



A Qualitative Survey of Postpolio Syndrome in the Leeds area.

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INTRODUCTION.

There were six major polio epidemics in the United Kingdom early this century. In the Leeds area, more than 400 cases of Polio were notified between the years 1940 - 1962 inclusive[1]. After the successful introduction of mass vaccinations with the Salk and then the Sabin vaccines in 1956 and 1961, new polio cases became extremely rare.

It is known that that many people with a history of polio may develop new symptoms after decades of stable functioning. The time lag varies but the usual period between the onset of these symptoms is about 30 years[2]. The risk of developing these symptoms appears to be correlated with the severity of the original paralysis[3].

Most common new health problems reported by Postpolio patients are fatigue, muscle pain, joint pain and weakness. Functional problems include walking, climbing stairs and dressing[4]. The suggestion is that these new symptoms should be labeled as the "Postpolio" syndrome.

Table1 Problems experienced by those who had polio many years ago.

- weakness, pain or cramp in muscles
- increasing arthritis
- increasing arthritis secondary to unusual use of muscles and joints
- increasing fatigue
- skin and circulatory problems secondary to autonomic nervous system involvement
- osteoporotic changes leading to fractures
- increasing deformity e.g. scoliosis
- increased risk of deep venous thrombosis
- increasing respiratory problems, including possibly undiagnosed sleep apnea
- increasing difficulty with mobility
- increasing difficulty with work and activities of daily living
- difficulty in obtaining orthoses
- difficulty in obtaining suitable wheelchairs

A qualitative study was carried out between the months of September and November 1998. Interviews were done on 14 patients suffering from the post-polio syndrome. They were between the ages of 40 and 72 years and eight males and six females. All of them had polio in childhood, before the age of 10 years

with various impairments.

The aim of this study was to explore possible influences on the perceived quality of life for people with PPS. This is a pilot case series in descriptive epidemiology.

METHOD.

A structured interview schedule was used. The questions covered various aspects employment, appearance, social support etc.

The answers were analyzed with NUD.IST software[5] using cross-case comparisons [6] assessing the similarities and differences emerging as patterns between and within cases.

The interviews were conducted in the patients residences with spouses present in some cases. All questions were answered to the best of their abilities.

RESULTS.

The results of the structured interview was as follows:

1. occupation: 8 were working but had to modify their practices
 4 had to give up work due to post polio syndrome
 1 had retired

2. family relationships: 11 had supportive families and spouses*
 2 lived alone and kept themselves in isolation
 1 had problems with their families understanding their illness

3. activities in the house: 10 needed help from their spouses, family members or home help
 3 managed their own household chores
 1 was wheelchair bound but had the house fully adapted

4. negative feelings: 12 experienced anxiety or depression about their condition
 2 were resigned to their condition (taking it as it comes)

5. sleeping pattern: 13 had disrupted sleep due to pain and exhaustion
 1 no problem

6. personal hygiene: 10 needed help ranging from complete dependence to aids
 3 managed independently with difficulty

1 was completely dependent

7. leisure/hobbies: 12 were restricted in amount of time or equipment
2 had to give up their hobbies

* Out of which only 2 reported a satisfactory physical sexual relationship, the rest had difficulties.

CONCLUSION.

It is apparent that these symptoms have significant potential consequences for the individuals experiencing postpolio sequelae in their functional capabilities to cope with activities of daily living (ADL). Obviously reports of fatigue, pain, muscle weakness and atrophy, respiratory difficulties have significant effects on mobility. Individuals experiencing PPS note difficulties in walking, using wheelchairs, transferring in and out of chairs, never mind negotiating stairs. As one might expect, mobility difficulties also potentially affects one's ability to remain employed.

In terms of being self sufficient, individuals faced increasing difficulties in dressing, washing among the activities performed at home as well as sexual functioning. In fact respondents have been forced to alter their activities of daily living, expand their reliance upon mechanical aids and personal assistants. Generally PPS sufferers report having to "slow down" in terms of activities in a day to day basis.

Not surprisingly these changes have an important emotional impact. The anxiety, frustration, uncertainty and isolation must have a significant influence on one's outlook and response to the demands of daily living, particularly in light of the likelihood of a more restricted lifestyle. A concrete manifestation of these changes is a decline in one's capacity to maintain a social life.

There may be comorbid or secondary medical conditions contributing to development or aggravation of symptoms. Being a diagnosis of exclusion, there are no specific tests for the Postpolio syndrome[7]. It is therefore important to compare quality of life with other neurological conditions having a similar set of symptoms, to compare differences associated with disturbance of activities of daily living.

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