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

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POLIOMYELITIS, LIKE SMALLPOX, is one of those ancient diseases that appears destined to have a modern ending. According to the Global Polio Eradication Initiative, 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 alone, resulting in 2400 deaths. The vast majority of those affected were younger than 5 years, which led to the name “infantile paralysis.”

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. 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. By 1913, polio had appeared in every state and province of the United States and Canada, afflicting over 25,000 children and adults. 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.”

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
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.9 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.”7,8 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.11 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
the years after this meeting, the Rehabilitation Gazette was reorganized into an entity now known as Post-Polio Health International (PHI), the only organization serving both the national and international postpolio communities. Besides sponsoring a series of conferences for lay and medical audiences, PHI is a resource for referral and education, and publishes a quarterly newsletter as well as an annual directory that lists community-based support groups, postpolio clinics, and health care professionals with expertise in PPS. In addition to the Chicago meeting, there were similar conferences in the early 1980s held in Oakland, California, and Ontario, Canada, which contributed to a growing realization that there were a number of basic questions to be answered, including the following: (1) How many polio survivors were still alive in the United States, and how many of them were experiencing new health problems? (2) What were the type and frequency of new health problems in this population, and what were the causes? (3) Were these problems real and indicative of some unexplored pathology, or were they simply due to aging? and (4) What were the most effective treatments? About this time, the term “postpolio syndrome” was introduced, which quickly became the unofficial designation for these new health problems, although many other terms have been used as well including “postpoliomyelitis muscular atrophy,” “the late effects of polio,” and “postpolio sequelae.”

Accurate totals of the number of Americans who had poliomyelitis are not available and probably never will be. There is no national registry, and there is no way, after all these years, to compile accurate figures from state and local health departments. The first estimate of the number of polio survivors in the United States was not available until 1987 and was based on data from the National Health Interview Survey (NHIS). This survey collects data each year from a representative sample of the U.S. population regarding their health and disability status. In 1987, NHIS calculated there were approximately 1.63 million polio survivors. A follow-up survey by the same governmental agency in 1994 and 1995 found this figure had declined to 920,000. Taking into account the age of this population, it was estimated that the number of polio survivors had further declined to roughly 700,000 by 2006. How many of these individuals were experiencing PPS was more difficult to calculate. With the use of data from the 1994 to 1995 survey, which recorded the number of persons in each household who had received a diagnosis of PPS or who believed they had PPS, the figure was probably in the range of 11% to 25%. Although there are many potential sources of error in these figures, the best estimate of the number of PPS survivors in this country as of 2006 was somewhere between 81,000 and 184,000.

The causes of the new health problems were unknown during the early days of PPS, although an article published in 1981, which described increased motor unit deterioration as a function of time since the original disease, provided an early clue to the possible pathology of late-onset weakness. While there is still some uncertainty about the underlying cause of ongoing denervation, the most widely accepted hypothesis is based on the electrodiagnostic findings of distal degeneration of enlarged motor units. In 1984, the first scientific conference devoted exclusively to PPS was held in Warm Springs, Georgia, on the grounds of the Roosevelt Warm Springs Institute for Rehabilitation founded by FDR. This meeting was attended by researchers and clinicians from the United States and 4 other countries. Presentations covered a wide array of topics including the pathophysiology of acute polio, normal aging of the spinal cord, the possible role of a reactivated poliovirus, the epidemiology of new health problems in polio survivors in Olmsted County, Minnesota, management of pain, and the role of exercise. This conference laid the foundation for the major advances in the years ahead and helped energize a far-reaching series of activities that defined the PPS era.

Almost as important as the scientific papers presented and discussed at this meeting was the appearance of national media on the final day of the conference, including many major newspapers, television and radio networks. News had leaked out about the conference, sparking rumors that the polio virus had been reactivated and raising fears of new epidemics. In subsequent weeks and months, there were countless news stories all across the country that provided an enormous boost to clinical and research interest in this “new” entity and the eventual formation of almost 300 support groups and 96 specialty clinics. Two years later in 1986, a second international scientific conference was held at Warm Springs, Georgia. This meeting, with participants from 7 countries, represented a substantial increase over the 1984 conference in the range and sophistication of the topics covered, and provided convincing evidence that PPS was an important clinical entity that was engaging top researchers both here and abroad.

During the latter half of the 1980s and throughout the 1990s, there was a steady escalation of PPS research and lay activity. Figure 1 shows the mean frequency distribution of medical articles published between 1980 and 2009 by 5-year intervals. (See Appendix 1 for search strategy and selection criteria.)
media and publications by lay and professional authors that can be found in books, newspapers, and magazines.

Figure 2 shows the number of support groups and postpolio clinics in this country every fifth year beginning in 1985. These data were obtained by reviewing the directories published each year by PHI from 1985 to 2010. In 1985, there were 45 support groups located in 24 states. The number of groups expanded rapidly as interest and knowledge about PPS spread across the country. The maximum number of organizations listed with PHI occurred in 1990 when there were 298 support groups in 49 states. In that year there were 26 groups in California, 20 each in Michigan and Ohio, and 19 support groups in Illinois. Postpolio clinics followed a similar pattern, which was stimulated by several factors. As each community or region of the country became aware of PPS, there was a fresh surge of newspaper, radio, and television publicity, often featuring the dramatic stories of local residents and their experiences with acute paralytic polio, as well as their new and largely unexpected health concerns. With the spread of this information, an ever-widening circle of people began to seek help. Often this led them to join a group of other polio survivors and to seek help from health professionals. In response to this demand, physicians established clinics tailored to meet polio survivor needs. In 1985, there were already 19 clinics in 14 states. This number grew steadily until 1990 when there was a peak of 96 clinics in 26 states. As with the support groups, the following years witnessed a gradual drop in the number of clinics as the population aged and effective new treatments failed to materialize. By 2010, the number of support groups and clinics declined to 131 and 32, respectively.

The Later Years

In 1994, the National Institutes of Health (NIH) and the New York Academy of Sciences organized a conference that brought together many of the leading polio researchers from around the world. Because of the prestige of the sponsoring organizations and the caliber of the presentations, this meeting helped confirm the importance and legitimacy of PPS as a clinical entity in this country and abroad. At the same time, it created the impression that the field of PPS had finally arrived and was on the brink of crucial breakthroughs that would accelerate our understanding of polio-related pathology and the arrival of more effective therapeutic interventions. And yet, very little of that happened despite the increased number of medical publications that peaked at more than 48 articles per year during the 5 years immediately after the 1994 conference. The reasons for the decline in major advances in basic science and clinical care are unclear. There were still many thousands of polio survivors who needed help and many critical scientific questions to investigate. One explanation might simply be historical timing. If PPS had become a significant clinical entity 20 years earlier, there might have been more time for the field to mature, more years to develop secure funding, and more opportunity for researchers to make long-term commitments. Such commitments might have produced a diagnostic test to replace the scientifically unreliable “diagnosis of exclusion” or, in the absence of a pathognomonic test, produced a classification that went beyond the basic dichotomy of PPS: present or absent. With more time and more research, there might have been a wider acceptance of the diagnosis of PPS. As it is, despite an extensive 30-year record of research, publications, and conferences in this country and abroad, there remains a persistent core of health care professionals and members of the lay public who will probably remain skeptical that PPS is a real entity until a reliable and valid diagnostic test is developed.

In the years after the NIH conference, there were 2 other important gatherings of medical and lay leaders in this country. One was the Post-Polio Task Force (PTF), which was organized in 1997 and sponsored by the manufacturer of the pharmaceutical pyridostigmine. The other was a conference convened in 2000 by the MOD. Both groups reviewed the relevant literature and developed consensus statements on best practices. Publications by these groups, while useful, nevertheless reinforced the feeling that there had been little progress of substance since the NIH conference in 1994, especially concerning pharmacologic treatment. In the absence of effective medications, the best practices recommended by both the PTF and MOD for managing PPS symptoms were multidisciplinary rehabilitation strategies including bracing, pacing, lifestyle modifications, and individualized exercise programs. Over the course of the past decade, little has changed. In a scholarly review of the management of PPS published in 2010, rehabilitation interventions were still the principal recommendations. The one exception may be the use of intravenous immunoglobulin, which has shown variable benefits in 2 randomized controlled trials.

The history of PPS is unlike most other chronic neurologic conditions. With illnesses such as multiple sclerosis and amyotrophic lateral sclerosis, for example, the populations are either slowly growing or constantly being replenished. In addition, the morbidity and mortality of these 2 disorders are unrelenting and provide significant clinical and research challenges. As a consequence, many investigators and research centers make long-term commitments to uncover basic pathology and effective therapies. Public interest and funding remain generally strong. New findings stimulate further studies, and the cycle repeats and expands. With PPS, there was a dramatic spike in productive activity within the research community when it was a “new” entity. For many investigators, the challenges were understandably alluring: a well-known disease with unexpected new symptoms, a large population suggesting ready access to study volunteers, intriguing possibilities for underlying pathology, and possible application of new knowledge to the understanding and treatment of other diseases. When studies failed to lead to other promising avenues of investigation, researchers and funding sources began to lose interest. Additionally, it was clear that for most individuals the disease progression was slow, and morbidity and mortality were not nearly as dramatic as with many other chronic diseases.

Declining interest by researchers led to fewer publications in the medical literature. Research centers dedicated exclusively to understanding PPS never developed, and young investiga-
tors did not see a career path that led into the future. There never would be a Nobel prize for PPS. Although it was rarely discussed openly, everyone was nonetheless aware that this population was finite, and the problems and challenges would eventually disappear, with or without a better understanding of the etiology and regardless of whether there was a cure. Anecdotal evidence suggests that the decrease in new research had a negative impact on the vitality of postpolio support groups. One of the main reasons people attended support groups was to keep abreast of the latest findings from the research community. When old facts kept being recycled at their meetings, members began to lose interest, attendance waned and many support groups stopped meeting. Most groups now meet only several times a year and some meet only online.

The Future

Perhaps the single most important fact about polio survivors in the United States in 2010 is their advancing age, which is taking a heavy toll. This is reflected in the decreased numbers of support groups and specialty clinics and, indirectly, in the declining number of publications. Although many persons remain employed or active in retirement, others are developing unrelated medical conditions that often trump the severity of PPS. While there is still some ongoing research, centered largely in Europe, for most it is too little, too late. In this country, acute poliomyelitis for most Americans is part of a distant past, and polio survivors are like veterans from some forgotten war. Despite their dwindling numbers, however, there are many thousands who will continue to need assistance from informed health care providers for several decades to come. In addition to these older survivors, there is a second cohort of unknown size of younger patients, typically under the age of 50 years, who contracted polio in developing countries, immigrated to the United States, and are now seeking help in postpolio clinics. On a global level according to the MOD, there are 10 to 20 million polio survivors worldwide. Although the number of these individuals with PPS is unknown, they will require medical attention well into the future. Complete eradication of acute poliomyelitis is still an unfulfilled aspiration, but recent progress by the World Health Organization and other international groups is encouraging. In the first 6 months of 2010, only 452 new cases of acute paralytic poliomyelitis were reported, which were located primarily in West Africa and the Indian subcontinent. This number is down dramatically from the late 1980s when an estimated 350,000 cases were reported in a single year. With the elimination of acute polio, PPS will finally vanish. Although the final chapter of PPS remains to be written, it is now possible to predict how it will end.

CONCLUSIONS

PPS has been described in the medical literature for more than 100 years but did not emerge as an important clinical entity in this country until the early 1980s. Over the next 30 years, many thousands of survivors organized themselves into self-help groups, attended specialized clinics, and helped energize a vigorous enterprise of basic and clinical research. More recently, as the population continued to age and the energy and enthusiasm of the early years waned, there has been a decline in published research and the number of clinics and support groups. Regardless of these trends, there are still thousands of survivors who, more than ever, require expert rehabilitation assistance as they cope with advancing age and declining function.

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APPENDIX 1: MEDICAL LITERATURE SEARCH STRATEGY AND SELECTION CRITERIA

The search terms included articles that met any of 3 criteria: (1) indexed under “poliomyelitis” and containing any of the terms “late effects,” “late onset,” “sequela,” “residual”; (2) articles containing any of the terms “postpolio,$” “post polio,$” “post-polio$”; or (3) indexed under “postpoliomyelitis syndrome.” The symbol $ indicates the term was truncated. We searched Ovid Medline and the Cumulative Index to Nursing and Allied Health Literature databases without language restrictions from January 1, 1980, through December 31, 2009.

References


