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# REHAB BRIEF

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into  
Effective Focus

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## THE LATE EFFECTS OF POLIOMYELITIS

Based on data from the Center for Disease Control in Atlanta, Georgia, there are an estimated 200,000 to 250,000 people in the United States who have residual paralysis resulting from polio.

Poliomyelitis has long been considered a stable chronic disease. Following an acute illness and a period of rehabilitation, patients typically achieve a plateau of recovery that then remains stable. For the majority of polio survivors, this still appears to be true. But it appears also that as many as 25% of polio survivors may be experiencing *new* health problems related to their illness of decades ago. These new problems are affecting their functional ability levels, their independence, and even their economic stability. While "ordinary effects of aging" has been the most common explanation, that may not be the only process involved.

This *Rehab BRIEF* will summarize current writings on the late effects of poliomyelitis. While its causes are still uncertain, research points toward several possibilities. Naturally, the best direction for specific treatment programs also remains ambiguous. One thing is clear, however: today's medical/rehabilitation community is losing familiarity with polio, and there is a growing lack of equipment and services to treat and support people who have residual paralysis from polio.

### THE HISTORY OF POLIO

The disease has had many labels: poliomyelitis, infantile paralysis, Heine-Medin disease, and poliomyelopathy. Polio has occurred for thousands of years in all parts of the world, but as an identified disease entity, it dates back to the late 18th century. By the 19th century it was reportedly widespread in both Europe and India. At that time polio was said to be caused by teething, bladders, or fever.

Presently it is known that poliomyelitis is an acute infectious virus disease that can be characterized by fever, paralysis, and subsequent atrophy of skeletal muscles. It has also been determined that silent (asymptomatic) infection in childhood provides long-lasting protection. The disease is spread by asympto-

matic persons through the shedding of virus from the throat and intestinal tract. Dissemination of the disease is enhanced by poor sanitation, crowding, and low standards of personal hygiene.

Major epidemics occurred in the United States in 1910 and 1916. In 1916, more than 27,000 people, mostly children, were disabled and more than 6,000 died. In 1921, Franklin Delano Roosevelt contracted polio. Following his struggle to overcome the illness, he founded the National Foundation for Infantile Paralysis (March of Dimes) in 1938. As the March of Dimes searched for a vaccine and provided care for survivors, waves of epidemics spread across North America and Europe. There were serious epidemics in the years 1936, 1937, 1941, 1944, 1946, 1949, 1951, 1952, and 1954.

During this time, the pattern of polio also changed, affecting increasingly older age groups. These devastating epidemics, peaking in the early 1950's, disabled millions of young children and mature adults.

In the early 1950's, the March of Dimes established and funded 16 regional respiratory and rehabilitation centers at teaching hospitals around the United States to care for polio patients more effectively and economically. The centers were so successful in the rehabilitation of polio survivors that it became possible for effective long-term maintenance care to be taken over by the patients, their families, and local community resources. When the regional centers closed their facilities in 1959, there were 1,200 polio survivors on ventilators in the United States.

In 1955, Dr. Jonas Salk developed the inactivated poliovirus vaccine (IPV) and widespread immunization against polio began. This was followed in 1960 by a live, attenuated oral poliovirus vaccine (OPV) developed by Dr. Albert Sabin. The effectiveness of the vaccines was stunning. Wherever either vaccine was used there was a spectacular decline in the incidence of polio. In 1955 there were 28,000 reported cases of polio. In 1956, after just one year of immunization, there were only 15,000 cases. From then on, incidence plunged. Between 1973 and 1981 the average annual number of reported cases in the United States was fewer than 15.

## SCOPE OF THE PROBLEM

The survivors of the polio epidemics have seemed medically stable and have lived productive lives for many years. Many have required little intervention by medical practitioners.

But in recent years, a minority of these post-polio patients, approximately 25%, have been seeking medical help for a number of problems that seem to represent changes in their neurological and functional status which are not fully accounted for by the ordinary effects of aging. Many of the people who have been experiencing these new symptoms are not particularly old. While some are in their sixties and seventies, others are in their thirties and forties or even in their late twenties. Aging does appear to play a role, but it may not be the full explanation.

Late effects of polio appear to progress very slowly and are just now coming to the attention of the medical profession. Because of this, there has been little organized activity to provide services, fund basic research, or educate the public and medical community.

The most commonly reported symptoms are:

- unaccustomed fatigue,
- weakness in muscles previously affected and unaffected by polio,
- muscle pain,
- joint pain, and
- breathing difficulties.

These clinical problems naturally affect functional abilities as well. Most notably, people report more difficulty in stair climbing, walking, dressing, and performing wheelchair transfers. It is interesting to note that the people who appear to be at greatest risk of developing these problems include those who:

- required hospitalization at the onset of polio,
- had paralytic involvement of all four limbs,
- required a ventilator, and
- were 10 years or older at onset of the disease.

## CAUSES

There is considerable diversity of opinion regarding the causes of these health problems facing people with post-polio residuals, and it is apparent that additional investigation is needed.

One of the leading hypotheses suggests that symptoms may comprise a sort of "premature aging." A component of the aging process in normal individuals is the attrition of motor neurons. Throughout our lifespans we accrue a total loss of about 30% of our original motor neurons. The effect in most people is imperceptible. But for those who have post-polio residuals, the gradual loss, superimposed on the original loss of motor neurons due to the polio infection, may result in premature weakness.

A second hypothesis suggests that certain anterior horn cells (the cell bodies of motor neurons) in the spinal cord (these are what polio damages) may have been *damaged*, even though they survived and

remained functional after the acute attack. In polio survivors with reduced cell populations, breakdown of these damaged cells may produce enough additional weakness to make normal activities such as walking or lifting more difficult.

Various pathogenetic mechanisms have been proposed, such as an immunopathological mechanism, as probable causes of these late effects.

Still other hypotheses suggest these symptoms have nothing to do with polio, but may be caused by arthritis, disuse atrophy following illness or injury, or by pinched nerve roots and radiculopathies.

Whatever the underlying causes may be, there appears to be a significant time component. The majority report experiencing the onset of new problems approximately 30 to 40 years after the acute illness with polio. Whether this timespan represents a limit on how much unusual or excessive wear the musculoskeletal system can tolerate, the limits of overworked motor units, or a combination of such factors is presently unknown. Research is needed.

## DIAGNOSIS AND TREATMENT: MAJOR FRUSTRATIONS

An essential component in the management of post-polio problems is a general medical evaluation. Common medical problems must be ruled out first in the evaluation of older people with post-polio residuals. Unfortunately, possible late effects of polio such as progressing muscle weakness are not well known among most physicians. It can be difficult to distinguish them from other degenerative disorders of muscles and joints. For example, some common musculoskeletal problems emerging late among polio survivors include osteoarthritis of the spine and peripheral joints, scoliosis, bursitis, tendonitis, osteoporosis, and myofascial pain syndrome.

Attempts to diagnose and treat these new problems can be frustrating to both patient and physician. People who develop new symptoms may be tested unnecessarily, and many say they cannot get their physicians to believe they are having difficulties. This is particularly frustrating for those experiencing rather dramatic changes but failing to demonstrate any major new findings upon physical examination. Frequently their complaints are regarded as malingering or other neurotic behavior because the physician is unable to find any definitive cause.

Early recognition, corrective procedures, and increased use of assistive devices can do much to alleviate the pain and distress caused by stabilized musculoskeletal residuals of poliomyelitis. Effective treatment programs to arrest or reverse progressive muscle weakness are not clearly defined. However, promising results have come from clinicians and researchers with expertise in exercise physiology and rehabilitation.

Keeping in good general condition and taking time to rest during repetitive activities has proved helpful

for those experiencing excessive fatigue. Exercise regimens carefully tailored to individual needs and functional ability have been helpful to others needing to recondition underused muscles. Caution is stressed for those partaking in exercise programs. Individuals are advised to exercise within their limits of comfort and capacity. It has been noted that overly intensive exercise programs can aggravate symptoms and in some cases cause irreversible damage.

In addition, some people have improved by paying more attention to their lifestyles, getting adequate rest, more prudently scheduling their professional and social engagements, and avoiding or better managing stress.

No drug treatment has proven effective in treating any of these late-emerging symptoms.

### ADJUSTMENTS IN LIFESTYLE

One of the most frustrating aspects of experiencing new limitations after adjusting to familiar ones is the change in lifestyle that can be forced upon one by muscle atrophy, weakness, and other similar conditions. Still, to compensate for increasing functional limitations that may be associated with polio, adjustments in lifestyle often are necessary. A person who has been ambulatory without aids may need braces or crutches. A person who used braces may need to use a wheelchair. The use of a ventilator may be required at night. Certain activities that were once taken for granted may become difficult and taxing, requiring extra rest afterward.

Many people have reported a renewed anger, feeling as though they were getting polio all over again. After a long battle to achieve functional and economic independence, they enter midlife only to discover that their lifestyles and economic stability are once again threatened.

Gerontological research and practice have shown that when a person's level of functional independence is changed, some degree of depression is normal. Returning to the use of a wheelchair, after struggling to overcome the need for one many years earlier, may activate some forgotten emotions. More than the mainstream of aging people, however, polio survivors have demonstrated remarkable adaptability over the years. Required changes in lifestyle are a bit more likely to be met with psychological flexibility and an open mind. While professional counseling may be necessary for some individuals, adjustment is usually easier for those who share their experiences with other polio survivors, particularly through participation in mutual support groups and publications.

Research data verify that support groups throughout the country have been helpful in assisting the polio survivor to adjust to the late effects of polio. In this way, people with post-polio residuals can share techniques for having more energy, maintaining independent mobility, and managing pain.

#### Reviewer Comment

Psychological support for polio survivors is perhaps their most important need. Support groups provide an invaluable way for them to cope by sharing long-denied feelings and emotions with others. Over 120 support groups have been formed. The International Polio Network (IPN) was established by Gazette International Networking Institute (GINI) to link the support groups, polio survivors, and concerned health and rehabilitation professionals.

GINI, which has maintained a worldwide polio network since 1958 through its journal, *Rehabilitation Gazette*, publishes *Polio Network News*, a quarterly bulletin for IPN members, who also receive national and international directories of post-polio support groups, clinics, and physicians. Annual membership dues are \$5 for polio survivors, and \$15 for health professionals. Write GINI, 4502 Maryland Ave., St. Louis, MO 63108.

Gini Laurie, Chairman  
Gazette International Networking Institute (GINI)

### THE CONTINUING NEEDS OF POLIO SURVIVORS: A REHABILITATION PERSPECTIVE

The polio epidemics and the solutions they generated had an enormous effect on the development of rehabilitation medicine. In the 1950's, polio survivors became the pioneers of new approaches and change in the public's attitude toward people with disabilities. In many ways, polio patients paved the way. Through a combination of medical care, education, activism, and personality strengths, several generations of polio survivors have demonstrated that disabled people can be integrated into the mainstream of life and make significant contributions to society.

But much of what is known about polio today was learned through experiences which largely came to a halt with the advent of successful polio prevention 20 years ago. Until recently, the majority of polio survivors have remained stable, requiring little or no medical intervention. But now that a significant number are seeking medical help for a constellation of new health problems, today's polio survivors have a renewed need for medical and rehabilitation services. Unfortunately, today's medical and rehabilitation community is generally unfamiliar with the ramifications of polio, and there is a growing lack of the kinds of equipment and services needed for the treatment of the late effects of poliomyelitis. There is a psychological perspective to consider as well. Along with the new physical problems affecting people who thought they had "mastered" polio, these survivors are experiencing anxiety, stress, and needs for emotional adjustments that are sometimes as great as those generated by the original polio onset. Many fear that orthotists can no longer make the braces they are used to. Home respirator users find it extremely difficult to get the parts needed to maintain their older, often outdated equipment—equipment with which most medical professionals are no longer familiar.

I have a few observations about what I'm experiencing 35 years after becoming triplegic as a result of polio. I've had all the "commonly reported" symptoms, but they usually turn out to be late effects of something else—menopause, midlife crisis, late-onset gluten allergy, stuff like that. Gluten allergy alone brings you fatigue, muscle weakness, and what feels like muscle and joint (and everything else) pain. Its elimination cures them all, too. As to breathing difficulties, I live in Los Angeles. They're cured by sorties to the desert or Oregon.

We all live with a lot more pollution in the air, food, and water we take in than was true 35 years ago. And, of course, we're 35 years older. Those of us who live closer to the margins—of energy reserves and muscular resources—than most folks do may notice their toll a little sooner.

Here's another thing. I think I may have done myself some damage when I started middle-age weight gain. After cutting calories a lot and still not losing, I stepped up my physical activity level. About the time I noticed losses in neck and shoulder functioning, I interviewed Dr. Jacqueline Perry for the "Fitness" BRIEF (vol. 8, no. 12). She said, "a runner hitting the wall may use only 50% muscle capacity but you may use 100% just picking up a dropped pencil. That, if overdone, could cause irreparable micro-tears in your muscle tissue."

"Now she tells me," I say to myself. I went right back to my ordinary level of physical activity. My neck and shoulder strength *partly* recovered. I bet I'm not the only one who's wiped out a few muscle fibers doing "diet" or "macho." I'm still 10 pounds overweight—at 100 instead of 90. A 200-pound rugby player told me he feels the drain on his energy when he gains as much as 7 pounds. "Un oh," says I . . . "and I bet I'm not alone here either . . . not the only 'old polio' who's getting in her own way by carrying around a few excess pounds."

I get some weird knots and kinks from time to time, too, which figures since I get into some strange positions to do things with muscles the Great Engineer never intended for such purposes. So far I've always been able to fix them with my handy dandy \$14 massager.

It occurs to me that the "late effects of polio" may be an early effect of the disability rights movement. Part of what we've won is the right to wear ourselves out! Now, we, too, can work a full-time job, moonlight half time, fly all over the country advocating for more rights or better enforcement of the one's we've got, and prepare for 20-mile marathons in our spare time on the weekends. The "old polios" of a couple of decades ago got plenty of rest in their proverbial "back bedrooms."

Is it really any wonder we're only now noticing a "late effects of polio" syndrome?

Carolyn L. Vash  
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For many polio survivors, the return to assistive devices such as wheelchairs or respirators challenges their independence and mobility. Others come to require attendant care to meet their daily needs or find it necessary to limit work or stop work altogether to accommodate increasing functional losses. The same kinds of grieving or mourning losses take place which accompany disablement initially, and which have been observed in the mainstream of elders.

The rehabilitation community can play a vital role in helping post-polio survivors work through the challenges.

- Medically, the person may need help in coordinating medical services and obtaining assistive devices.
- Economically, help may be needed to solve problems related to insurance, third-party payments, and income maintenance.
- Socially, help may be needed for those experiencing increased accessibility, housing, transportation, and attendant care needs.
- Psychologically, rehabilitation professionals may have to help deal with depression, "real" or "imagined" losses of independence, and educational/vocational problems.
- Vocationally, second career or late career adjustment counseling may be called for as well as job change assistance and related supportive services.

Clearly there is a need to promote appropriate education and training programs for doctors, nurses, technicians, and rehabilitation professionals regarding the needs of polio survivors as well as other respiratory-disabled and mobility-limited people. Locally, community agencies need to be ready to provide support to post-polio survivors by offering such services as attendant care referrals, housing placements, counseling, and vocational services.

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