

POLIO NETWORK NEWS

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Defining Post-Polio Problems

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The term late effects of polio is the umbrella over three subdivisions.

The cause of post-polio problems is neuromusculoskeletal failure from chronic overuse of a polio altered system. How has that system been altered? The pathology of polio involves destruction of the anterior horn cell, and the only functional residual is weakness. New polio problems are the effects of the functioning of muscle which had less than normal capability.

So, who's under the umbrella? First are the asymptomatic post-polio individuals who have a known history of polio but who are not having troubles now. Their lifestyle and their physical ability are balanced. These persons can, for example, go on running and continue what they are doing as long as they have no symptoms. If symptoms do occur, it is time to become more cautious about their activities.

The second group has symptoms which indicate the lifestyle demands now exceed their muscles' ability to meet those demands. The symptoms of pain, fatigue, and new weakness are signs of overuse with a penalty. We have a list of about 1,000 polio survivors and of that group we found 107 who thought they had full recovery. Eighty nine percent of them lived very active lives while 24% of them had been in athletics. They came to the clinic because they were having symptoms. Ninety three percent showed weakness with at least one muscle less than grade 5. (See chart below.)

When a muscle creates a force to control or create motion, it also creates a force internally and can cause

some damage. It has been demonstrated that as muscles contract they need time to repair and refuel. If the muscles are functioning almost continually, they do not have time to repair. Muscles and their ability to function are the main problem.

Another problem is the neuromuscular junction. This is evidenced by information from Gunnar Grimby, MD, PhD, Sahlgren Hospital, Göteborg, Sweden. He studied the anterior tibialis and demonstrated that a 3+ muscle, which is about 25% of normal on the Beasley scale, has marked hypertrophy (enlargement) compared to a 4+ muscle which would be about a 45% muscle. Both of them have degrees of weakness, but the 3+ is much more weak than the 4+.

Grimby also found that the 3+ tibialis anterior was not only markedly hypertrophied, but its activational rate was twice normal. One gains new or additional strength either by activating more muscle fibers or making the current muscle fibers work twice as hard. In 3+ muscles there are not very many muscle fibers, so they are worked twice as hard to meet the functional demand.

The individuals most difficult to get in balance are the ones with 3+ and 2 muscles all over. Their muscles are not strong enough to function without overtime use.

The third group, which we often overlook, is the polio survivor with joint degeneration problems. It is just plain wear and tear, either from substitutive posture used to replace inadequate muscles, or by the impact of loading a joint instead of letting it yield on the muscles. For instance, a hyper-extended knee causes bones to hit together with every step, and the joint becomes degenerative and arthritic. Joint degeneration problems do not result in muscle pain. There is pain and tenderness in the specific joint, resulting in deformity and x-ray changes.

Again, feeling that the primary cause is overuse, the principal management is lifestyle modification. No matter what else we do, we find that about 95% of people have to make lifestyle changes in order to make exercise or other devices work.

Out of 250 patients we have studied quantitatively on a scale of "better, same, worse." The majority of them were "better," meaning that they lost their symptoms of

Beasley Scale

Muscle Grade		% of True Normal
5	Normal	50%
4	Good	40%
3	Fair	20%
2	Poor	10%
1	Trace	1%

pain and fatigue by modifying their lifestyle. A small percentage did not make a change because they reject the whole idea of lifestyle modification. Some became worse and are the individuals with all muscles of grades 2 and 3. We have trouble finding a lifestyle for them which does not cause any strain.

**Neil Cashman, MD, Neurology,
Montreal Neurological Institute, Montreal, Quebec**

Today, there is no consensus, no position paper, no diagnostic test, no agreed-upon criteria about this syndrome, so there will be differences of opinion and some overlap.

From a neurologist's point of view, post-polio syndrome has to begin in the spinal cord and brain stem with the original infection and destruction of motor neurons causing paralytic polio. A common question arises: "I had non-paralytic polio. Am I susceptible to the post-polio syndrome?" A neurologist would have to say "no." There is no evidence that people who had no infection of motor neurons can develop classical post-polio syndrome. In fact, the worse the paralytic poliomyelitis, the more likely new symptoms are to develop.

Another common question is: "Am I out of the woods with post-polio syndrome after 40-years?" Burk Jubelt, MD, (SUNY, Syracuse, NY), and I reviewed every recorded case of post-polio syndrome that had been reported up to 1987 and found the mean onset was 36 years. Some people develop new symptoms 10 years after polio, and others develop symptoms 60 years after polio. Unfortunately, there is no out-of-the-woods threshold age.

There is a running controversy in the medical literature of "lumpers" and "splitters." Some authorities like to put diseases together under certain rubrics, and others like to break off certain diseases. My opinion is that it is too early to split sub-syndromes off the post-polio syndrome. My conservatism, in part, is based on work with people who had post-polio muscular atrophy. People with atrophy were just as likely to have pain and fatigue as people without new atrophy. There is not enough data to make a distinction and say this is merely musculoskeletal; that is neurogenic. They act differently and, they are treated differently.

The original meaning of the word "syndrome" comes from the Greek — "running together." These symptoms present in polio persons time after time, and the symptoms really do run together. There is something going on and, in my opinion, it is too early to dogmatize sub-groups.

The safest term, to date, is post-polio syndrome, and the safest definition of the post-polio syndrome is a new clinical syndrome of pain, weakness, and fatigue in individuals who recovered from acute paralytic poliomyelitis.

**Lauro S. Halstead, MD, Physical Medicine and
Rehabilitation, National Rehabilitation Hospital,
Washington, D.C.**

From the point of view of a clinician who sees polio individuals in a clinic, "What diagnosis do I use?" often makes a great deal of difference, because of the implications for insurance and disability payments. We do not have enough information, insight, or wisdom to separate specific definitions except for clinical use.

The three major diagnostic terms — the late effects of polio, post-polio syndrome, and post-polio muscular atrophy — can be described by imagining three concentric circles. A large outer circle labeled the late effects of polio represents a grab bag. Anyone who has serious involvement with a neuromuscular disease, and it does not have to be polio, will experience a variety of problems, if they live long enough.

The late effects of polio refers to a group of symptoms and signs which people who had polio many years ago now experience and include weakness, fatigue, muscle pain, joint pain, decreased endurance, and new atrophy. They also include increased weight gain, osteoporosis, increased risk of fractures, scoliosis, increase in pulmonary problems, sleep difficulties, and psychological problems.

People can experience a whole list of problems that are in this big circle as a result of having had polio, but they do not have post-polio syndrome.

Inside the big circle is a smaller circle labeled post-polio syndrome. More narrowly defined, a diagnosis of post-polio syndrome requires the presence of new neurogenic weakness. This new weakness is caused by some dysfunction of the motor neuron that was originally affected. Post-polio syndrome is a neurologic disease which occurs as a result of having had an invasion of the polio virus to part of the nervous system many years earlier.

**There are five elements to make the
diagnosis of post-polio syndrome:**

1. a history of paralytic polio;
2. a fair to good recovery (something had to recover to have loss later on);
3. a period of neurologic stability;
4. onset of new weakness; and
5. exclusion of other causes for the new weakness.

Currently, making a diagnosis is difficult because there is no diagnostic test; unfortunately at this stage, diagnosis is still primarily by history and physical examination.

The smallest and most inner circle is post-polio muscular atrophy and is reasonably straightforward. It is post-polio syndrome in someone with new muscle atrophy.

Another better term that might be used for these last two diagnoses is post-polio motor neuron disease which focuses on the motor neuron as the primary source of pathology.

Frederick Maynard, MD, Physical Medicine and Rehabilitation, MetroHealth Center, Cleveland, Ohio

In the broadest terms, there are many new health problems that persons with a previous history of polio may experience. These health problems can include those that are clearly unrelated to the history of polio, such as glaucoma or gall stones.

For other health problems, such as coronary artery disease, it may be unclear whether there is a relationship to previous paralytic because a sedentary lifestyle in polio survivors may cause an increased risk of developing coronary artery disease.

Systemic health problems, such as heart disease or diabetes, can impact and produce symptoms that overlap and mimic those of post-polio syndrome (fatigue, weakness, and pain). This issue has led to confusion, misunderstanding, and lack of consensus about what is meant by post-polio syndrome.

The term "late effects of polio" implies that new health problems are related to the original polio impairments, such as muscle weakness and related joint deformities. The term "post-polio syndrome" is a looser term which does not specify etiology, or cause of symptoms. Post-polio syndrome commonly develops in people with polio residuals and mild symptoms are almost inevitable in people who are growing older with polio.

As a "syndrome," post-polio is a common symptom cluster — classically, pain, fatigue, and new weakness — that is seen over and over again in post-polio people.

The bottom line for having post-polio syndrome is new loss of function. Individuals with post-polio syndrome have new disability.

Post-polio muscular atrophy (PPMA) refers specifically to people who definitely had old polio weakness and are now having new weakness and atrophy from no other identifiable cause. PPMA is new or additional anterior horn cell disease that appears to be unexplainable.

A slightly different concept has recently been proposed by the Institute of Medicine (see below) to describe new disabilities in people with long-standing disability.

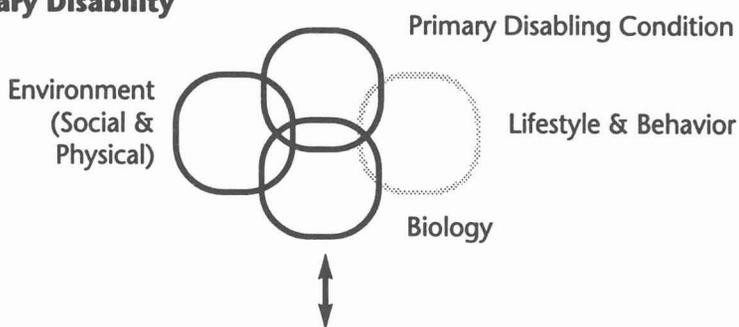
This has also been referred to as the development of secondary disability in a person who has always had a primary disability. For example, people with post-polio residuals, after full recovery and rehabilitation, were left with a primary disabling condition. Other health problems may then cause the residuals (weakness, deformity) to become worse and result in additional new functional limitations.

Another new concept is the notion of "life course" of people with a history of polio. As people with paralytic polio histories become older, they can be expected to experience a level of functional decline when they are 70 or 80, similar to what non-polio people experience. However, their expected life course of slowly progressive weakness can be drastically accelerated by other life events, such as injury or the onset of other medical conditions, for example diabetes, heart disease, and arthritis. □

Institute of Medicine's Model of Secondary Disability

Figure 1.

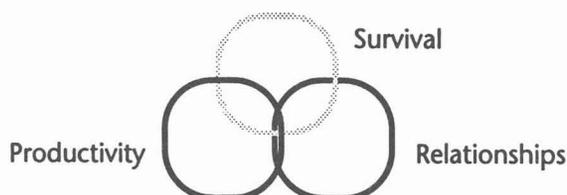
◆ Risk Factors



◆ Process of Secondary Disablement



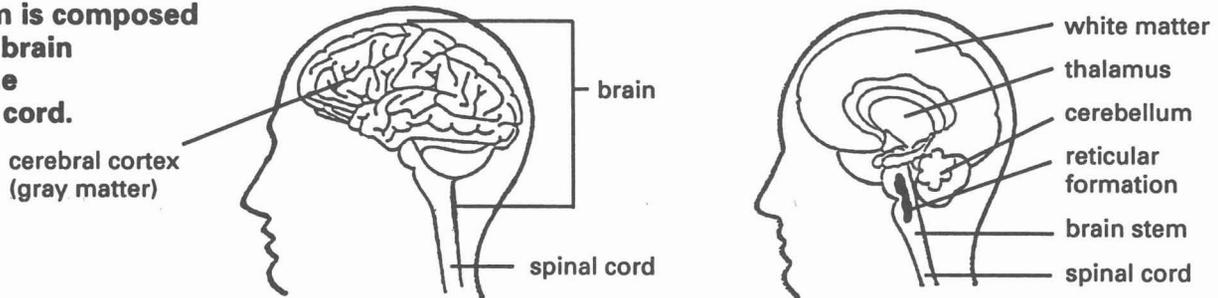
◆ Quality of Life



NOTE: Descriptive sentences in Figures B and C were inadvertently shortened. This is the completed version.

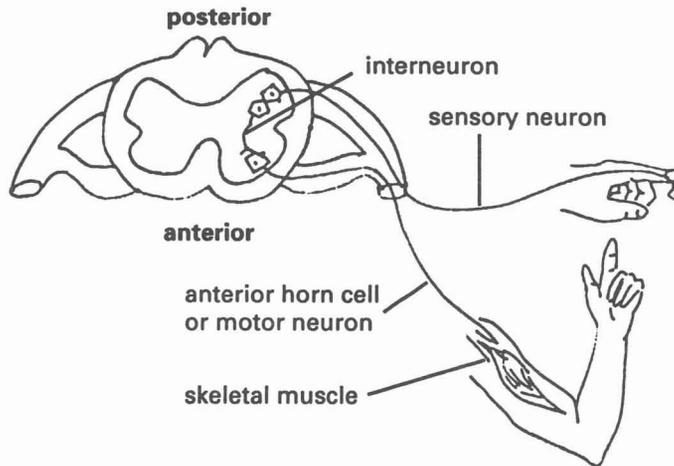
DIAGRAMS AND DEFINITIONS FOR POST-POLIO SYNDROME 101

The central nervous system is composed of the brain and the spinal cord.



The polio virus infected the anterior horn cells, thus affecting the skeletal muscles causing partial or complete paralysis.

Cross section of spinal cord



A motor unit is composed of a nerve cell and all the muscle fibers it innervates. The neuromuscular junction is the junction between the nerve cell and the muscle fiber.

Figure A
During infection

Two of the five nerve cells have been infected by the polio virus. The middle one has temporarily stopped functioning.

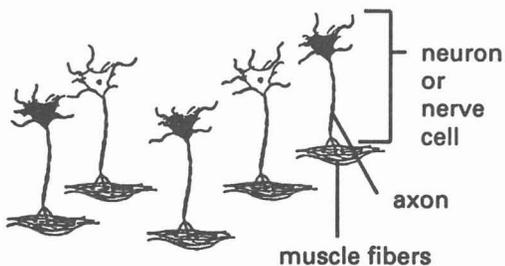


Figure B
A few weeks later

The middle nerve cell has recovered. Two nerve cells have died leaving the muscle fibers denervated or orphaned.

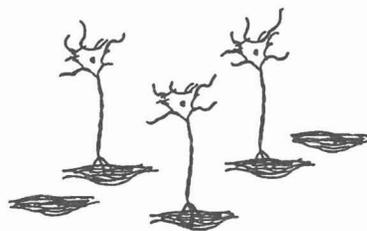
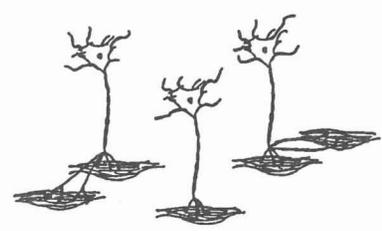


Figure C
Months, even years later

The surviving nerve cells "sprouted" to innervate the orphaned muscle fibers.



Incidence & Prevalence of Post-Polio Problems

P. Ellen Parsons, PhD, MPH, National Center for Health Statistics, Hyattsville, Maryland, presented information from the 1987 National Health Interview Survey and previewed the 1994-1995 survey.

The first national population-based survey of polio survivors will soon be in the field. The survey is sponsored by the National Center for Prevention Services, the National Center for Environmental Health and Injury Control, and the National Center for Health Statistics (all part of the Centers for Disease Control and Prevention), and by the National Institute on Disability and Rehabilitation Research (NIDRR). Polio survivors and their advocates who initially instigated the study and provided a push and a shove at crucial moments should also be acknowledged.

The 1994-95 survey of polio survivors is being conducted as part of the National Health Interview Survey (NHIS) which is one of the National Center for Health Statistics (NCHS) major national health data systems. The NHIS is a continuously conducted survey of a nationally representative sample of the civilian, non-institutionalized population. It covers a broad range of health-related topics through personal interviews in the home. Interviews are conducted by specially trained interviewers employed by the Bureau of the Census. The survey includes about 50,000 households, and 120,000 persons every year.

The NHIS uses two questionnaires each year. The first is a basic health and demographic questionnaire which asks questions about health status, utilization of health services, and family and individual characteristics about everyone in each household. The second is a special questionnaire on current health topics, which changes from year to year. In this case, one sample person per household is questioned.

We first collected information from polio survivors in 1987. Our objectives were to identify a sample for a follow-up study to estimate the number of polio survivors in the United States, and get a handle on the number of people who might be at risk for post-polio syndrome.

The questions used to identify polio survivors in the 1987 NHIS were asked of all persons age 26 and over in each of the households. So, most of the responses were by the persons themselves.

The questions allowed us to identify paralytic and non-paralytic polio survivors on a self-reported basis and to determine current impairment status. We intended to collect data for two years but were surprised when 821 polio survivors were identified in the 1987 sample alone.

Although we do not have much confidence in the estimates of the numbers of non-paralytic polio survivors (1.6 million) because the data are self-reported and non-paralytic polio was often not diagnosed by a physician,

the estimate of 640,000 paralytic polio survivors is still much higher than previous national estimates which had been based solely on reported cases.

We were unable to conduct a follow-up study of survivors identified in 1987, but have completed a descriptive analysis of their characteristics. More than half of polio survivors were between 35 and 54 years of age in 1987, and 78% of impaired paralytic polio survivors were 45 years or older. The age distribution is consistent with the history of polio epidemics in the United States.

Overall, polio survivors are as well or better educated than the general population, and their incomes were also similar. However, impaired paralytic polio survivors more often lived in low income families with 17% in families with less than \$10,000 in income per year. About 45% of impaired paralytic polio survivors were employed. At the same time, 20% were unable to work for health reasons.

Eight percent of paralytic polio survivors reported poor health; twice the percentage of people in poor health in the general population. A full 25% of paralytic polio survivors were in fair or poor health.

On a variety of measures, impaired paralytic polio survivors were more likely to report restrictive activity and other limitations. However, those who are employed reported fewer work loss days (mean of 4.3) than did people in the general population (5.6).

The objectives of the 1994-95 survey of polio survivors are to validate estimates from the 1987 (since we did get

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such a large number), to extend the knowledge of the natural history of polio, and to estimate the prevalence of post-polio syndrome.

This effort has the advantage of being linked to the 1994-95 NHIS disability survey which is based on a two-phase approach. Phase one will screen about 200,000 persons over the two-year period and will ask questions of the household respondent. Phase two will go back to about 40,000 people including people who were identified as polio survivors.

The disability survey, in phase one, will include questions on limitations and impairments, health conditions, assistive devices, and special needs; phase two questions will include information on housing and transportation, social and work situations, use of health and personal services, and personal characteristics.

The follow up study, in phase two, will include both the second disability questionnaire and the polio survivors questionnaire. The questionnaire has gone to print and interviewing will begin in August, 1994. We do anticipate getting a smaller sample of polio survivors than we did in 1987 because the cohort has aged and because the proxy response rate will be much higher.

The 1994-95 polio survivors questionnaire will trace the natural history of the disease from the initial illness through any rehabilitation period, the period of physical best, and through the current period. At each stage, information on the extent of weakness and ability and use of assistive devices will be collected.

Questions will center around new problems related to polio, what type of problems, what parts of the body, when the symptoms appeared, and if there has been any medical diagnosis. We are going to collect information about other relevant conditions so it will be possible to eliminate other causes. Questions will also explore personal attitudes and coping behaviors.

The amount of information we can collect in a population-based survey is limited, but we hope to collect enough so researchers are able to produce estimates of the prevalence of post-polio syndrome among polio survivors in the U.S. and to provide a very rich source of information about polio survivors.

Data collection for the polio survey will continue for two years. Results will be disseminated in public use data tapes which researchers will be able to purchase for a moderate price sometime in early 1997. Reports and articles will also be published. □

MOVING??

Please send your old and new addresses to:

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Jonathan M. Ramlow, PhD, MPH,
Dow Chemical Company, Midland, Michigan,
discussed research he conducted when a graduate student in epidemiology at the School of Public Health at the University of Pittsburgh.

Due to the lack of information available concerning the late effects of polio or post-polio syndrome and its prevalence, we set out in 1986 to define a population-based cohort of people who had had polio in a defined geographical area, namely Allegheny County, Pennsylvania, surrounding the City of Pittsburgh.

During the early 1950s Allegheny County, Pennsylvania, was actually an area with fairly low reported polio area, not quite as high as the rest of the country.

Our data confirms that polio was a disease of childhood. The majority of the 828 cases were under the age of 10 at the time of the acute disease. More were males than females, typical for the epidemic period at that time.

After identifying polio survivors in the hospital records, we set out to determine whether they were still alive, if their poliomyelitis was confirmed using a set of uniform criteria, what their current health status was, and whether or not they were a resident of Allegheny County at the time of the acute illness, because we wanted to work with a population-based group of people who had polio.

Our data found these were people currently in their early 40s, well-educated, with more than three fourths having had some college education. The majority had been married; almost all had been able to work at some time; 75% of the women had had children after the acute illness.

We specifically asked about new muscle weakness, muscle pain, and fatigue. What we observed was that while cases who had confirmed paralytic poliomyelitis in the hospital reported these symptoms more frequently (38%, 38%, and 34% respectively) than those who had confirmed non-paralytic polio, the non-paralytic cases were also reporting these symptoms in fairly substantial numbers (14%, 8%, and 21% respectively).

We asked about actual functional problems and found that people who had confirmed paralytic polio were reporting generally poor health (35%), inability to meet the demands of their everyday life (29%), and some specific kinds of functional problems — poor ability to climb stairs, get in and out of bed, etc. But in some cases the kinds of problems were not very frequent at all.

Our operational definition of post-polio syndrome was based on that developed by Drs. Halstead, Maynard, and others: 1) a reliable history of acute poliomyelitis; 2) at least partial recovery of functional status; 3) at least 10 years of functional stability after recovery; and 4) late-onset muscle weakness with or without muscle pain or atrophy for which no other explanation can be found.

We designed a questionnaire to use in a mail survey of the Allegheny County polio survivors. Michael

Alexander, MD, now at Alfred I. duPont Institute, Delaware, a polio survivor, examined a random sample of 40 polio survivors to see how well the questionnaire responses would match up with a clinical determination of post-polio syndrome. About 25% of the 551 people we surveyed met our criteria for having post-polio syndrome. The percentage would increase to about 28% among those who had had the spinal form of confirmed paralytic polio. Two of the 77 cases of non-paralytic polio also met our criteria for post-polio syndrome. We do know that approximately 10% of individuals who were diagnosed with non-paralytic polio went on to develop clinically detectable weakness after being discharged from the hospital. And these may have been such cases.

We did find somewhat of a relationship between occurrence of post-polio syndrome and the acute severity of the illness. Those who had moderate and severe polio were more likely to develop the syndrome than those who had had a milder case. The frequency for the moderate and the severe cases is about the same. It is not clear that having had a more severe acute case all by itself is a strong predictor for the syndrome.

We found, rather, that how people ended up after their recovery from their acute illness seemed to be a much better predictor. Those people who needed to use some kind of assistive device — braces, canes, walkers, wheelchairs, etc. — in addition to having residual weakness had a significantly greater frequency of meeting our criteria for post-polio syndrome — 50%.

We compared the frequency of symptoms and functional problems of polio survivors with post-polio syndrome to polio survivors without post-polio syndrome. Because there was substantial difference in the frequency of all symptoms, we were confident that our questionnaire actually did distinguish between two very different groups of former polio survivors.

We asked people to tell us when they started to notice new muscle weakness and new muscle pain. We found that the incidence of the post-polio syndrome does not seem to be increasing continually with increasing age. Even though there were not that many people in our sample in the 50 to 59 year age group, it looks like the incidence started to level off after about age 50. We felt we saw a plateauing effect.

We found that the risk seemed to be somewhat greater in women than in men. We found it did not seem to matter how old people were when they originally had the disease. If they were going to develop the syndrome, as we understood it, it was going to be at somewhere between 30 and 35 years after the original illness. After that point the reporting falls off. □

Bibliography: "Epidemiology of the Post-Polio Syndrome" by Jonathan Ramlow, Michael Alexander, Ronald LaPorte, Caroline Kaufmann, and Lewis Kuller; *American Journal of Epidemiology*; Volume 136, Number 7; October 1, 1992.

Post-Polio Research

The Latest from the Later Life Effects (LLE) Study

JOAN L. HEADLEY

In 1990, I read about a five-year study funded by the National Institute on Disability and Rehabilitation Research (NIDRR), *Later Life Effects of Early Life Disability: Comparison of Age-Matched Controls on Indicators of Physical, Psychological and Social Status (LLE Study)*, and was intrigued.

Many studies and surveys of post-polio sequelae are criticized because the sample is not selected randomly; there is no comparison to non-polio individuals; and data are not collected over time in a longitudinal design. Because the Later Life Effects (LLE) study included a control group, I called co-investigator Margaret L. Campbell, PhD, and offered our network to her, immediately catching some of her enthusiasm.

Five years have lapsed and the final 168-page report of hypotheses, procedures, comparisons, results, summaries, and conclusions has been released.

Campbell's colleagues, Bryan Kemp, PhD, and Kenneth Brummel-Smith, MD, are now preparing major articles for publication on the "stress-buffering effects of family functioning on physical independence and psychological well-being in the later years." Campbell and Victor Ettinger, MD, are also putting final touches on an article comparing the risk of osteoporosis for female polio survivors and sex-and-age-matched controls, ages 50 to 88. Hopefully, the results of this analysis will assist us (women with polio) in making better health care decisions surrounding menopause which, interestingly, lists among its symptoms fatigue, decrease in ability to concentrate, and problems with sleep.

While waiting for these major articles, I decided to highlight some of the conclusions. But first I would like to include Dr. Campbell's description of the "life course perspective" and share a pertinent quote.

The Life Course Perspective

"Unlike more traditional rehabilitation models, which emphasize physical impairment or functional limitations, the life course perspective enhances our understanding of the meaning and consequences of polio by placing polio-related events, such as acute onset and period of 'physical best,' within the broader context of the individual's whole life and the social and family resources individuals have available to cope with their changing needs and circumstances."

Why Study Polio?

"The importance of studying chronic polio, however, is due as much for its precedence as it is to its prevalence. Developing a better understanding of the later life effects of polio can serve as an important prototype for studying the secondary complications associated with other long term physical disabilities, such as cerebral palsy, rheumatoid arthritis, and spinal cord injury."

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Who Was Studied?

The focus is on aging with a disability, so the minimum age for participation was 50 and the historical period of onset was noted. (21.5% had polio between 1906 and 1929; 24% during the '30s; 35.5% during the '40s; 19% during the '50s.) Sixty-five percent were female, 35% male, reflecting the consistent finding that females are disproportionately represented in survey studies.

The average polio survivor studied was 11.9 years old at time of acute onset, and 50.9 years have lapsed since the original polio. The average year when they had polio was 1939, and they spent 26 weeks in the hospital.

Thirty-eight percent were recruited from the newspaper; 46% support groups; 16% friends/personal contacts. Ninety-eight percent of the polio survivors were Caucasian. In other words, the participants were not selected randomly.

Twenty-two (22.3) percent had no or one limb affected at acute onset; 40.5% two limbs; 37.2% three or four limbs. Fifty-eight (57.8) percent met all five criteria for post-polio syndrome (see Halstead, page 2, shaded box); 25% reported no new physical health problems and no new functional loss in activities of daily living (ADL); while 17.2% acknowledged the onset of new health problems, but no new loss of function. These three groups were categorized as "PPS," "no," and "maybe."

Findings

- ◆ Consistent with earlier epidemiological studies done in the 1940s, lower extremity involvement was more prevalent than upper extremity involvement, and the left lower extremity was more likely to be affected than the right.
- ◆ Taking all types of change in method of locomotion (walking, using crutches, canes, wheelchairs, etc.) into account, a total of 68% of the polio sample declined in mobility status between their time of "physical best" and the time of participation in the study (or T.O.M.).
- ◆ Depression scores observed were well within the normal range for all polio sub groups with the exception of one. Only those who contracted polio after 1940, and before the age of 10, had scores which exceeded the threshold for clinically significant symptoms. It is important to point out that clinical symptoms are not synonymous with a diagnosis of clinical depression. Women meeting the criteria for PPS had significantly higher depression scores compared to their female counterparts in the "no" and "maybe" categories. Women with PPS also had significantly higher mean depression scores than men with PPS. Males meeting the criteria for PPS did not report more depressive symptoms than did men without PPS.
- ◆ There was a newly-detected weaker association between depressive symptoms and a basic physical

health indicator, TSH level. This last association underscores the need to perform thyroid screening tests for persons aging with polio in order to assure a correct diagnosis and treatment.

- ◆ As both the age at acute onset and the historical period (or decade in which polio occurred) increase so does the percentage of the sample with three and four limbs affected. In other words, of those who got polio during infancy and before 1930, over 40% were mildly impaired. However, only 20% of those who contracted polio in adulthood and during the peak of the epidemics in the '50s were mildly impaired.
- ◆ The data indicate that there was no mean difference in current chronological age between those who meet the criteria for PPS and those who do not. This finding is important because it suggests that contrary to early speculation in the literature neither "aging" per se nor the mere passage of time are adequate explanation for who is most at risk for later life effects of polio.
- ◆ Regardless of the time interval between acute onset and T.O.M., those most at risk for experiencing the new health problems and functional losses associated with PPS are those who were most severely impaired at acute onset and who recovered the most between initial rehabilitation and their period of "physical best" for stability.

These findings are important because they provide initial empirical support for the first half of the prediction by Jacquelin Perry, MD, as to who is most at risk for developing the later life effects of polio. According to Perry, polio survivors most likely to experience PPS are those who were most impaired at acute onset — which is consistent with our data — and who recovered the most between onset and time of physical best.

- ◆ Data support the conclusion that both the age of onset and severity of acute onset are significantly related to the functional independence and psychological well being of survivors an average of 51 years later. In general, it is a combination of being both older and more severely impaired at acute onset that increases the chances of depressive symptoms and of being more functionally limited when compared to those who were equally impaired at onset but who contracted polio before the age of nine.

The Next Five Years

The Rehabilitation and Research Training Center (RRTC) on Aging with Disability was funded by NIDRR for another five years to continue their investigation of later life effects and secondary conditions associated with long-term disability. In the second funding cycle, both the sample size and number of disabling conditions have been expanded from the previous polio and stroke survivors to include approximately 1,000 individuals aging with cerebral palsy (N=120), polio (N=400), rheumatoid arthritis (N=250), and stroke (N=225). □

Margaret L. Campell, PhD, may be reached at the RRTC on Aging with Disability, Rancho Los Amigos Medical Center, 7600 Consuelo St., Downey, CA 90242.

From the Archives

Excerpted from *The New York Times*, Wednesday, April 13, 1955.

ANN ARBOR, Mich, April 12 — “The formal verdict on the Salk vaccine was disclosed today amid fanfare and drama far more typical of a Hollywood premiere than a medical meeting.

“The event that made medical history took place in one of the University of Michigan’s most glamorous structures — Rackham Building. Television camera and radio microphones were set up outside the huge lecture hall. Inside the salmon-colored hall a battery of sixteen television and newsreel cameras were lined up across a long wooden platform especially built at the rear.

“At 10:20 a.m. Dr. Thomas Francis, Jr., director of the Poliomyelitis Vaccine Evaluation Center and the man of the hour, was introduced. A short, chunky man with a close-cropped mustache, he was wearing a black suit, white shirt and striped gray tie.

“He stepped behind a lectern decorated with a blue and gold banner bearing the seal of the university. He appeared small, hidden up to his breast pocket by the lectern, as he looked out toward his audience of 500 scientists and physicians. Cameras ground and spotlights played upon him. Then Dr. Francis adjusted his horn-rimmed glasses and began to read his long-awaited report in a slow, conversational tone. It was the report of a meticulous and dedicated scientist presented without dramatics.

“Nevertheless, the moment was a dramatic one, no matter how hard the Professor of Epidemiology tried to make it otherwise with his charts and statistics and careful qualifications. The nation and the world had been

waiting for his report, a report that could mean hope for millions of parents and a great step forward in the control of paralytic polio.

“Dr. Francis talked for an hour and forty minutes. Occasionally he would step back from the lectern. The lights would dim out and a slide would be flashed on a screen behind the lectern. Dr. Francis would call attention to various statistics and chart illustrations by pointing a flashlight on the screen.

“The audience was quiet and respectful. There were no bursts of applause even at the end of Dr. Francis’ address, after he made it clear that the Salk vaccine has been proved an effective weapon, the applause seemed restrained.”

“It was disclosed today that Dr. Francis did not finish his report until 3 A.M. last Friday. It was not until late Thursday evening, according to Robert B. Voight, statistician for the center, that Dr. Francis and his staff reached the point where they could set down accurate estimates.

“There was other evidence of tight security. Dr. Jonas E. Salk, who developed the vaccine, acknowledged that he had not had an opportunity to read the report. Basil O’Connor, president of the National Foundation for Infantile Paralysis, indicated that he had not seen it in advance either.

“Much attention was focused throughout the day on Dr. Salk, who had spend (sic) long hours in the laboratory to make this day possible.”

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Polio Survivors Remember

Richard Owen, MD, born in 1928, had polio in 1940. He recently retired as Medical Director at Sister Kenny Institute in Minnesota. He has clear recollections of the onset and initial treatment of his acute polio.

"Since I was 12 years old when I had polio, I can remember many of the details about it. Polio is an unusual disease in that there are two periods of illness as the virus enters the system. The first is associated with an infection of the nose and throat and sometimes the stomach. I had an illness that lasted for a few days, and I was even ill enough to stay home from school. I felt well the next day though, and went back to school and carried my newspaper route. The following day, however, I was feeling ill again. I got up for breakfast and then went back to bed. After an hour or so, I woke up and tried to get out of bed but fell to the floor because my legs wouldn't move me, and I was rather limp. I was taken to the University Hospital in Indianapolis where I was diagnosed with polio.

"At that time they had some idea that it was an infectious disease. I was given what was called 'therapeutic serum' which was made from the blood of people who had polio once before, a practice in vogue at that time; whether or not it had any effect seems unlikely since the disease progressed to rather pronounced paralysis with no movement in either leg and no movement in my abdominal muscles. They then put me in isolation, and I think I might've been told that I had poliomyelitis. I didn't know what poliomyelitis was, and nobody told me that I had infantile paralysis which I would've recognized because Roosevelt was president at that time, and I knew that he had suffered significant paralysis from the disease."

Bob Gurney, born in 1923, had polio in 1940. Bob worked as a draftsman for many years before his disability forced him to take early retirement. He was one of the first individuals in the U.S. to be treated with the Sister Kenny method. The following excerpt describes his first meeting with Elizabeth Kenny.

"I don't remember the exact date, but I was laying there, and my mom walked in and said, 'I've got somebody here that may be able to help you. This is Sister Elizabeth Kenny.' Of course, when she said sister, I was thinking, 'what's going on here.' But she was standing on the left side of the bed, and she looked down at me and said, 'No Bobby, my name is Elizabeth Kenny. The sister means that I am a registered nurse from the Australian Army. That's our title.' I looked up at her, and I remember thinking, 'Wow, what a big woman.' She must have been about six foot one and weighed close to 200, 205, maybe 210 pounds. She was one big woman, and oh man, she carried herself like a queen. Her size sure didn't bother her at all.

"She looked me right in the eye and said, 'I'm here to try to help you. But, before I can help you, I've got to hurt

you.' Well, what could I say? She reached across the bed, grabbed my hand and started shaking it. Then she said, 'Now, we'll get started.' She lifted up my left leg and started trying to find out how good or bad it was, and I was damned if I was going to let anybody know how bad it hurt. I mean, I wasn't going to yell, but the next think I knew, I was crying from the pain. She noticed, so she put down my left leg, but then she started on my right leg, and a few more tears came. Finally, she let go and said 'We won't do anything with your arms right now; I'll come back later this afternoon.'"

Gail Bias, born in 1949, had polio in 1951. She is currently employed as a social worker. Because of her polio, Gail had six surgeries, all on her legs. The following passage seems to capture the surgical experience perfectly.

"I remember getting scrubbed with antiseptic the evening before my surgery. They had these huge, metal tubs, and you had to climb up steps to get in them. And when you were done, they laid towels on the steps and on the floor all the way to your bed for you to walk on so your feet wouldn't touch the floor. Once you got back in bed, you weren't supposed to get up again until your surgery. Then at midnight, they'd come into your room, wake you up, and put this red vest on you. That red vest meant that you were all prepared for surgery. They'd actually tie it on, so you couldn't take it off. Of all the colors, I've often wondered why in the world they chose red!

"Of course, I could never sleep the night before any of my surgeries. It was always morning by the time I'd fall asleep. The next morning, I'd hear the cart coming down the corridor. You'd hope the cart was coming for someone else, and if it would go past your door, you'd breathe a little bit easier. But then your door would fly open, and you knew the cart was there for you. It was your turn. And then you just got on the cart. You didn't fuss.

"I remember that the operating room was always cold. And you'd have to crawl off of the cart onto that cold operating table. They'd put these big, leather straps over your leg and tighten them up. I remember laying there terrified and thinking that they were going to cut me open, and I wasn't even asleep yet. The nurses would try to comfort you, but it really didn't help."

Edmund Sass, one of the authors of this project, was born in 1947. He had polio in 1953. His childhood was filled with years of braces and casts. He vividly recalls the first day he wore his Milwaukee brace to school.

"If you've never seen a Milwaukee brace, it's quite a contraption. The bottom is made of leather which fits around your hips and pelvis and buckles in front. I wore that part under my pants. A long metal bar that attaches to the leather and runs up the front. That goes outside of your clothes. It extends up to your neck where it attaches to a padded chin rest. The chin rest bolts to an additional padded piece that fits behind your neck. And,

of course, another bar attaches to that and extends down your back where it connects to the bottom leather. Mine also had a leather strap that fit around my side to hold in my scoliosis. I guess it was the ultimate portable traction device. I wore that thing nearly twenty four hours a day.

"I vividly remember the first day that I wore the brace to school. It was the middle of the school day. Apparently I had gone to the doctor that morning to have the brace fitted. My mom dropped me off at the door, and as I approached the room, I heard somebody say, 'Here he comes!' Apparently they were expecting me. After I took my seat, the teacher asked me if I wanted to say anything to the class. Everyone was staring at me with great anticipation. I think I managed a feeble 'no.' I just wanted to hide under the desk ...

"I got so tired of explaining why I wore the brace that when other kids would ask me about it, I'd say, 'well, my dad's a carpenter, and one day he got careless with the electric saw and cut my head off. The brace holds it on.' The looks I got were amazing. What's even more amazing is how many kids believed that's really why I wore the brace!"

David Kangas, born in 1937, had polio in 1952, the year of the largest epidemic. He is employed as a research analyst for Ramsey County in Minnesota. David's experiences being out and about in a wheelchair during the 1950s and 60s present a compelling argument for improved accessibility.

"I met with the Vocational Rehabilitation Department, and it was their education plan for me to go to the university. I came down and looked around for an accessible apartment, which was almost impossible to find. I was really quite naive about going to college and was surprised to find that the university wasn't accessible for a person in a wheelchair. But, that was 1955, and that's the way it was then. I saw that there were steps all over the place. It wasn't like high school where I had a group of friends to carry me around, but I still needed to find a crew of people to get me up and down the steps. Many times, I guess I could say many, I remember I would have to get a bunch of volunteers or just recruit people as they were rushing from class to class. Sometimes they would say, 'I just don't have time.' 'I can't help you.' Or, they would say, 'well, I really have a bad back,' which they may have had. So, it was tough."

Janice Johnson Gradin, born in 1941, had polio in 1956. She and her husband live on their family dairy farm in Ashby, Minnesota. Janice started an area post-polio support group which she feels has allowed her to find herself through finding others.

"I was put in isolation for a week. It was a very scary and lonesome time for me. I was very sick and hurt all over. I fell down if I tried to get out of bed and walk. I couldn't have any visitors except my mom, and she could only stay for five minutes. I did get a lot of cards and letters though, and they helped keep my spirits up.

"When the people in the Evansville area found out that I had polio, they changed their minds about the vaccine. Suddenly, long lines formed in front of the clinic so that everyone could get their shots. I guess my illness really woke up the town.

"They told me that I had non-paralytic polio. Yet, I had to learn to walk, sit, stand, and even to go to the bathroom over again. Each time I learned to do something independently, I felt a real sense of joy.

"Most of the time I had to just lay in bed flat on my back. I had no pillow, and my feet were flat up against a foot board. They wrapped my legs in hot packs twice a day, and then I would do exercises. After one month, they finally told me that I could stand for three minutes. I was so sick of being in bed that I thought three minutes wouldn't be long enough. Well, after standing for one minute, I was ready to lie down again." □

The excerpts above were provided by Edmund J. Sass, EdD, polio survivor and Director of Teacher Education at the College of Saint Benedict and Saint John's University in Minnesota, who is working on an oral history of polio survivors. Over the past three years, he and two of his colleagues (Anthony Sorem, PhD and George Gottfried, PhD) interviewed 36 polio survivors. Sass is currently seeking a publisher for the project.

Post-Polio Directory 1995 is now available. Pre-paid orders are being mailed. The cost of the 1995 edition is \$4 for survivors; \$8 for others. Canada, add \$1; overseas air, add \$2.

CALENDAR

• **Polio Update Conference, April 1-2, 1995**, Pooks Hill Marriott Hotel, Bethesda, MD. Contact Jessica Scheer, PhD, Polio Society, 4200 Wisconsin Ave., NW, Suite 106273, Washington, DC 20016 (301/897-8180).

• **Maximizing Your Psychological and Physical Potential, April 2, 1995 (1:30 to 4:30)**, Workmen's Circle, 45 East 33rd St., New York, NY. Contact New York Support Group, P.O. Box 182, Howard Beach, NY 11414 (718/835-5536).

• **Post-Polio Conference, April 8, 1995**, Best Western Sterling House, Anderson, IN. Contact Ellen Crim, 338 West 38th St., Anderson, IN 46013 (317/649-3648).

• **Polio: Yesterday, Today, and Tomorrow**, Sheraton Perimeter Park South Hotel, Birmingham, AL, May 19-20, 1995. Contact: Ellen Peak, 625 26th Ave., N.W., Birmingham, AL 35215.

• **International Symposium and Exhibition on Orthopedic and Paralysis Sequelae Rehabilitation**, Beijing, China, October 16-20, 1995. Contact: Mr. Hejian, China International Conference Center for Science and Technology (CICCST), 44, Kexue Yuan Nan Rd., Shuang Yu Shu, Hai Dian, Beijing 100086, P.R. China.

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The World Will Remember



*The World Health Organization has designated 7 April 1995,
World Health Day, Target 2000 — A World Without Polio.
For further information please contact:*

**WHO Headquarters, Avenue Appia, 1211 Geneve 27, Switzerland
(41.22) 791 21 11 — FAX: (41 22) 791 07 46.**

**WHO Regional Office for Africa, P.O. Box No. 6, Brazzaville,
Congo (242) 83 91 11 — FAX: (242) 83 94 00.**

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**Regional Office for the Western Pacific, P.O. Box 2932,
1099 Manila, Philippines (63 2) 521 8421 —
FAX: (63 2) 521 1036 or 59 6813.**

■ **Rotary International** has produced a Rotary guide for promoting Target 2000 — A World Without Polio. Contact: Rotary International Public Information Department, 1 Rotary Center, 1560 Sherman Avenue, Evanston, IL 60201-3698, USA.

■ **On April 12, 1995, Dr. Jonas Salk** will return to Rackham Hall, University of Michigan in Ann Arbor to commemorate the 40th anniversary of the announcement that the Salk vaccine was safe and effective. The Southeast Michigan Chapter of the March of Dimes Birth Defects Foundation has issued an invitation to all polio survivors. For more details contact Jayne Strauss, 810/423-3200. Seating is limited. RSVP required.