolio support groups and polio-dedicated clinics was compiled from directories published annually by Post-Polio Health International at 5-year intervals from 1985 to 2010. Beginning in the mid-1980s, the number of articles published each year increased dramatically, peaking during the years 1995 to 1999 when a mean of 48.2 articles were published each year. This figure steadily declined over the next 14 years. Support groups and clinics showed a similar pattern of rise and fall, with a maximum of 298 support groups and 96 clinics in 1990 and a decline to 131 and 32, respectively, by 2010. During the 1980s and early 1990s, there was a period of optimism that energized research, clinical, and self-help initiatives. As the limits of these efforts became apparent during the late 1990s and early 2000s, resources and activities declined as the postpolio community continued to age and decrease in size. Regardless of these trends, there are still thousands of survivors who continue to require skilled physiatric management as they cope with advancing age and declining function.

Key Words: History of medicine; Postpoliomyelitis syndrome; Rehabilitation.

POLIOMYELITIS, LIKE SMALLPOX, is one of those ancient diseases that appears destined to have a modern ending. According to the Global Polio Eradication Initiative,[1] acute paralytic poliomyelitis, after a run of many millennia, is on track to be eliminated from the world not only in our lifetime but hopefully in the coming decade. In this country, the history of polio is much shorter. The main events were packed into a span of only 39 years, barely 2 generations, beginning with the first major epidemic in 1916 that was centered in New York City, and ending in 1955 after the national field trial of the Salk vaccine.[2] Since then, for most Americans, the epidemics have passed into oblivion, and the word "polio" no longer refers to a disease but to a vaccine. Yet for many thousands, the legacy of our nation's brief rendezvous with polio is still very much a part of the personal histories and daily lives of many of our patients.

In the late 1970s, reports began to surface that people who had recovered from paralytic polio decades earlier were developing unexpected health problems such as excessive fatigue, pain in muscles and joints and, most alarming of all, new muscle weakness. Because there was little in the modern medical literature about delayed neurologic changes in polio survivors, the initial response of many physicians and other health care workers was skepticism if not outright ridicule. To complicate matters, this cluster of symptoms had no name. And without a name there was, in essence, no disease. Having a name helps establish an identity and makes it possible to begin the long road from ignorance to understanding. This journey finally began in the 1980s, when the many thousands of persons experiencing the late effects of polio started to attract the attention of the medical community, and the term postpolio syndrome (PPS) came into use. This article describes this journey in the United States over the past 3 decades in the context of the broader and much longer history of acute poliomyelitis.

ACUTE POLIOMYELITIS: THE EPIDEMICS

Most of us think of polio as an epidemic disease. Yet, it wasn't until the end of the 19th century when the first epidemic was recorded in Stockholm, Sweden.[2,3] Before that, polio made many isolated appearances throughout history, beginning as far back as the 13th century BC in ancient Egypt. A stone plaque (the Stele of Ruma) that dates from that period shows a priest with an atrophied limb characteristic of polio paralysis. In America, there were sporadic reports of poliomyelitis as early as 1841, but the first U.S. epidemic did not occur until 1894 near Rutland, Vermont.[2,3] By 1913, polio had appeared in every state and province of the United States and Canada, afflicting over 25,000 children and adults.[2] It was not until 1916, however, that polio took center stage, even briefly, in our national awareness. In that year, the first major U.S. epidemic occurred. More than 9000 cases were reported in New York City alone, resulting in 2400 deaths. The vast majority of those affected were younger than 5 years, which led to the name "infantile paralysis."[2,3]

During the 1930s, 1940s, and 1950s, the polio epidemics seemed unstoppable. As they grew in size, they became more deadly, creating a climate of fear and awe that is difficult to

List of Abbreviations

FDR	Franklin Delano Roosevelt
IPV	inactivated polio vaccine
MOD	March of Dimes
NHIS	National Health Interview Survey
NIH	National Institutes of Health
OPV	oral polio vaccine
PHI	Post-Polio Health International
PPS	postpolio syndrome
PTF	Post-Polio Task Force

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imagine today. From 1951 to 1955, approximately 40,000 cases were reported each year, with infections striking increasingly at older children and young adults. Starting in 1951, an effort was made to improve the accuracy of diagnosis and to report cases as either paralytic or nonparalytic. Perhaps partly because of improved reporting, the next year, 1952, became the largest epidemic year on record when almost 60,000 cases were documented. Of these patients, more than one third had paralysis, and more than 3000 persons died. By 1953, more American children died of paralytic poliomyelitis than any other communicable disease. Unlike the acquired immunodeficiency syndrome epidemic of the 1980s and 1990s that threatened only certain at-risk populations, polio haunted everyone: families stayed at home, swimming pools were closed, and public events were canceled.[2,4,5]

At all ages, polio affected males slightly more than females. In the middle and upper classes, paralytic polio was more common than in the lower classes. The most probable explanation for this socioeconomic difference was that children in lower classes were more likely to be exposed to the virus at a young age when the illness was generally milder, and lifetime immunity was acquired. All races contracted the disease in proportion to their representation in each socioeconomic class, although in the late epidemics the death rate was higher among African Americans, who often had less access to specialized treatments, such as the iron lung.[6] Epidemic poliomyelitis was found throughout the United States in rural and urban settings alike, with particularly high rates in the growing suburbs of post–World War II America. Despite the enormous amount of scientific information regarding polio, there is still no fully satisfactory explanation of why and where epidemics occurred in any given year.[2,6,7]

FRANKLIN DELANO ROOSEVELT AND THE POLIO VACCINES

Five years after the epidemic of 1916, Franklin Delano Roosevelt (FDR) contracted "infantile paralysis" at the age of 39 years, and the course of polio history was changed forever. Although his legs were badly paralyzed, FDR never lost faith that he might walk again. With remarkable courage and a flair for denial, FDR continued his political career and private life, masking his disability. Over the years and during his frequent visits to Warm Springs (the great polio Mecca he established in southern Georgia), FDR stayed in touch with other polio survivors and actively supported the search for better treatments and a vaccine. This commitment ultimately led to the creation in 1937 of the National Foundation for Infantile Paralysis, later known as the March of Dimes (MOD). During the next 2 decades, the MOD played a central role in raising the money necessary to develop the polio vaccines.[4,5]

On April 12, 1955, 10 years to the day after the death of FDR, it was announced in a dramatic national radio and television broadcast that the Salk vaccine or inactivated polio vaccine (IPV) was both safe and effective. It was a triumphant moment for U.S. medicine and brought enormous pride and relief to the American people. To use a metaphor of the time, the war against polio was over. Newspapers carried full-page headlines, "Polio Conquered" and "Victory Over Polio."[6,7] The Salk vaccine is injected intramuscularly and uses killed virus; thus, it is extremely safe and cannot cause new cases of polio. The Sabin vaccine or oral polio vaccine (OPV), which became available in 1961 in this country, uses live attenuated virus and is given by mouth. OPV is generally considered superior to IPV because of increased immunogenicity and because the weakened live virus can be "passed" from person to person, thus immunizing other individuals with a single dose. However, in rare cases, it can cause paralytic disease. After the widespread use of the vaccines, the incidence of polio dropped dramatically in the late 1950s and early 1960s. In 1979, 24 years after the introduction of the Salk vaccine, the last case of paralytic polio caused by a live wild virus was reported in the United States.[8]

LATE EFFECTS OF POLIO: FIRST REPORTS

For more than 100 years, late effects of polio have been known to occur in some individuals many years after the initial illness.[9] The first descriptions appeared in 1875 in the French medical literature.[10] The cases involved 3 young men who had paralytic polio in infancy and developed significant new weakness and atrophy as young adults. All of the subjects had physically demanding vocations that required strength and repetitive activities. In a commentary on one of the cases, the great 19th century French neurologist, Jean-Martin Charcot, suggested several hypotheses for these changes.[10] He believed an initial disease of the spinal cord (such as polio) might leave some individuals more susceptible to a subsequent spinal disorder. He also hypothesized that the new weakness was caused by overuse of the involved muscles. His observations are surprisingly relevant to the current understanding of PPS.

For many decades after those initial reports, there was only sporadic interest in the late effects of polio. In the century after Charcot's observations, there were fewer than 35 published reports, describing fewer than 250 cases.[9,11,12] As with the first subjects, most of these reports described late-onset weakness, atrophy, and fasciculations, occurring up to 71 years after an attack of paralytic polio. Why these aftereffects of polio remained an obscure and largely unexplored area of medicine until recently is not clear. Few diseases are as prevalent in the world or have been as intensively investigated as polio. Because of the rapid and dramatic onset of symptoms, polio was viewed as a classic example of an acute viral infectious disease. As a result, most of the scientific energy and resources were directed at early management and prevention, with virtually no research into long-term sequelae.

POSTPOLIO SYNDROME

The Early Years

With widespread use of the vaccines, polio quickly became a medical oddity in the industrialized world, and interest and funding in polio-related problems waned. However, polio and its complications only appeared to have been defeated. Because the major epidemics occurred in the 1940s and 1950s and late-onset neurologic changes typically did not appear until 30, 40, or 50 years later, many thousands of polio survivors did not begin to experience unexpected problems related to their polio until the late 1970s and early 1980s. As occasionally happens in medicine, persons experiencing these symptoms finally started attracting attention in several parts of the country more or less at the same time.

In 1979, the *Rehabilitation Gazette*, a newsletter for polio patients, published a letter by a 57-year-old male polio survivor who wrote, "During the past few years, I find myself being able to do less and less and tire far too easily."[13(p 64)] He also described increased difficulty walking, getting out of bed, and going from sit to stand, which led him to take early retirement. To the surprise of many, this short letter provoked an avalanche of testimonials by polio survivors who were experiencing similar health problems. In response, the publishers of the *Rehabilitation Gazette* organized a conference held in Chicago in 1981 entitled "What Ever Happened to the Polio Patient?"[14] In