

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,

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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??

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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

Section N. POLIOMYELITIS

RT 97 3-4

N1	<i>Refer to age</i>	N1	1 <input type="checkbox"/> Under 26 (NP) 2 <input type="checkbox"/> 26+ (N2)	5
N2	<i>Mark appropriate box</i>	N2	1 <input type="checkbox"/> Available (1) 2 <input type="checkbox"/> Callback required (Arrange callback, THEN NP) 3 <input type="checkbox"/> Noninterview (NP)	6
These next questions are about polio.		1.	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No 9 <input type="checkbox"/> DK } (N3)	7
	1. Were you EVER told by a doctor or other health care professional that you had poliomyelitis, usually called "polio", whether or not it resulted in physical disability?	2.	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	8
	2. Did you EVER have paralysis of any kind caused by polio?	3.	1 <input type="checkbox"/> Yes 2 <input type="checkbox"/> No	9
N3	<i>Enter person number of respondent for Polio questions</i>	N3	_____ Person number of respondent	10-11

FOOTNOTES

Table 1. Polio survivors 26 years of age and over, by paralytic status: United States, 1987

Polio status	Sample size	Estimated population	Percent distribution
All survivors	821	1,634,187	100.0
Paralytic	314	641,416	39.2
Nonparalytic	473	832,852	51.0
Don't know	84	159,919	9.8

SOURCE: NCHS, National Health Interview Survey, 1987

Table 2. Percent distribution of polio survivors 26 years of age and over, by paralytic and impairment status: United States, 1987

Impairment status	Paralytic Status			
	All survivors	Paralytic	Non paralytic	Don't know
Total	100.0	39.2	51.0	9.8
Currently impaired ^{1/}	37.7	22.9	14.1	*0.7
Not impaired	50.4	15.4	33.9	*1.1
Don't know	11.9	*0.9	3.0	8.0
Total	100.0	100.0	100.0	100.0
Currently impaired ^{1/}	37.7	58.3	27.6	*7.5
Not impaired	50.4	39.3	66.5	*11.3
Don't know	11.9	*2.3	5.9	81.3

* Relative standard error for population estimate is greater than 30 percent.

^{1/} Includes persons who responded "yes" to the question "Do you NOW have (paralysis of any kind), any deformity, weakness, or ANY impairment or health problem caused by polio?" The words "paralysis of any kind" were read only to persons reporting paralytic polio.

SOURCE: NCHS, National Health Interview Survey, 1987

Table 3. Percent distribution of persons 26 years of age and over by region, according to polio status: United States, 1987

Polio status	Total	Region			
		Northeast	Midwest	South	West
All persons	100.0	21.9	24.0	33.6	20.6
Polio survivors ^{1/}	100.0	17.4	25.5	29.6	27.4
Paralytic	100.0	18.4	26.8	28.4	26.4
Nonparalytic	100.0	14.8	26.8	31.3	27.1

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

SOURCE: NCHS, National Health Interview Survey, 1987

Table 4. Percent distribution of persons 26 years of age and over by age, according to polio status: United States, 1987

Polio status	Years of Age					
	Total	26-34	35-44	45-54	55-64	65 and over
All persons	100.0	26.2	23.3	16.0	15.1	19.4
Polio survivors ^{1/}	100.0	7.3	27.4	26.1	20.1	19.2
Paralytic	100.0	*5.0	21.7	27.5	22.6	23.2
Impaired ^{2/}	100.0	*5.3	16.8	29.4	21.4	27.0
Nonparalytic	100.0	7.2	31.0	27.4	18.2	16.2

* Relative standard error for population estimate is greater than 30 percent.

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 5. Percent distribution of persons 26 years of age and over by race and sex, according to polio status: United States, 1987

Polio status	Total	Race			Sex	
		White	Black	Other	Male	Female
All persons	100.0	86.7	10.4	2.9	47.1	52.9
Polio survivors ^{1/}	100.0	94.1	4.9	*1.0	43.9	56.1
Paralytic	100.0	96.7	*2.5	*0.9	44.8	55.2
Impaired ^{2/}	100.0	95.5	*3.5	*1.1	43.6	56.4
Nonparalytic	100.0	93.8	5.2	*1.1	43.3	56.7

* Relative standard error for population estimate is greater than 30 percent

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 6. Percent distribution of persons 26 years of age and over by education, according to polio status: United States, 1987

Polio status	Total ^{1/}	Didn't complete high school	High school graduate	Some college
All persons	100.0	23.6	37.8	37.5
Polio survivors ^{2/}	100.0	18.9	36.8	43.9
Paralytic	100.0	22.0	40.4	37.4
Impaired ^{3/}	100.0	20.9	39.3	39.6
Nonparalytic	100.0	16.2	33.3	50.3

^{1/} Includes persons with unknown level of education.

^{2/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{3/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 7. Percent distribution of persons 26 years of age and over by income and poverty status, according to polio status: United States, 1987

Polio status	Total	Income					Poverty status		
		Less than \$10,000	\$10,000-19,000	\$20,000-34,999	\$35,000- or more	Un-known	Below poverty level	At or above poverty level	Un-known
All persons	100.0	11.4	18.4	25.7	29.9	14.5	7.9	83.7	8.4
Polio survivors ^{1/}	100.0	13.2	17.4	24.2	32.0	13.2	7.2	85.5	7.4
Paralytic	100.0	15.0	15.9	23.6	28.4	17.2	7.3	81.6	11.1
Impaired ^{2/}	100.0	17.1	14.7	23.8	27.0	17.1	*8.0	78.3	*13.6
Nonparalytic	100.0	11.5	18.1	25.9	34.7	9.8	6.5	89.6	3.8

* Relative standard error for population estimate is greater than 30 percent

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 8. Percent distribution of persons 26 years of age and over by perceived health status, according to polio status: United States, 1987

Polio status	Total ^{1/}	Perceived health status				
		Excellent	Very good	Good	Fair	Poor
All persons	100.0	32.0	27.4	25.6	10.2	4.2
Polio survivors ^{2/}	100.0	27.0	23.9	29.7	13.2	5.8
Paralytic	100.0	20.9	18.7	34.5	16.7	8.3
Impaired ^{3/}	100.0	17.1	15.2	36.6	20.6	*9.4
Nonparalytic	100.0	31.1	27.5	26.3	11.5	*3.6

* Relative standard error for population estimate is greater than 30 percent.

^{1/} Includes persons with unknown perceived health status.

^{2/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{3/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 9. Percent distribution of persons 26 years of age and over by employment, according to polio status: United States, 1987

Polio status	Total	Employment		
		Currently employed	Unemployed	Not in labor force
All persons	100.0	62.8	2.8	34.4
Polio survivors ^{1/}	100.0	58.0	3.4	38.6
Paralytic	100.0	51.3	*4.4	44.5
Impaired ^{2/}	100.0	44.9	*5.3	49.7
Nonparalytic	100.0	63.1	*2.3	34.6

* Relative standard error for population estimate is greater than 30 percent

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 10. Percent distribution of persons 26 years of age and over by work or other limitation, according to polio status: United States, 1987

Polio status	Total	Limitation				
		Unable to work	Limited in work	Limited in other activities	Not limited in work	70 years of age and over ^{3/}
All persons	100.0	6.1	4.5	3.5	73.2	12.7
Polio survivors ^{1/}	100.0	10.3	9.4	7.1	59.9	13.2
Paralytic	100.0	14.5	12.2	*6.1	51.0	16.4
Impaired ^{2/}	100.0	20.3	14.7	*7.8	39.0	18.4
Nonparalytic	100.0	7.8	7.7	8.5	64.7	11.3

* Relative standard error for population estimate is greater than 30 percent

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

^{3/} Persons 70 years of age or over were not asked this limitation question.

SOURCE: NCHS, National Health Interview Survey, 1987

Table 11. Percent distribution of persons 26 years of age and over by limitation of major activity^{1/}, according to polio status: United States, 1987

Polio status	Total	Unable to carry on major activity	Limited in amount or kind of major activity	Limited, but not in major activity	Not limited
All persons	100.0	5.8	6.9	6.1	81.2
Polio survivors ^{2/}	100.0	11.4	11.6	10.6	66.5
Paralytic	100.0	16.4	15.3	10.3	58.0
Impaired ^{3/}	100.0	22.5	19.8	13.1	44.7
Nonparalytic	100.0	8.5	9.0	11.4	70.9

1/ "Major activity" during the past 12 months - working, going to school, keeping house or something else.

2/ Includes persons who did not know whether they had paralytic or nonparalytic polio.

3/ Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 12. Mean annual number of days of activity restriction due to acute and chronic conditions for persons 26 years of age and over, by type of restriction and polio status: United States, 1987

Polio status	All types ^{1/}	Bed-disability days	Work-loss days ^{2/}
All persons	17.9	7.6	5.6
Polio survivors ^{3/}	26.6	12.6	6.2
Paralytic	32.6	16.1	5.2
Impaired ^{4/}	41.1	20.9	4.3
Nonparalytic	22.0	9.1	5.0

^{1/} Includes restricted-activity days.

^{2/} Restricted to persons currently employed.

^{3/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{4/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 13. Mean annual doctor visits and percent distribution of persons 26 years of age and over by number of doctor visits, according to polio status: United States, 1987

Polio status	Mean visits	Total	Number of visits			
			Zero	1	2-4	5 or more
All persons	6	100.0	26.4	22.0	28.8	22.8
Polio survivors ^{1/}	8	100.0	20.9	17.6	30.1	31.4
Paralytic	8	100.0	23.2	16.6	26.1	34.0
Impaired ^{2/}	7	100.0	24.1	14.4	25.4	36.1
Nonparalytic	8	100.0	18.6	18.8	33.3	29.3

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 14. Percent distribution of persons 26 years of age and over by interval since last doctor visit, according to polio status: United States, 1987

Polio status	Total ^{1/}	Interval since last doctor visit			
		1 year	1-2 years	2-5 years	5 years or more
All persons	100.0	74.3	9.5	10.3	4.4
Polio survivors ^{2/}	100.0	79.6	8.3	7.0	4.8
Paralytic	100.0	77.2	7.5	8.6	*6.2
Impaired ^{3/}	100.0	75.9	*8.0	*7.8	*8.0
Nonparalytic	100.0	82.0	9.0	5.0	*3.6

* Relative standard error for population estimate is greater than 30 percent.

^{1/} Includes persons who never have visited a doctor and those with unknown intervals since their last doctor visits.

^{2/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{3/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987

Table 15. Percent distribution of persons 26 years of age and over by annual number of hospital stays and average length of stay, according to polio status: United States, 1987

Polio Status	Total	Number of hospital stays				Average length of stay in days
		0	1	2	3 or more	
All persons	100.0	89.7	8.1	1.5	0.7	6.7
Polio survivors ^{1/}	100.0	88.2	9.4	*1.8	*0.7	6.5
Paralytic	100.0	86.7	10.6	*1.4	*1.1	7.2
Impaired ^{2/}	100.0	85.8	11.2	*1.6	*1.3	8.4
Nonparalytic	100.0	89.0	8.4	*2.3	*0.4	5.8

* Relative standard error for population estimate is greater than 30 percent

^{1/} Includes persons who did not know whether they had paralytic or nonparalytic polio.

^{2/} Includes persons who reported having paralytic polio and who responded "yes" to the question "Do you NOW have paralysis of any kind, any deformity, weakness, or ANY impairment or health problem caused by polio?"

SOURCE: NCHS, National Health Interview Survey, 1987