

Polio - The Living Legacy - Executive Summary

Network Vice-President Merle Thompson's comprehensive research report "Polio – the living legacy", subtitled "Ten years on – A new assessment of the impact of the late effects of polio on the lives of polio survivors", has now been published. Merle had conducted the painstaking research over two years and has previously made presentations on the evolving results at the Network's Annual General Meeting in November 2006 and at the Polio Australasia "Designing a Future" Conference in May 2007 (where delegates from all Post-Polio Networks in Australia and New Zealand were in attendance). The research was supported by a grant from the Australian Seniors Foundation, but printing of the resultant report has largely been funded from the Network's own resources which means that initially only a limited print run has been possible. As well as making the required statutory deposits, copies have been distributed free of charge to the other state Networks and to the New Zealand Post Polio Support Society, the Australian Seniors Foundation, research associates, appropriate health professionals, and to relevant members of the Federal and State Governments and Oppositions. A number of copies have also been purchased by libraries throughout Australia.

The report's Executive Summary follows, which should whet your appetites to read the complete report (over 150 pages). At this time, a limited number of copies are available for sale to members on a cost-recovery basis. If there is sufficient interest from members a further print run will be organised. To order your copy, please write to the Network's Office enclosing a cheque/postal order for \$50 (which includes postage and GST).

In 1998 the Post-Polio Network conducted a survey of its members. The information obtained was extremely valuable in providing a greater understanding of the level of restrictions and difficulties experienced by members in their daily lives. It enabled officers to speak with authority on these issues and provided resources for use when conducting training programs for people such as health professionals and home care workers.

The data contained in that Report was gathered during the previous 2 years and is, therefore, 8 to 10 years old. The desire for up-to-date and additional information on the post-polio experience of Network members and the continuing membership of so many people made it possible to have a study which built on and added to the information obtained in the earlier study.

This research provides an unusual and valuable opportunity for comparison between two studies which had many of the participants in common and in which many of the issues addressed were the same.

The current research aimed:

- to obtain up-to-date information on a range of issues which were assessed in the earlier report;
- to see if respondents consider that their difficulties have increased over the past ten years;
- to re-consider those factors which were of particular concern in the previous study, namely having to retire early due to polio-related difficulties and the reliance of survivors on family and carers for assistance with daily living;
- to assess matters which had been raised by other researchers as well as other factors which had not been assessed in the 1998 research.

Methodology

A 12-page questionnaire was developed to cover these areas. This was mailed to all full members of the Post-Polio Network (NSW) Inc as at March 2006, that is, those members who have had polio. This totalled 863 members. The response rate was 56.7%.

Some of the issues which the research aimed to assess are also relevant to other older members of the community, such as reliance on family and carers, who are also ageing, and experience of falls. This was a factor in obtaining funding from the Seniors' Foundation.

A parallel questionnaire was developed in order to be able to compare polio survivors with other 'senior' people. This was to be completed by a friend or relative who is of the same sex and similar age to the polio survivor.

Changes Over 10 Years

The survey asked participants in the polio survey to respond to questions which covered similar topics to those covered in the Network's 1998 research. This provided both up-to-date information in each of these areas, often of a more detailed nature, and also the opportunity to compare response profiles with the earlier research.

The fact that many of the respondents also participated in the 1998 research, and that many of the factors assessed are similar, means that comparisons of ratings on similar items are more likely to be valid than comparisons with other research projects.

For many items respondents were also asked to indicate whether the specific activity had become more difficult for them over the last ten years.

Statistical data

The data obtained from the questionnaires is shown in a series of tables and graphs with associated written analysis and comments on the implications of the findings. In some areas the responses of the polio group are differentiated for age and/or gender. For some items data was also assessed in relation to other factors such as the interval from initial polio illness to the onset of the late effects, the age at the time of the initial illness and the year of polio illness.

In addition, the responses of the polio and parallel groups are compared. In some aspects of the sections on the problem of falls, comparison is also made with a study conducted by the University of New South Wales (UNSW). Reference was also made to other research about the late effects of polio, both in Australia and overseas.

A study of the response patterns indicated that, despite the complexity of the questionnaire, Network members had put considerable thought into their responses.

Biographical information

The proportion of females to males was 60.5% to 38.1%, a similar ratio to that of the Post-Polio Network membership. The average age of those who stated their age was 66.3, with a range of 38 to 95 years.

The year in which they contracted polio ranged from 1916 to 1980, with the highest numbers being in the years of major epidemics, that is 1937–38, 1945–46 and 1950–55. The community perception is that polio is a disease of young children but, while 70% were under the age of 10 at the time of the initial illness, 35 (7%) were between 21 and 30, and 8 respondents (2%) were over 30.

The average age of the parallel group was 65.1 years, with a gender ratio similar to the polio group.

The Late Effects of Polio

Respondents were asked to indicate whether they experience those symptoms which are generally regarded as being involved in the late effects of polio or Post Polio Syndrome and to specify whether the problem has been on-going for over 10 years without increased severity, has been on-going for over 10 years with increased severity in that time, or is new during that period.

The responses confirmed that the nominated 15 symptoms are all relevant in the late effects of polio and that those experienced by the greatest number of respondents are also those which have been identified previously as of major significance by a wide range of researchers. They show that almost all polio survivors experience the debilitating problems of muscle weakness (92%) and fatigue (89%).

It was also seen that at least 64% report, in order of frequency, muscle pain, joint pain, sensitivity to cold, muscle atrophy, tendency to fall, sleep problems and muscle cramps. More than half experience muscle twitching and problems with finding words. The other listed symptoms – breathing difficulties, headaches, change in voice and swallowing difficulties – were reported by between 37% and 43%.

The number of symptoms which individual survivors experience was assessed and 10% of respondents reported having all 15 symptoms. The average number was 9.2 symptoms. There was little variation between males and females or between the responses within age groups.

The interval between the initial polio illness and the onset of the new problems of the late effects of polio was also studied. For around 14% the onset was less than 30 years after the initial illness. This development was between 30 and 39 years for about 30% and over 40 years for more than 40%.

While these conditions may be exacerbated by ageing, they are not directly age related as most difficulties are experienced across the full age range of participants, with younger respondents experiencing many problems equally, or even at a greater rate, than older participants, and sooner than would be considered to be the result of ageing in the general population. It is also apparent that many of these difficulties have increased over the past ten years.

Difficulties with Personal Living

Participants provided information on a number of aspects of personal life including personal care, undertaking household tasks, mobility and transport, exercise and, for the polio group, their use of aids and appliances.

Since the average age is over 60, it could be anticipated that participants' natural ageing would mean that they would experience the same problems in living as others of their age. The parallel survey enabled comparisons to be made between the polio group and a non-polio group. It cannot be assumed that the parallel group is a fully representative sample of the general population of a similar age range to the polio group but it is large enough to enable inferences to be made.

It is apparent throughout the survey that the majority of polio survivors have significant problems in handling many aspects of daily life, although there is a great deal of variance in the level of their difficulties. It was seen that many in the parallel group also have difficulties in daily living, especially with transport, household tasks, personal care and falls. In general these are not experienced by as large a proportion of this group as of the polio group.

In the Home: The number of respondents who live in assisted accommodation is very small, particularly when the age range is taken into account. Over 90% of both groups live in independent houses or units/villas or in retirement villages without assistance.

In the course of daily life, the ability to attend to personal care, to undertake household tasks, prepare meals and to shop influences one's independence and the possible need to rely on others.

For 24% of the polio group even walking around the home is difficult.

Only a very small number of this group find specific personal care activities impossible but at least a quarter of participants, who can manage to care for themselves, find it difficult to do so. This particularly applies to having a bath/shower. Overall at least a quarter reported an increased level of difficulty in personal care.

Similarly, only a few people find the most essential daily activities of preparing meals and basic housekeeping impossible but many have varying levels of difficulty in doing so. Apart from light household tasks, such as washing up, and cooking snack meals, which could be managed by two-thirds of respondents, all tasks in the home and garden present problems.

Again, at least a quarter of respondents reported increased difficulty over the past ten years for each item and some more demanding activities, such as heavy housework, major shopping and gardening, have become more difficult for larger proportions of respondents.

The parallel group were only asked whether they need assistance with these activities. Only 3% reported having difficulty. Getting dressed and showering were the most difficult.

In view of the above difficulties it would be expected that many participants would use professional or community services. However, only 28% of polio respondents use such services. Predominantly the services used are for housework, gardening and home maintenance. Only a small number use services such as personal care and bed changing. With the exception of housework, where a greater number have Homecare, most assistance is fully or partially self-funded. Some do not access services because they do not wish to do so but many are unable to do so. They may not be eligible for Government funded services or they find the cost of self-funded services prohibitive or suitable providers are not available. For those who do have assistance many report that the level has increased in recent years.

In the parallel group 17% reported that they access services.

Reliance on Family: In the Network's 1998 report it was noted that respondents' comments showed that many polio survivors were reliant on their family and, in particular, their spouse, in order to manage many aspects of daily living. This raised concern that, as many of their spouses are also ageing, they, as a family unit, might not be able to manage in future, particularly if the spouse became ill.

This concern is substantially endorsed as 62% receive assistance from family members and, of these, two thirds do not receive any other assistance. For 21% of all participants their carer has become less able to provide care, with ageing and their own medical problems being the main reasons. Over a quarter of participants live alone, including some who have difficulty managing personal care.

While only 14% consider that the need for the provision of care has caused a strain in their relationship, the written comments describe some very difficult situations. This was also the case for some of the polio survivors (15%) who provide care for others.

About a third of participants think they will need more assistance within a few years but only 14% think they will need to change their living arrangements.

In the parallel group 65% do not need assistance. For those who do, assistance is mainly provided by the spouse then a son/daughter. The percentage of respondents who say that the provision of care has caused a strain in their relationship is marginally higher than in the polio group but a smaller proportion stated that they will need to change their living arrangements or have more assistance.

Mobility and Exercise: The fact that many respondents have considerable difficulty in personal mobility is evident from their reports of inability to handle a number of specific aspects of walking. Activities which do not generally present difficulty to most people are demanding for polio survivors with 14% reporting that they cannot walk or are very restricted in the ability to do so. As the aspects of walking become more demanding fewer can manage without difficulty with, at best, 40% reporting no difficulty with the task.

Many respondents have found these activities to have become more difficult in the last 10 years, even for those who said that the activity does not cause them any problems. Up to two thirds indicated that individual activities have become more difficult.

For some participants the limitations in mobility have developed more recently with the onset of the late effects of polio. Of those who now report that they cannot walk, 20 indicated in the Exercise section that they had previously undertaken strenuous activity or demanding sport during their years of maximum recovery. At least 89 whose past activity was at that high level now have some degree of difficulty climbing stairs.

Others have had restrictions since their initial illness. Fifty-one percent indicated that they could undertake a lot less physical activity than other people of their age during their period of maximum recovery.

Despite their difficulties more than half stated that they undertake some form of regular exercise. Many have innovative approaches to exercise and at least 40% include at least some non-walking exercise. Professional opinion varies on the advisability of exercise for polio survivors but consensus is that exercise should not lead to excessive pain and fatigue but only 24% have a prescribed program.

Tiring is a significant factor. For both walking and exercise, over 60% of polio respondents report being restricted by tiring.

Transport: The ability to drive oneself and to use public and private transport is necessary to participate in community life. In the polio group a number commented that they had never been able to use public transport or could no longer do so. Fewer than 30% indicated that they can use buses, trains and ferries without difficulty or the need for assistance and over a third have found using public transport has become more difficult in recent years. In the later section *Worry about Falls*, nervousness regarding crossing roads and using public transport emphasises how transport issues can restrict one's life.

While 80% say that they still drive a car, only 35% can get into or out of a vehicle without difficulty or assistance and only 42% can be a passenger in a car without difficulty. Ten percent have special modifications or wheelchair/scooter lifts but others have found the cost prohibitive.

Respondents to the parallel questionnaire are generally more able to walk and use public transport than the polio group but a significantly high number of 23% indicated that they are restricted in the ability to walk and 20% cannot use public transport without difficulty or assistance.

Health and Medical: The majority of participants have check-ups with their general practitioner. Of the other health professionals listed, podiatrists and physiotherapists were the services most often used by polio survivors but very few of the parallel group accessed

such services. Medical screening programs were accessed by significant proportions of both the polio and parallel groups, particularly for breast, prostate and cervical cancer and for diabetes.

Over 80% of participants in the polio group rely on at least one appliance and 12% use at least 6 appliances. Many have found their need to use aids has increased, particularly with mobility aids. The lack of availability of appropriate and/or affordable appliances is a source of difficulty for members as is the distance to, and accessibility of, suppliers.

Polio respondents nominated the non-prescription medications which they use and the major usage was of proprietary pain and arthritis medications and dietary supplements. Very few used what might be termed alternative medications.

It has been conjectured that a number of medical conditions, in addition to those regarded as being late effects of polio, are more prevalent among polio survivors than in the general community. The problems which were experienced by the most respondents were difficulty with memory for words and names (62%), depression (47%), being overweight (46%), and a range of sleep problems (total 74%). A number of other conditions were also reported frequently – oesophageal reflux problems, swallowing difficulty, urinary problems, carpal tunnel syndrome, osteoporosis, osteoarthritis and scoliosis.

Only 4% of participants said that they are current smokers and 30% are former smokers, while 55% have never smoked.

Employment and Financial Matters: Only 24% of respondents indicated that they are in paid employment or are self-employed. The need to retire early because of polio-related problems was noted in the Network's 1998 survey and this factor is confirmed in the current survey. Overall 122 people indicated that their retirement was at least partly resulting from polio-related problems, more than half of whom are in their 50s or less. Others had reduced their hours of work because of their polio-related problems, including some who were only in their 40s and 50s.

The age pension and self-funded superannuation are the major other sources of income. Only 13% have a disability pension. The number of respondents who receive a Mobility Allowance or whose carer receives the Carer's Allowance is less than might be expected. While all aspects of income were not studied, it seems likely that many members have financial limitations.

The Problem of Falls: A tendency to fall is an important symptom of the late effects of polio and falls are regarded as a major issue for older people generally. Two sections of the questionnaires asked respondents to indicate aspects of their experiences with falling and their nervousness about falls.

There was very little difference between males and females but a study in age groups revealed some interesting patterns with younger participants having had as many or more falls than in the older groups.

In the polio group 66%, and in the parallel group 44%, indicated that they had fallen during the past five years. Among those who had fallen, 81% of the polio group and 58% of the parallel group reported having fallen in the past year, with some reporting large numbers of falls. The UNSW figure was 37%.

Participants' nervousness about falling was assessed. Only 11% of the polio group and 47% of the parallel group did not have any fear of falling. On the other end of the 5-level scale 15% of the polio group and 3% of the parallel group were 'extremely' nervous. In the UNSW study 42% said that they were 'not at all' nervous and only 2% 'extremely' nervous.

Respondents were also asked to rate their concern about falling in a number of specific circumstances. Confidence in undertaking activities without falling varied according to the nature of the activity, with those within the home generally being regarded as safer. Both groups considered using public transport and crossing roads as of most concern.

General impressions from respondents' written comments on the issues studied

Comments throughout the survey revealed some recurring and contradictory themes among the polio group. These included:

- The need to be 'normal' has been a significant factor in the lives of many respondents.
- An approach to life which embraces learning to live with one's physical limitations and make the most of life.
- Lack of willingness to accept help or even to acknowledge the need for it.
- A view of life which puts responsibility on oneself.
- Optimism to deal with future problems.
- Love, commitment and mutual caring within many families which has enabled them to face problems.
- Difficulties which appear insurmountable for a small number of respondents.
- Isolation and/or separation from families for some.
- Lack of care and understanding in a minority of families.

FAMILY AND CARER PARTICIPATION

An innovation in this survey was the provision of an opportunity for family members and carers to write comments on the polio survivors' experiences and their effect on their relationship and their lives in general. These provide a revealing insight and elucidate both the high and low points of the life of polio survivors and their families.

CONCLUSION

The legacy of polio for those who contracted it, and for those who are significant in their lives, can be clearly seen in the responses of the survivors to the survey questions and in their and their families' comments. The overall picture is of a group of people who have many personal physical limitations and many difficulties in handling daily life.

The experiences of survey participants endorse the relevance of those symptoms which have been identified in previous research and in clinical practice as being indicative of Post Polio Syndrome and the late effects of polio.

From a social perspective of the lives of polio survivors, especially when considering their current and future needs, theoretical distinction between Post Polio Syndrome and the late effects of polio and the application of different clinical diagnoses seem artificial and even irrelevant.

It is important to highlight the diverse patterns of symptoms and difficulties experienced by individuals and to focus on the problems with which survivors have to contend and the impact of these difficulties on their lives. It is essential that there be understanding of the totality of the person's needs and to ensure that rigid diagnoses do not impair access to services.

It is apparent from the parallel survey that many non-polio people have difficulties in daily living, especially with transport, household tasks, personal care and falls but these are not experienced by as large a proportion of this group as of the polio group.