

Post-Polio Population Statistics - A Review.

Chris Salter Lincolnshire Post-Polio Network.

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The starting point of this review is an extract from a recent book by Dr. Lauro. S. Halstead, one of the leading specialists in Post-Polio conditions. In "Managing Post- Polio"[1] he writes:

"Accurate numbers of Americans who had paralytic poliomyelitis are not available and probably never will be. There is no national registry of persons who had polio. Also, there is no way, after all these years, to compile accurate figures from state and local health departments. The best estimate is based on data from the government's National Center for Health Statistics, which conducts a National Health Interview Survey each year. This survey collects data from a random sample of the U. S. population regarding various health and disability issues. In 1987, surveyors specifically asked questions about the number of persons who were given a diagnosis of poliomyelitis with or without paralysis. Based on the results of this survey, the Center calculated slightly more than 1.63 million polio survivors. Of these, 641,000 (39.2 percent) persons had paralytic polio; 833,000 (51 per-cent) had non-paralytic polio; and 160,000 (9.8 percent) didn't know. Unfortunately, some of these data have been miscopied or misrepresented and then erroneously published in the medical literature as fact. The most common error is the statement citing 1.63 million persons with paralytic polio when the correct estimate is really 641,000 as cited above.

The latter figure, however, is based on a survey conducted 10 years ago. Since then, it has been estimated that 5 percent to 10 percent of the polio population has died, which means the current number of survivors is closer to 600,000. How many of these 600,000 persons with paralytic polio have PPS is unknown. Several studies indicate a large number, perhaps 60 percent or more, is experiencing one or more new difficulties related to old polio, such as muscle aches and joint pains. However, the number with PPS (new weakness with or without other symptoms many years after acute polio) is undoubtedly smaller, probably in the range of 20 percent to 40 percent. Using these figures, it is estimated that approximately 120,000 persons to 240,000 persons in this country are currently experiencing symptoms of PPS."/1/

Although the above was written as recently as 1998, it has been in part superseded regarding one significant criteria. Dr. Halstead's final PPS estimate excludes persons with a history of non-paralytic polio. For several decades there has been a tendency to require a history of paralytic polio before any diagnosis of PPS will be considered. Such a pre-requisite is not supported by medical papers written in the

1950's and earlier. Those papers report evidence of a level of neuronal damage by the polio virus that does not present any clinical signs of paralysis at the time of infection. Indeed, there can be a significant level of damage without any clinical indications. The Lincolnshire Post-Polio Network commissioned an article [2] early in 1999 to present the case for not excluding non-paralytic polio as a pre-requisite for PPS. The authors, Marcia Falconer and Eddie Bollenbach, have recently been successful in getting a commentary on the subject [3] published in the peer-reviewed American Journal of Physical Medicine & Rehabilitation and Dr. Halstead has also written on the subject in the same journal.[4] In that article Dr. Halstead writes

"Although the diagnosis of postpolio syndrome traditionally has required a remote history of paralytic polio, many persons such as the ones described here with typical symptoms of postpolio syndrome have no clear history of paralytic disease and are being misdiagnosed. With this in mind, we believe that the diagnostic criteria for postpolio syndrome should be modified to include the following: a history of remote paralytic polio or findings on history, physical examination results, and laboratory studies compatible with poliovirus damage of the central nervous system earlier in life." [4]

This inevitably leads to the conclusion that an indeterminate percentage of the 833,000 persons with nonparalytic polio in the US calculation will eventually present PPS symptoms. The worst case scenario would be that all 833,000 suffered viral damage just below the clinical level.

I will now move on to the UK and specifically Lincolnshire. There are no records available of numbers of cases of prior polio being currently treated in Lincolnshire for new symptoms. A 1996 letter to the Lincolnshire Post-Polio Network from Dr. Le Geyt, Lincolnshire Health Authority, gave three separate figures for current numbers of cases of prior paralytic polio in Lincolnshire, each sourced or derived from a specific report. I have extrapolated UK figures from his figures and other sources using a Lincolnshire population of 631,466 and a UK population of 57,400,000 from 1990 National Health Service Statistics. In the case of Dr. Le Geyt's Lincolnshire estimates which are themselves extrapolations from UK figures, any difference between the original UK figure and my UK extrapolation from his Lincolnshire estimate is probably due to our using a different Lincolnshire/UK population ratio. My UK extrapolations are only intended to emphasise the significant variation found in estimated cases of prior polio.

The first figure he gave was 100. The source for this figure he quotes as a 1998 paper in the Lancet[5] 23,000 infections 1920 to 1950. The UK extrapolation is 8,610. (In comparison, another UK statistic, source unknown, puts UK notified polio cases from 1912 to 1961 as 74,280).

The second figure he gave was 300. The source for this figure he quotes as the British Polio Fellowship saying of 100,000 infections, 30,000 survive. The UK extrapolation is 26,404.

The third and last figure he gave was 1,200. The source for this figure he quotes as a paper by Ahlstrom [6] of a Swedish survey from which a figure of 186 per 100,000 population is derived. The UK extrapolation is 106,764.

From a recent Edinburgh University survey of Lothian [7] a figure of 200 per 100,000 population is derived, i.e. 114,800 out of a Lothian population of 750,000. Using national population statistics again, the Lincolnshire extrapolation is 1,262 and the UK extrapolation 114,800.

The Lothian survey also refers to a Norwegian survey by Gilhus[8] in 1998 which derives a figure of 250 per 100,000 population. The Lincolnshire extrapolation is 1,577 and the UK extrapolation is 143,500.

Returning to Dr. Halstead's US census based estimate of 270 per 100,000 population our Lincolnshire extrapolation is 1,703 and our UK extrapolation is 154,980.

It is important to re-emphasise that Dr. Le Geyt's figures and therefore our extrapolations are limited to cases with a history of prior paralytic polio. Include non-paralytic polio and the US estimate increases to 680 per 100,000 population. All the Lincolnshire and UK extrapolations are similarly affected, i.e. increased by a factor of 2.5.

As can be seen, when trying to determine the number cases of PPS in a population we are confronted with a number of problems.

- 1. No current statistics of persons currently diagnosed as PPS.
- 2. Estimates of the percentage of cases of prior polio likely to develop PPS vary considerably. Few if any take into account that a historical clinical diagnosis of non-paralytic polio does not preclude a diagnosis of PPS.
- 3. Although in recent years records of notified and confirmed cases of polio have been maintained by the World Health Organization, records predating the eradication campaign are more difficult to locate and may be unreliable.
- 4. Estimates of the numbers of cases of prior polio vary considerably and as with PPS estimates, tend to be limited to so called paralytic polio. It is worth noting that a 'mild' polio infection may not even be diagnosed at the time of the infection but may still result in sufficient damage to cause problems in later life.

While the above observations arise from data specific to the USA, UK, Sweden and Norway there is no reason not to believe that they do not apply to all countries. As far as I am aware no individual, organisation or institution has attempted to gather statistics on a world-wide basis in order to arrive at a reasonably accurate estimate of the number of polio survivors (by definition living) in the world today let alone the number presenting or likely to present PPS symptoms. It also worth emphasising that while the polio survivor population in the polio free regions is by definition reducing in numbers over time, until the WHO eradication campaign achieves its goal, there are regions where cases of polio still occur.

ACKNOWLEDGEMENT

This review is an expansion and continuation of an analysis by Hilary Hallam referenced in <u>Polio</u> <u>Survivors Need Holistic Multi-Disciplinary Assessment Because The Standard Physical Assessment Is Not</u> <u>Adequate</u>, LincPIN Newsletter Volume 2 - Issue No. 5 - June 1999.

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