



POST-POLIO SEQUELAE: Physiological and Psychological Overview

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When the Salk and Sabin vaccines brought an end to the annual summer nightmare of polio epidemics, most Americans simply forgot about polio. Even many of those who had paralytic poliomyelitis put the disease out of their minds once they had achieved maximum recovery of function. Unfortunately, polio has again forced itself into the nation's consciousness. Over the past five years, many of those who had polio have been experiencing new and unexpected symptoms that range in severity from being merely unpleasant to severely debilitating:

- *unaccustomed fatigue*, so severe in some individuals that they must lie down to rest in the middle of the day - a phenomenon called the "Polio Wall"; [[1](#)]
- *new joint and muscle pain*;
- *new weakness* in muscles affected and in those apparently unaffected by the polio;
- *new respiratory difficulties* in those who had bulbar or upper spinal polio that require some to return to using a respirator;
- *cold intolerance*, where exposure to even mild cold temperatures results in noticeable muscle weakness, marked coldness and discoloration of the limbs and burning pain - symptoms that increase with aging. [[1](#),[2](#),[3](#),[4](#),[5](#),[6](#),[7](#)]

INCIDENCE AND PREDICTORS OF NEW SYMPTOMS

Of the hundreds of thousands of persons who contracted poliomyelitis during the past fifty years, how many are now experiencing these new symptoms, when do new symptoms occur and are there any factors

that predict their occurrence? At this time, there are only preliminary studies that speak to these questions. The only population-based study of incidence was conducted by researchers at the Mayo Clinic.^[8] This initial study determined that at least 22% of the 201 persons who contracted paralytic poliomyelitis in Rochester, Minnesota between 1935 and 1955 developed new symptoms. The National Health Interview Survey of 1977 reported that there were 254,000 persons alive in the United States who had been paralyzed by poliomyelitis.^[9] If one combines the data from these two sources, it appears that there are at least 55,880 persons who were paralyzed by poliomyelitis and are experiencing new symptoms.

However, it has become clear that individuals who were diagnosed as having had non-paralytic poliomyelitis also can develop new symptoms. Between 1933 and 1983, a total of 484,862 cases of paralytic and non-paralytic poliomyelitis were reported to the Centers for Disease Control (R. Bruce, personal communication, 1984). The CDC admits that this number is an underestimate of the true incidence of polio because reporting requirements were not instituted until the late 1950's. Mindful of this caveat, if the case fatality ratio from the Mayo Clinic study (14.5%) is applied to the CDC total, there are at least 414,557 persons alive today who are at risk for developing new symptoms.

With regard to the chronology and predictors of the new symptoms, a questionnaire study of over 500 persons who had polio documented that the occurrence of new symptoms is related to the number of years since the initial polio infection, and not to chronological age.^[1] New symptoms were found to appear approximately thirty years after the acute infection. This study also identified four factors which, if present during the acute phase of polio, predict an increased likelihood of developing new symptoms: having been hospitalized, having been 10 years of age or older at the time of the acute infection, having had paralytic involvement of all four limbs or having used a ventilator. ^[1]

TERMINOLOGY AND ETIOLOGY

The new symptoms reported by persons who had polio have been given a variety of names by the popular press, including "Post-Polio Syndrome" and Post-Poliomyelitis Progressive Muscular Atrophy (PPMA). The initial magazine articles that named the new symptoms also proffered their probable cause. It was suggested that the polio virus, lying dormant in the spinal cord for thirty years, had become reactivated and was giving people polio for a second time. It was also suggested that new weakness was the result of "some kind of amyotrophic lateral sclerosis." These two suggested etiologies are now regarded as incorrect. The researchers and clinicians who gathered at Warm Springs, Georgia for the First International Symposium on the Late Effects of Poliomyelitis in May, 1984 rejected both explanations because neither has been supported by empirical evidence. The name "Post-Polio Syndrome" was rejected since most persons report some but not all of the five major symptoms listed above. The term Post-Poliomyelitis Progressive Muscular Atrophy (PPMA) was also rejected as a general descriptor of the new symptoms since the over-whelming majority of persons reporting new symptoms are not experiencing progressive muscular atrophy.^[10] The Post-Polio Task Force, meeting again in Boston in October, 1984, adopted the term *Post-Polio Sequelae* as the general descriptor of the new symptoms.

PATHOPHYSIOLOGY OF POST-POLIO SEQUELAE

If Post-Polio Sequelae result neither from reactivation of the polio virus nor from ALS, what is their cause? Once medical conditions unrelated to polio have been ruled out as causes of new symptoms, the symptoms can be grouped into two categories: Post-Polio Sequelae with explainable causes and those with unknown etiologies. Many instances of pain, muscle weakness and fatigue can be attributed to readily diagnosable causes that are in some way related to the original paralysis caused by the poliomyelitis. For example, carpal tunnel syndrome frequently arises in persons having lower extremity

paralysis who have ambulated on crutches for thirty years.^[1] The original muscle paralysis can also predispose to scoliosis and its related respiratory difficulties, as well as knee instability and deformities that produce joint and muscle pain.^[2,3,4,11]

The second category of Post-Polio Sequelae includes those symptoms that cannot be attributed to any other diagnosis. Testable hypotheses are just being proposed to explain the cause of these symptoms. Although hypotheses to explain fatigue and pain have not yet been clearly outlined, there are several hypotheses describing the cause of muscle weakness.

The most parsimonious hypothesis suggests that normal age-related losses of anterior horn motor neurons reduces the size of the pool of functioning anterior horn cells - a pool that was markedly diminished by the original poliomyelitis - and that these reductions lead to new muscle weakness. It is a remarkable fact that persons who had spinal poliomyelitis were shown to have normal muscle function even after the loss of 60% of their anterior horn cells.^[12] Since normal anterior horn cell loss is suggested to occur at a rate of 5% per decade after age twenty, aging-related losses of spinal motor neurons could reduce the total number of anterior horn cells to below 40% and thereby cause decreased muscle functioning.^[13]

A second hypothesis relates to the process of functional recovery following poliomyelitis. One mechanism by which muscle function is restored following the acute infection is by surviving motor neurons producing axonal "sprouts." Through the growth of axonal sprouts, remaining motor neurons innervate not only their own muscle fibers but also thousands of additional muscle fibers "orphaned" when surrounding motor neurons died.^[14] Electromyographic studies indicate that the number of sprouts and their ability to function are decreased in persons who had polio - decreases that correlate with the number of years since polio onset and not chronological age. Further, recent animal studies indicate that exercise and stress cause the destruction of axonal sprouts and that sprouts are not replaced in aged animals (Smith and Rosenheimer, personal communication, 1984). While clinical reports indicate that exercise and stress do precipitate decreases in muscle function in persons who had polio, a relationship between failed axonal sprouts and muscle weakness has yet to be empirically documented.^[11,15,16]

Finally, it has been suggested that the transient muscle weakness that follows exercise may be caused by the metabolic fatigue of polio virus-damaged or extensively sprouted anterior horn cells.^[14] These motor neurons may become unable to meet the metabolic demands of functioning after years of operating in a damaged state or supplying more muscle fibers than they were "designed" to innervate.

TREATMENT OF POST-POLIO SEQUELAE

Although research into the cause of Post-Polio Sequelae is in its infancy, a number of important facts have come to light regarding treatment for the symptoms of unknown etiology. The "use it or lose it" dictum of polio rehabilitation during the 1940's and 1950's appears not to apply to the post-polio population today. Many persons report that strenuous and fatiguing activities result in decreased muscle strength, generalized fatigue and pain.^[4,15,16] Continuing to walk without assistive devices or with originally prescribed braces, canes or crutches has become too exhausting or painful for many. The use of new or additional assistive devices and the appropriate bracing of weak and abused joints have been very successful in reducing symptoms and maintaining function.^[1,2,15] Also, the combination of a reduction in strenuous activities with carefully prescribed and monitored progressive resistance exercises and cardiopulmonary conditioning has been shown both to reverse weakness and reduce fatigue in a number of individuals.^[7,16,18] However, it is crucial that even therapeutic exercise be stopped at the first indication of fatigue.^[16]

It is becoming clear that for the majority of persons experiencing Post-Polio Sequelae changes in daily schedule, decreasing strenuous and fatiguing activities and new physical therapies or assistive devices will be required to treat the new symptoms. However, to the persons experiencing them, such changes in lifestyle often feel as if they are becoming disabled for a second time by the same disease.

THE PSYCHOLOGY OF POST-POLIO SEQUELAE

Many medical conditions cause more than one disability. Atherosclerosis, causing a function-limiting heart attack, can progress to also cause a disabling stroke. Diabetes can cause late onset blindness and peripheral vascular disease that not infrequently necessitates multiple amputations. Usher's syndrome is a hereditary condition that causes profound congenital deafness and progressive blindness. [19,20] In all of these instances affected persons know that additional symptoms are possible and know their cause. It is unique to Post-Polio Sequelae that neither the persons who had polio nor their physicians knew there was any potential for additional symptoms to occur or knew their cause when they appeared.

When persons who had polio first began reporting new symptoms to their physicians, almost no one was told that their problems might be related to a bout with polio thirty years earlier. Thousands across the country have undergone extensive medical testing that was unable to establish a diagnosis. As a result, many persons experiencing new symptoms have become frustrated and desperate after being repeatedly told there was nothing wrong or that they would "get used to" pain, fatigue, weakness, etc. Some individuals have even been admitted to hospital with a diagnosis of depression because no physical cause could be found for their complaints. On the opposite end of the spectrum, many others have been diagnosed as having "some kind of ALS" or were told that they were actually having polio again. [17] Most did not even know that others were experiencing similar symptoms and difficulties since persons who had polio have not traditionally affiliated with each other as a disability group. These persons felt completely alone, without medical or social support. Further, individuals who had polio regained function through great physical and emotional effort. Now, after thirty or more years, they were being forced to deal with disabling symptoms that felt very much like the symptoms they overcame and supposedly left behind following the initial polio infection.

The occurrence of a second disability as the result of Post-Polio Sequelae is psychologically devastating because of the combined effects of the occurrence of unexpected symptoms whose cause is unknown, a lack of knowledge and understanding on the part of the medical community, feelings of isolation and the loss of hard-won physical abilities whose recovery was thought to be permanent. Although clinical and research emphasis has thus far been placed on the physical symptoms reported by persons who had polio, in many cases the psychological trauma connected with Post-Polio Sequelae may be more damaging than the physical problems.

PSYCHOLOGICAL SEQUELAE OF SECOND DISABILITY

One individual who had polio has walked with a limp using a long-leg brace since he attained maximum function twenty-eight years ago. His physiatrist recently recommended that he begin using a cane to reduce energy expenditure and decrease pain. Later he told a friend, "I would not want to live like *that!*"

This statement expresses the attitude of most of society toward the disabled. Most people would not want to live "like that" since society devalues the disabled because they have lost something of value - full use of their bodies. [21,22,23,24,25,26] However, since disabled persons live in this society and are as subject to its beliefs and mythologies as anyone, they devalue themselves as the rest of society does. [27,28] Thus, when Post-Polio Sequelae affect persons who were disabled by polio with what is perceived as a *second*

disability, they are psychologically traumatized by the devaluing attitudes always associated with becoming disabled.

Society's devaluing and generally negative attitude toward the disabled can readily be observed in the ways the disabled are usually portrayed in the media. Television and print coverage of the "story" of Post-Polio Sequelae has relentlessly referred to persons who had polio as "polio victims" or as "suffering from polio." Neither of these phrases is acceptable because each gives the impression that the lives of persons who had polio are primarily the result of a polio virus. The terms "Polio Survivor" and "Post-Polio" are also objectionable to many persons in the post-polio community because the former is felt to make unjustifiable reference to the Nazi Holocaust and the latter refers to those who had polio as if they were a diagnosis, not individuals.

THE PROCESS OF ACCEPTANCE OF SECOND DISABILITY

How does one adjust to the fact of a second disability in the face of negative societal attitudes and self-devaluation? The following processes have been described for disabled person to work toward acceptance of disability. [[21](#), [22](#), [23](#), [24](#), [28](#)] Here, these processes have been modified to apply to the Post-Polio experience:

A period of mourning is usually needed for the loss of physical prowess. Such mourning is appropriate and usually occurs no matter how often disability occurs in a person's life. In this phase, persons experiencing Post-Polio Sequelae might reject new assistive devices because those devices are symbols for the loss of physical ability earned through great effort.

Devaluing physique is the process whereby physical achievement and appearance become less important than personal competencies and effort. This process diminishes the devaluing of the individual and leads to coping with the disability rather than succumbing to its difficulties. This process will allow persons with Post-Polio Sequelae to be better prepared psychologically to deal with using new or additional assistive devices and with other changes in life style.

Enlarging the scope of values precludes allowing the single value of "the body" to become decisive in determining a person's worth. An individual can become interested in work, study, politics, leisure activities, etc. as means to judge his worth rather than focusing on what his body can or cannot do. The Mayo Clinic study found that 78% of the persons in their group were employed full time. [[8](#)] This statistic is staggering when one considers that among the gamut of severely disabled persons, only 15% to 20% of the men and 7% to 8% of the women are employed full time. [[29](#)] Information from the Sister Kenny Institute indicates that persons who had polio marry at about the same rate as the general population (M. Knapp, personal communication, 1984). These data suggest that many persons who had polio already have an enlarged scope of values and, therefore, may be better equipped to deal with a second physical disability.

Upholding asset evaluation entails emphasizing and learning to value what a person can do within the limitations of his disability instead of judging that person by so-called "normal" standards that are inappropriate for him. If it is best for persons who had polio to reduce their schedules or to start using assistive devices, then such sensible alterations in behavior should be made based on the needs and abilities of the individual. When persons experiencing Post-Polio Sequelae see such required changes as safeguarding their lifestyle, rather than eroding it, they are upholding asset evaluation.

THE POST-POLIO SUPPORT GROUP

A valuable technique for facilitating these processes and for dealing with the psychological aspects of Post-Polio Sequelae is the post-polio support group. Such groups have been established across the country and have been found to be helpful for a number of reasons: 1) individuals come together because they share a common problem; 2) peers come together with the expectation of helping themselves and each other through changing attitudes and behavior; 3) peers make themselves available to each other between regularly scheduled meetings; 4) the group process consists of receiving and giving feedback, sharing hope, experiences, coping strategies and encouragement.^[30] In addition, social support has been found to be protective against the negative effects of stress.^[31]

STRATEGY FOR THE FUTURE

Since research on the causes of and treatments for Post-Polio Sequelae is just beginning, it will be some time before all of the answers are found. In the interim, the Post-Polio Task Force suggests that persons who are experiencing new symptoms should first consult a physiatrist (a specialist in physical medicine and rehabilitation) to obtain a complete physical examination, advice on reducing strenuous activities, assessment of assistive devices and the prescription of carefully monitored physical therapy and new assistive devices when appropriate.

Second, all persons who had polio should become knowledgeable about Post-Polio Sequelae in order to be their own best advocate for appropriate medical care and needed community services. Post-polio support groups will gather information concerning local resources (e.g. names of informed and interested physicians, hospital-based rehabilitation clinics, independent living centers) as well as access the national information network that these groups are creating. In addition, the book *Late Effects of Poliomyelitis* (the proceedings of the Warm Springs Symposium on the Late Effects of Poliomyelitis) and the July, 1985 issue of the journal *ORTHOPEDICS*, which is devoted to Post-Polio Sequelae, are available. The papers included in these volumes will enable persons who had polio to become familiar with the latest information on Post-Polio Sequelae and to inform and educate their own physicians.

Third, state and federal officials must be apprised of the problems and needs of the post-polio community. Members of Congress must be asked to hold hearings on Post-Polio Sequelae so that federal funds will be made available for treatment programs and research grants.

CONCLUSION

It is now clear that persons who had polio are in fact experiencing new and unexpected symptoms. Ours is the first generation of persons to document what happens to bodies that have been working for thirty or more years under the special stresses caused by having had polio. Surviving the acute polio infection, overcoming its paralytic sequelae and attaining quality of life required determination and tremendous effort. No less determination and effort will be required of both the post-polio and rehabilitation communities to overcome Post-Polio Sequelae and maintain that quality of life.

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