When the Salk and Sabin vaccines brought an end to the annual summer nightmare of polio epidemics, most Americans put thoughts of polio out of their minds. Once those of us who had the disease regained maximum function through rigorous and extensive physical therapy did the same, believing that our level of recovery would be permanent. However, over the last 35 years most of the 20 million polio survivors around the world have been reporting that their bodies are changing once more and, in many instances, that their quality of life is being adversely affected. The changes most frequently reported are unaccustomed fatigue, joint and muscle pain, muscle weakness and respiratory difficulties. These symptoms range in severity from merely unpleasant to severely debilitating. 1-4

When polio survivors began reporting new symptoms to their physicians in the early 1980s, the response of the medical establishment sent psychological shock waves that are still being felt. Many persons were diagnosed as having “some kind of amyotrophic lateral sclerosis (ALS)” or were told that poliovirus, lying dormant somewhere in their bodies, had become reactivated and that they were actually having polio again. Thousands of others across the world have undergone extensive diagnostic testing that has been unsuccessful in establishing a diagnosis. As a result, many persons experiencing new symptoms have become frustrated and desperate after years of going from one physician to another and being told that there was nothing wrong or that they would “get used to” pain, fatigue and weakness. Some individuals have even been admitted to hospitals with the diagnosis of depression because no physical cause could be found for their complaints.

Physicians are realizing that the new symptoms reported by polio survivors are real. Research has been conducted to understand the cause and outline treatment for these new symptoms. This research is showing that excessive exercise and stress decreases muscle strength and increases fatigue. 5 For some, since continuing to walk with canes or crutches has become too exhausting, using a wheelchair for part or all of the day, or bracing weak muscles and abused joints, have necessary. 2, 5, 6 Physical therapy to promote energy conservation is often necessary. In addition, stress reduction techniques may need to be incorporated into each day’s schedule. 7

It is becoming clear that for the majority of persons experiencing Post-Polio Sequelae, changes in lifestyle -- such as reductions in schedule and level of activity, new physical therapies or assistive devices -- are required to treat new symptoms. However, these changes are more than just a change in lifestyle. For the persons experiencing them, they represent what feels like becoming disabled for a second time by the same disease.

The Psychology of Post-Polio Sequelae. It is well known that other conditions can cause more than one disability. Atherosclerosis, causing a function-limiting heart attack, can also to cause a disabling stroke. Diabetes can lead to late-onset blindness and peripheral vascular disease, which can necessitate amputations. Usher’s syndrome is a hereditary condition that causes profound congenital deafness and progressive blindness.8,9
In all of these instances, affected persons know that additional symptoms or disability are possible and know their cause. It is unique to Post-Polio Sequelae that neither the persons who had polio nor their physicians were aware that there was any potential for additional symptoms to occur or their cause when they appeared. Since persons who had polio traditionally did not affiliate with each other as a disability group, they had no way of knowing that others were also experiencing similar difficulties. Polio survivors felt completely alone, without medical or emotional support.

There is another disturbing aspect of Post-Polio Sequelae. Individuals who had polio attained maximum function only with great physical and emotional effort. Many have become the most active and productive members of their communities. After 30 or more years of hyperactivity and productivity, they must deal with disabling symptoms that feel very much like the symptoms they overcame and supposedly left behind following the initial polio infection.

Thus, the occurrence of a second disability as a result of Post-Polio Sequelae is psychologically devastating because of the combination 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 when recovery of functioning was thought to be permanent.

**The Psychological Sequelae of Disability.** One polio survivor had walked with a limp using only a brace since he attained maximum function. His physician recently recommended that he begin using a cane to reduce his energy expenditure and to decrease pain. Upon returning from the physician’s office 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 denigrates persons who are disabled because they have lost something of value: the full use of their bodies.” The point of the above example is that, since disabled persons live in this society and are as subject to its beliefs and mythologies as anyone else, it is inevitable that people with disabilities would devalue themselves as the rest of society does. Thus, when persons who were disabled by polio develop PPS – their second disability -- the psychological trauma of devaluation that accompanies becoming disabled is again experienced.

The devaluation of a disabled person is determined predominantly by two factors: 1) an individual's attitude about disability in general and 2) the “spread” of this general attitude to an individual’s opinion of a specific disabled person.

Both attitude and spread were examined in a study of undergraduates asked to rate “disabled persons” in general on 24 character and personality traits. The task was seen by the students as sensible; that in itself is an important finding with regard to attitude. When one considers the fact that the only information provided was that the persons to be rated were disabled, it is amazing that the task could be completed at all. Yet, these students felt comfortable with making personality judgments when they knew only one fact about the group and that fact had to do with physique, not personality.

The students’ attitude toward disability was evidenced by their assessing disabled persons as being more conscientious, intelligent, kind and altruistic, as well as being less aggressive, less able to adjust to new situations and more likely to engage in reverie than the average person.

Spread is commonly seen to operate in an even more absurd fashion than attitude when, for example, persons who cannot see are expected to be deaf and those who are mobility impaired are also thought to be cognitively impaired.
The generally negative attitude of society toward the disabled can be observed in the ways the disabled are usually portrayed in the literature and by the media. Literature portrays disabled persons as unhappy, hopelessly enmeshed in the difficulties of their disability, bitter and manipulative, or more “in touch with God” because of their suffering. The media, because it reflects societal stereotypes, emphasizes the “misfortune angle” with regard to disabled persons. 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 those who had polio are primarily the result of a poliovirus. The terms “polio survivor” and “post-polio” have also been the subject of heated discussion within the post-polio community. Many persons object to one or both of these terms because it is felt the first makes an unjustifiable reference to the Nazi Holocaust and the second refers to those who had polio as if they were a diagnosis, not individuals.

All pejorative terms are not only demeaning but also reinforce the characterization of disabled persons as saintly or bitter, but always as tragic and unfortunate. Disabled persons are characterized as unfortunate by default simply because they have experienced an unfortunate event, i.e., becoming disabled. However, events themselves are neutral. The persons to whom unfortunate events happen become “the unfortunate” only when they are categorized in that way by society and by themselves.15, 22, 23

**The Process of Acceptance of a Second Disability.** How does one adjust to the fact of a second disability in the presence of negative societal attitudes and both public and personal devaluation? The following processes have been described for disabled persons to work toward acceptance of disability. 1-14,19 Here these processes have been modified to apply to the post-polio experience.

**A Period of Mourning.** 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. During this period persons experiencing Post-Polio Sequelae might reject returning to braces or a wheelchair because those devices become symbols for the loss of physical ability earned through great physical and emotional effort.

**Devaluing Physique.** When physical achievement and appearance become unimportant as compared to other competencies and effort, devaluation of the person will be diminished. This activity has been called devaluing physique and leads to coping with the disability rather than succumbing to its difficulties. This process will allow persons with PPS to be better prepared psychologically to deal with using new or additional assistive devices and changes in lifestyle to manage new symptoms.

**Enlarging the Scope of Values.** Enlarging the scope of values precludes allowing the value of “the body” to become decisive in determining a person’s worth. Individuals can become interested in work, study, politics and leisure activities as a means to judge their worth, rather than focusing on

One survey found that 78% of persons who had paralytic polio were employed full time. 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 10% of women are employed full time. Data from our 1985 Post-Polio Survey found that polio survivors marry at a rate that is nearly 50% higher than the nondisabled population. 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. Upholding asset evaluation entails emphasizing and learning to value what persons can do within the limitations of their disability instead of judging them by so called “normal” standards that are unachievable by them. If it is best for persons who had polio to reduce their schedules, to rest in the afternoon or to begin using or reinitiate use of assistive devices, then such sensible alterations in behavior should be made based on standards that apply to the needs and abilities of the individual. When persons experiencing PPS see such required changes as safeguarding their lifestyles rather than eroding them, they are upholding asset evaluation.

The Post-Polio Support Group. A particularly valuable method for facilitating these processes and for dealing with the psychological aspects of PPS is the post-polio support group. 25 Such groups have been established in numerous locations around the country and recently on the Internet. Post-polio support groups counter devastating feelings of isolation, establish access to vital community resources (programs, services and medical care), reveal the coping strategies of others and make possible sharing of information about the cause and treatment of PPS. It has also been found that social support is protective against the negative effects of stress. 26

All polio survivors are encouraged to become knowledgeable about Post-Polio Sequelae in order to be their own best advocates for appropriate medical care and needed community services.

Conclusion

It has now been determined that persons who had polio are in fact having additional problems. 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 associated with Post-Polio Sequelae are more damaging than the physical problems. The psychological difficulties caused by this unique second disability need not only to be acknowledged but also to be treated with information and compassion.

References


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https://www.papolionetwork.org/encyclopedia.html
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