

Summary of Research Presentations from Strategies for Living Well, June 2005

Edited by Baldwin Keenan, Irvine, California

Who is likely to report a diagnosis of post-polio syndrome?

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In 1994 and 1995, the National Health Interview Survey identified and questioned a national sample of polio survivors—not just survivors seeking medical attention or associated with support groups. Based on the number of respondents, it is estimated that 920,000 polio survivors were living in the United States at that time. The survivors were asked a series of questions about their past and current health, including whether they had been diagnosed with post-polio syndrome (PPS).

- 25% reported they believed that they had PPS, while only 11% reported that they had been diagnosed by a physician. (*Note: Today, 11 years later, more survivors and more doctors know more about post-polio syndrome.*)
- Survivors who had polio as an adult were three times more likely to report PPS than those who had contracted polio during their childhood. This may be due, in part, to these survivors' current age. They may have better access to regular medical care because of their Medicare coverage, and therefore, be more likely to receive a timely diagnosis.
- No relationship was found between the length of time of the respondents' polio infection and the time of the survey and the likelihood that they reported a diagnosis of PPS.
- There was no difference in the rates of diagnosis of PPS in men versus women. Since the vast majority of respondents were white, it was not possible to tell statistically if there were differences in rates by racial or ethnic group.
- Respondents whose polio infection was more severe (for example, those who had more than five muscle groups affected, or those who required hospitalization for their original treatment) were more likely to report a diagnosis of PPS.
- Respondents were asked a series of questions about their view of life, similar to Type A personality questions that have been used in other surveys. Respondents who scored higher on the answers to these questions had a slightly *lower* likelihood of reporting a diagnosis of PPS.
- Future research on PPS needs to be expanded to include all polio survivors, with a special effort to include those who are not European-Americans. They may not have received an accurate polio diagnosis or standard treatment for their polio at the time of the epidemics due to the segregation that existed in the health care system in the US at that time.
- Future research should also identify what factors—not just physical factors—put polio survivors at risk of developing post-polio syndrome. ▲