

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

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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). □

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