POST-POLIO NETWORK (NSW) INC

SURVEY OF MEMBERS

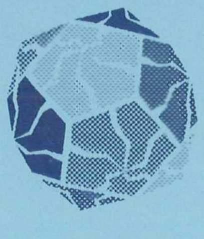
MERLE THOMPSON
NOVEMBER 1998

Cover Design

The front cover graphic design is a three-dimensional schematic representation of the external shape of a single poliomyelitis virus particle. The particle is symmetric, like a soccer ball (but ten million times smaller!) constructed from five-sided segments (pentagons). The pentagons are artificially differentiated in the graphic by their different colours. On each pentagonal face of the virus particle there is a symmetric "hill". To graphically depict these hills, the design shows five jagged "paths" which extend from each pentagonal side and traverse each hillside to the hill peak.

The outer layer of a poliomyelitis virus particle is a thin shell constructed from proteins. The shell protects a molecule of ribonucleic acid (RNA) which resides at the centre of the particle. The virus particle readily reproduces itself and so a single virus particle is infectious.

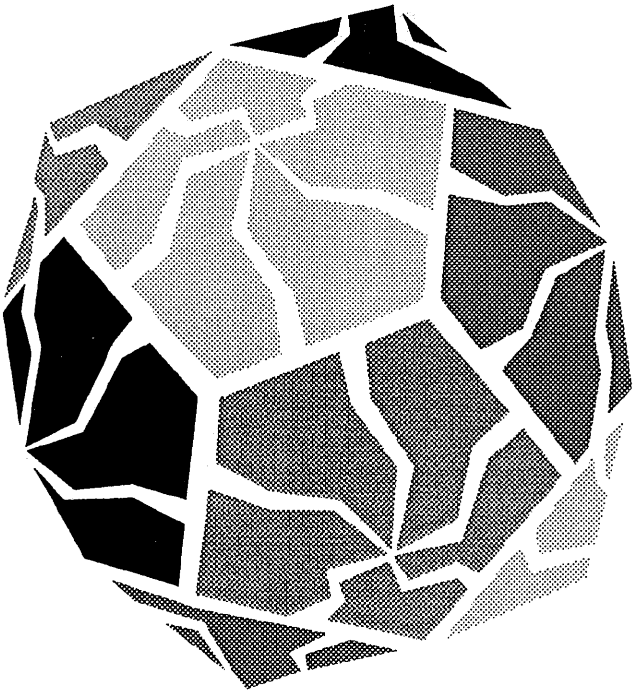
Concept and original design: Peter Garde
Virology consultant: Dr Peter Robertson
Final design: Billy Blue Design and Writing



POLIO

A CHALLENGE FOR LIFE

THE IMPACT OF LATE EFFECTS



Post-Polio Network (NSW) Inc
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ACKNOWLEDGMENTS

The Network wishes to thank members Merle Thompson and Alicia Lee for their painstaking work in devising and refining the questionnaire used in the Survey of Members.

The Network also offers its sincere thanks to all those members who took the time and trouble to complete the questionnaire, and especially to those members who added thoughtful and insightful comments to their responses.

Post-Polio Network (NSW) Inc
PO Box 888
Kensington 1465

THE POST-POLIO NETWORK (NSW) Inc

The Network was established in 1989 to support people who have had Poliomyelitis and who may be experiencing its late effects.

The objectives of the Network are:

- to provide advice on Polio and the management of its late effects
- to encourage the interchange of thoughts and experiences of Polio through seminars and local support groups
- to encourage research into the late effects of Polio.

Full membership is open to any person of 16 years of age or over who has had Polio. Associate membership is open to all other people or organisations who are interested in the Network.

In 1998 membership is approximately 750.

Seminars are held regularly in Sydney and are being extended to other areas. Newsletters and information bulletins are provided to members four times a year.

The Newsletter informs members of current research on the late effects of Polio and publishes articles from local and international sources. It reports on information seminars and offers self-help tips.

The Information Bulletin provides information on services and programs which are available to people with disabilities.

Over 20 local support groups have been established around the State. These groups operate in a number of different ways according to the nature of the area to assist people handle the late effects of Polio.

The Network was formed following the realisation that thousands of people around the world who have had Polio were experiencing a number of difficulties such as undue fatigue, muscle fatigue, muscle and joint pain, respiratory and muscle weakness. The similarity of these symptoms could not be a coincidence.

The Network is a voluntary self-help organisation incorporated under the Associations Incorporation Act and is an authority holder under the Charitable Fundraising Act. Gifts to the Network are tax deductible.

POLIOMYELITIS

The history of Polio

Poliomyelitis has been known for millennia but it is only in the last century or two that its incidence has become the series of epidemics with which Australians of middle age and older are familiar.

Evidence that Polio existed long ago comes from a carving in Egypt over three thousand years old which shows a young man with a withered leg supporting himself on a stick, as we would use a crutch and from a description by Hippocrates two thousand years ago. An ancient skeleton has also been discovered of a young girl with limbs which resemble those of a person who has had Polio.

Polio was first clinically described in the early nineteenth century. It would appear that for centuries Polio was persistent but it was an illness predominantly affecting children between the age of six and 36 months and only occasionally resulting in paralysis.

It is only during the nineteenth century that paralytic Polio became known in adults and it was found that Polio in adults can be more severe and more frequently result in paralysis. Occurrence of Polio came to be in epidemics, especially in summer and autumn, particularly in industrialised countries in temperate areas.

Nature of Poliomyelitis

Polio is caused by a virus which was first identified in 1908. It is highly infectious. During epidemics, 90 -95 % of people infected by the virus have no symptoms apart from a minor flu-like illness. Other people develop the disease but it does not result in paralysis. It is only 1-2% of patients who develop neurological problems and paralysis. Of this small number about 10% die during the initial illness, most frequently in those patients where paralysis affects the muscles required to breathe. About half of these patients make a full recovery. Therefore only 40 -50% of those with paralysis have long-term weakness.

Polio is initially a gut infection. It goes on to affect the anterior horn cells, that is, cells within the spinal cord which supply the muscles throughout the body. It also affects other areas of the brain, including the motor strip, and areas in the brain stem. A long nerve goes from the anterior horn cell to the limb supplying a number of muscles fibres, perhaps hundreds. When the cells are affected and the nerve stops functioning the muscles cannot work. The surviving anterior horn cells and nerves send out new terminal axons to supply the muscle fibres. The muscle fibres can then function as before. This compensation allows the muscles to retain strength although the neurones may be serving 7-8 times as many muscle fibres.[1]

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[1] From the keynote address given by Dr Pesi Katrak at the Network's Conference 'Managing the Late Effects of Polio, Canberra, August 1998

Treatment of Polio

The conventional method of treatment involved splinting affected muscles to prevent them from shortening and contracting. This even involved tying a child to a bed. A major controversy resulted from the work of Sister Kenny who recommended the use of hot, moist packs to relieve muscle spasm and physiotherapy to maximise the strength of unaffected muscles. Despite the controversy many of these techniques were later used. In some hospitals there was extensive use of 'no pain, no gain' types of therapy which were traumatic for some patients.

The experience of Polio

At meetings of the Post-Polio Network and its support groups the range of effects on the lives of the person and their families and the depths of the trauma endured by many are apparent as members describe their experiences.

Many contracted Polio as infants and young children and never knew the freedom of movement enjoyed by most children. Some were fortunate enough to have not been hospitalised and were cared for in the familiar and loving environment of their own home. Others were taken to "isolation" in infectious diseases hospitals, were too young to understand and, even if they were old enough to comprehend, were not told what was happening. They could only see their mother looking in at a window. Many spent perhaps several years in hospital when regulations only allowed weekly visits by your family and threats that even these visits would be stopped if you cried when they left. This separation combined with painful treatment has left emotional scars on many Polio survivors.

For those who were older children and adults, the pain and separation were compounded by the loss of the ability to perform many tasks and the loss of enjoyment of many familiar activities.

Living with the residual effects of Polio

The level of restriction to individual lives depended on the level of the residual effects. For some there was a history of special schools, a myriad of operations and a very restricted life.

For others their experience can be understood from this quote from one survey respondent:

My greatest hurdle has been not being 'disabled' and not being 'normal'. Just in limbo.

The drive to get rid of calipers and crutches and 'be normal' characterised the life of many Polio survivors and the stereotype of Polio survivors is that they are a striving, stubborn and achieving group of people or, as Professor Jones said, (see p.9) *"super-achievers"*.

The resilience and adaptability can be seen in the comment:
No problem on a bicycle although riding style is unorthodox! Pedal, pedal, pedal, pedal, pause, pedal, pedal, pause etc

THE INCIDENCE OF POLIO IN AUSTRALIA

National Figures

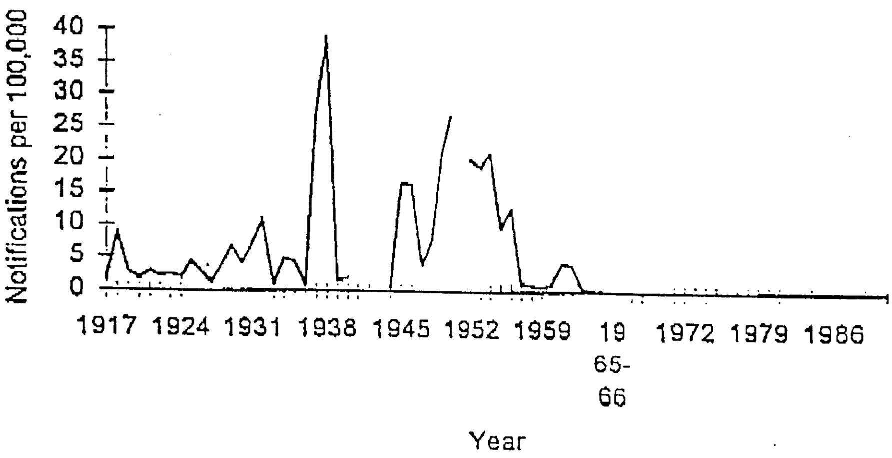
The first reports of Polio in Australian were around 1895.

Records are available, but not necessarily complete, from 1917. From 1922 it was a notifiable disease

The participants in this survey include some whose Polio precedes these records with one person who contracted the disease in 1915 and four whose 'Polio year' was 1916. Eighty years is a long time to have lived with one's disability - and still be able to share one's experience by completing a complex questionnaire.

The following graph (from *National Plan of Action for Certification of Eradication of Poliomyelitis in Australia Sept. 1997)* provides information on notifications expressed as the incidence per head of population. It shows a peak in 1937 -38. This was an epidemic which was at its worst in Victoria. There were 1,983 cases and it was said to be five times greater than the previous epidemic. There were extraordinary measures. Many schools were closed and children from them were not permitted to transfer to other schools. One hundred police were stationed along the border to check if cars entering New South Wales carried children who had been exposed to the infection or had attended one of the closed schools.*(Australia through Time 1993)*

Poliomyelitis notifications, Australia, 1917-1997



The 1937-38 peak is also apparent in the survey results.

The following table from *Medical Journal of Australia, Nov. 4, 1967* sets out national figures for the period 1950/51 to 1965/66. It shows the very high level of cases in the 1950 -56 period. This also is very apparent in our survey figures.

Notifications of Poliomyelitis

Year	Paralytic Polio	Total cases	Year	Paralytic Polio	Total cases
1950-51		3918	1958-59	78	98
1951-52		2729	1959-60	43	46
1952-53		2084	1960-61	174	192
1953-54		1836	1961-62	524	572
1954-55		1277	1962-63	38	40
1955-56		1314	1963-64	23	25
1956-57	186	236	1964-65	4	4
1957-58	20	21	1965-66	2	2

The figures cannot be comparable with those in this survey as:

- our survey uses raw numbers, not per population figures. There was a great increase in population between 1938 and 1952, which is the peak year in our survey.
- the above graph is based on Australia-wide figures whereas the survey participants are mainly New South Wales residents,apart from a possible few interstate members and the 22 participants from Bunbury in Western Australia [whose Polio was predominantly in 1954-56 when there was a major epidemic in that state] All New South Wales participants were not necesssarily born in New South Wales. In fact a number are from overseas and some are from interstate and suffered Polio when epidemics were greater in other states.
- the official figures should be relatively complete. Our survey figures only represent the people who were members of the Network in 1996-98 and who chose to participate. They do not include all those in New South Wales who have died in the last 80 years, those who do not belong to the Network and the approximately 50% of members who did not complete the questionnaire.

Introduction of vaccines

The need to eradicate this terrible disease led to work on vaccines. Salk vaccine was introduced to Australia in 1956. The dramatic decline in cases since that time is evident from the above table. There were 1,095 cases in the 60's; 11 in 1970-75 and 2 in 1977.

The last recorded case of Poliomyelitis caused by wild virus was in 1978.

It is thought that the total number of cases in Australia was about 40,000.

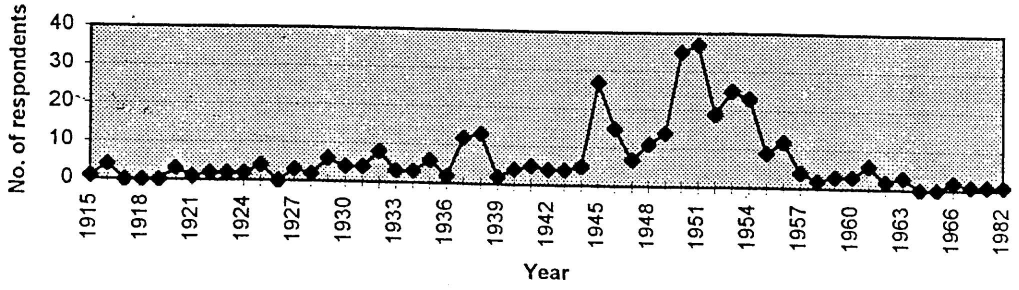
Survey results

The following table and graph show the year of Polio for survey participants.

Year Polio Contracted

YEAR	NUMBER	YEAR	NUMBER	YEAR	NUMBER
1915	1	1933	3	1951	37
1916	4	1934	3	1952	19
1917	0	1935	6	1953	25
1918	0	1936	2	1954	23
1919	0	1937	12	1955	9
1920	3	1938	13	1956	12
1921	1	1939	2	1957	4
1922	2	1940	4	1958	2
1923	2	1941	5	1959	3
1924	2	1942	4	1960	3
1925	4	1943	4	1961	6
1926	0	1944	5	1962	2
1927	3	1945	27	1963	3
1928	2	1946	15	1964	0
1929	6	1947	7	1965	0
1930	4	1948	11	1966	2
1931	4	1949	14	1967	1
1932	8	1950	35	1977	1
				1982	1

POLIO YEAR



THE RESIDUAL AND LATE EFFECTS OF POLIO AND POST-POLIO SYNDROME[2]

During the acute illness people experience paralysis and then, over a period of weeks or months, there is a gradual recovery of muscle function because of the process of the development of new neurones as described in the previous section. After the initial recovery over 6 - 8 months there is a stable period, with perhaps some paralysis, which may remain stable for the rest of the person's life.

Some people tend to get new symptoms about 35-40 years later. They develop a number of new neuro-muscular symptoms, particularly new muscle weakness, fatigue and pain in joints and muscles. This is referred to as Post-Polio Syndrome - 'an otherwise unexplained constellation of symptoms'.

This needs to be distinguished from Polio related problems, that is, symptoms which would normally be expected to occur with time from long-standing weakness, body asymmetry etc, such as a shortened leg leading to joint deformities or curvature of the spine. The distinction may be difficult to make.

The clinical features of Post Polio Syndrome are of three types:

- systemic
    - The most prominent symptom is fatigue (over 85%). This manifests in a lack of energy, heavy sensation in the muscles, loss of strength during exercise. The description is often given as 'hitting a wall'. Both physical and mental fatigue can be involved, including loss of concentration and attention.
    - Other systemic symptoms are increased sleep requirement, cold intolerance and dizziness.
    - New weakness in previously affected weak muscles and/ or in muscles which were normal from the person's perception. [Muscles may be working on half the normal nerve cells. They may feel as though they are working normally. The reduced number of nerve cells may be a cause of people getting new problems.]
    - Progressive respiratory insufficiency and increasing weakness in swallowing are less common.
    - Sleep apnoea is more common in Post-Polio patients.

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[2] Information in this section is based on the keynote address given by Dr Pesi Katrak at the Network's Conference 'Managing the Late Effects of Polio, Canberra, August 1998

- muscular-skeletal

    - Unexplained pain in muscles and joints

- neurological.

Medical surveys show that fatigue is the most commonly noted problem, followed by muscle and joint pain and new weakness.

The most common functional problems are difficulty in walking, climbing stairs and self-care functions such as dressing and showering.

The onset of symptoms is generally insidious but may be precipitated by a minor accident, a period of bed rest or weight gain.

The true incidence of Post Polio Syndrome is not known. New symptoms do not necessarily mean Post Polio Syndrome. The incidence of Post Polio Syndrome is probably about 25%.

It must be noted, however, that a much larger proportion of Polio survivors experience increased problems which are Polio-related but which are not technically diagnosed as Post Polio Syndrome.

Quotes from respondents to the survey reflect the experience of either Post Polio Syndrome or other Polio-related problems.

Use of transport etc is *pending on whether legs are working or not*

The problem which I and perhaps others struggle with which I call 'fading'. ...
I have never been able to do heavy work but managed most tasks with ever diminishing power over the years. I am able to do household tasks and other activities without difficulty and without help ... for a limited time only.

The GP and orthopaedic specialist has told me my condition has nothing to do with Polio. I just wore out. But I'm a bit young for this. [She is only 52]

Other comments which are included in the relevant section are very telling:

No interest or energy
Just coping from day to day
Handcrafts - still do but tire easily
No leisure
I still love walking but NOT as far as I used to
I have had to give up walking for pleasure; I find social activities too tiring in the evening
I no longer leave the house.

SURVEY OF MEMBERS

Purpose

In 1996 the Network Management Committee decided that it needed information on its members if it were to be able to provide supporting data in, for example, promotions, discussions with health authorities on services required and in applications for funding.

Questionnaire design

Network members have completed questionnaires previously in relation to research into the late effects of Polio and Post-Polio Syndrome and when undertaking an assessment at the Polio Clinic at Prince Henry Hospital. The Committee was aware that members are not enamoured of such questionnaires. Nevertheless it was determined that a survey would be undertaken.

It was decided that the questionnaire be restricted to four pages and kept as simple as possible. Simplicity was not readily achievable as the subject matter is so complex. When analysing the responses it became obvious that there were a number of issues which had been omitted in trying to achieve brevity and simplicity. It also revealed additional issues which are pertinent.

In designing the questionnaire it was considered desirable to have a similar response type for all questions eg all ticks or all numbers and numbers having similar meaning. This proved impossible as the questionnaire would have had to be made much larger or even more matters omitted..

The number of respondents who did not adequately cope with the changes in response type was relatively small and in most instances it was possible to understand the intent of the response even when different response types were used. In a few cases where ticks were used instead of numbers the meaning was not obvious and no response was recorded.

It was decided that the surveys would be confidential and names were not requested. A number, however, were not concerned and wrote their names on their forms or on attached notes.

Survey processes and response rate

A sample run of 30 questionnaires was distributed in August/ September 1996 and 21 were returned. Members were provided with an addressed envelope but this was not postage paid because of limited funds. Age was not asked in the first version.

Following examination of these responses some minor amendments were made and a questionnaire sent to all members in August/ September 1997. From this mail-out 287 completed forms were received - a response rate of between 40 and 50%.
Further forms were returned following a reminder some months later. In 1998 a form was sent to all members who had joined since August 1997 and from mid 1998 forms were sent to all new members. These brought to 350 the number of New South Wales respondents. Slight

membership fluctuations over the time span involved make an accurate assessment of the proportion of members responding not possible but the rate is nearing 50%.

These processes mean that the date of completion covers a two year period. This could have a minor effect on the age distribution but is unlikely to have any significant effect on other elements of the survey.

The WA Post Polio Support Group Bunbury (Inc) copied the questionnaire and gave it to its members. From this exercise 22 forms were returned and were sent to New South Wales for analysis and are included.

This brought the total number of respondents to 372.

It is possible that there is some 'doubling up' from the trial run. One known 'double' was deleted and only one other seemed to be an obvious repeat. It is unlikely that any doubling up of these respondents has had a significant effect on the overall analysis with the exception of the possible addition of one person to the under 40 age group which is the smallest age category.

In 1997 the Network's Hunter Area Post-Polio Support Group conducted a survey of its own members, A summary of the results is provided as Appendix 1.

The report is released for broader audience to draw attention to the needs of Polio survivors. To quote Professor Richard Jones (Director, Department of Rehabilitation Medicine, The Prince Henry and Prince of Wales Hospitals who established the Prince Henry Hospital Post-Polio Clinic) writing in 1996:

It is an absolute necessity that the difficulties being experienced by sufferers from chronic poliomyelitis be brought to the attention of the community at large and in particular, to family physicians and specialists alike, many of whom even today do not recognise the particular effects of poliomyelitis and that the Post-Polio syndrome is not just the attrition of age but a real entity with a neuro-physiological basis.

I would like to add that in my experience, the people whom I have come into contact with who had had poliomyelitis many years in the past have done their very best and perhaps have over-achieved, bearing in mind their physical limitations, to be independent in the community and to have become fully independent. One could say that they have been super-achievers and have certainly, in the vast majority of cases, never called upon the public purse for support. Perhaps their time of need is at hand and a very friendly helping had might be extended to those now in need.

BIOGRAPHICAL DATA

The following information was obtained from the introductory section of the questionnaire.

1. Sex

Table (i): The sex distribution of respondents

Male		Female		Unknow		Total	
No.	%	No.	%	No.	%	No.	%
136	37	214	58	22	6	372	100

The discrepancy between the numbers of men and women is consistent with the membership of the Post Polio Network (NSW) Inc in which the female membership is 65%.

The reason for this discrepancy can only be conjecture. Information on the sex of people who contracted polio has not been obtained. It is possible that there were fewer males who contracted polio but anecdotal evidence would not support this. Did more males die at the time of the initial illness? Only a search of hospital records would shed light on this.

The average lifespan of women is higher in Australia and among the older members the discrepancy between males and females may partially be a reflection of this.

Or is it just that men are less likely to join organisations or that they are less likely to think that they need help to deal with their difficulties?

The answers to these questions are only conjecture but the last issue is one of significance in the planning of support services.

2. Age

Table (ii): Age range of respondents

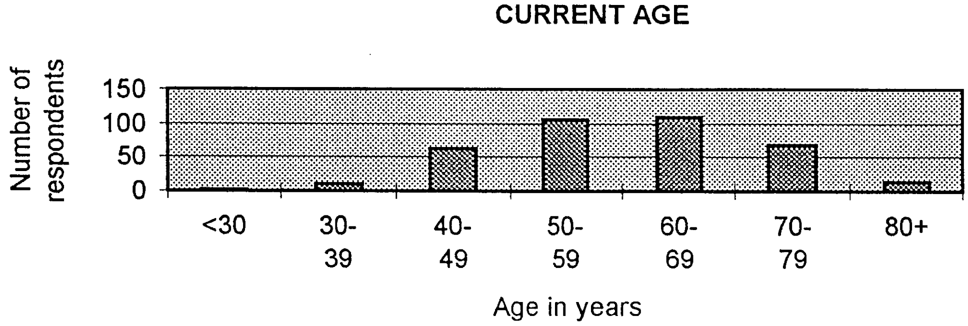
Age range	Number	Percent
80+	13	3.5
70 – 79	69	18.5
60 – 69	109	29.3
50 – 59	106	28.5
40 – 49	63	16.9
30 – 39	10	2.7
<30	1	0.3
No response	1	0.3
Total respondents	372	100

The average age of respondents was 59.9 years.

The older age range of respondents is expected. There have been no major epidemics of Polio in Australia for over forty years, so that even those who were infants at the time of their initial illness must now be in their mid-forties. Only those whose Polio was an isolated case or who have come to Australia after their illness are likely to be under this age.

A significant concern for Polio people and their carers is that the increasing problems of the late effects of Polio are exacerbated by the general effects of ageing. This results in major issues in the provision of care.

From the Network's perspective, it means that the proportion of members able to participate in its management and activities is relatively small and must decrease while their need for support will increase..



3. Age at Initial Polio Illness

Poliomyelitis used to be known as Infantile Paralysis. This name was associated with the idea that Polio generally affected young children.

While a very high proportion of respondents contracted Polio at a young age, this name is not entirely accurate as a significant proportion of respondents indicated that they contracted Polio at an older age.

In this survey:
- 257 (69.1%) contracted Polio by the age of 10;
- 65 (17.4%) between the ages of 11 and 20;
- 40 (10.8%) between 21 and 30 and
- 8 (2.3%) aged 31 and over.

The average age at which Polio was contracted is 9.1 years.

It is of interest, however, that in the small sample from Bunbury, Western Australia:
- only 5 out of 22 (22.7%) were aged 10 and under
- 9 out of 22 (41.9%) were aged 11- 20
- 8 out of 22 (36.4%) were aged 21 -30.

Anecdotal information suggests that the term 'infantile' was dropped in the epidemics of the 1950s because more adults were affected. The survey shows no person who contracted Polio before 1949 with an onset age over 20. It is not possible, however, to determine if there were fewer adult sufferers before 1950 or whether the lower participation rate in the survey is the result of ageing.

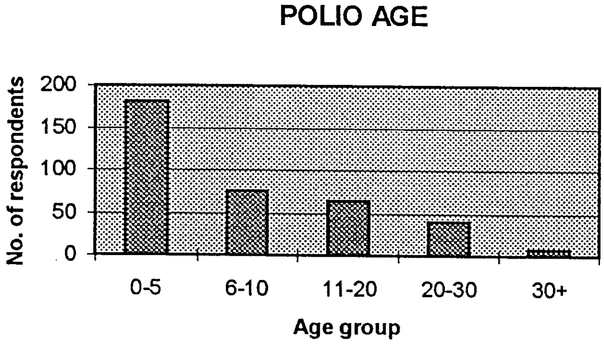


Table (iii): **Age at which Polio contracted**

Age range	Number	Percent
<1	19	5.1
1	35	9.4
2	31	8.3
3	33	8.9
4	29	7.8
5	35	9.4
6	15	4.0
7	23	6.2
8	17	4.6
9	8	2.2
10	12	3.2
11 – 15	32	8.6
16 – 20	33	8.9
21 –30	40	10.8
31 – 40	6	1.6
41 –50	1	0.3
50 +	1	0.3
No response	2	0.5

Total respondents: 372

Average: 9.1

QUESTIONNAIRE

ANALYSIS

Tables representing the responses to the survey questions

and

comments on this data.

SECTION 1: PHYSICAL CONDITION

a. The parts of the body affected by Polio

The range of effects of Polio on those who experienced it is very broad. No two Polio survivors seem to have the same groups of after-effects.

The aim of this question was to portray the range of disabilities as depicted by the portions of the body affected. While the number of areas of the body affected in each person has not been calculated, it was apparent while undertaking the data entry that most people had a range of areas affected, some being affected in every area of their bodies. The fact that the totals shown in the table are considerably higher than the number of respondents is indicative of the multiple responses.

The additional factor to be explored in this question relates to the effects of Post-Polio Syndrome and /or the late effects of Polio. As shown in the introduction many people who have had Polio experience new or intensified difficulties a number of years after the initial illness. These difficulties include muscle and joint weakness and pain. The question enabled people to show in which areas of their body they now experience difficulties where they had not done previously and in which areas their difficulties had increased.

The discrepancies between the responses reflect the new or increased severity of respondents' difficulties from the effects of Post-Polio Syndrome and /or the late effects of Polio. For those respondents who are younger and whose initial illness was only about 40 years ago it is possible that the late effects of Polio are not yet manifest and they could experience these effects within the next few years.

Separate calculations on the number of individuals experiencing new difficulties were not made but would be possible with further examination of the raw data.

Of course, if the initial rating is '3' any further deterioration cannot be shown.

There is a possibility that the proportion of people who have experienced increased difficulties in the hips and back reflects the relatively high incidence of problems of this nature in the general community. However, the figures are similar for both left and right leg/ foot where there is not the same level of difficulty within the general community.

The initial analysis has not included examination of factors such as how many people's effects are restricted to the upper or lower halves of the body; how many have unilateral versus bilateral effects or how many have cross-lateral effects such as right arm and left leg. These issues could also be explored with further examination of the raw data.

It is apparent, however, that the stereotypical view of Polio survivors as having only lower limb damage is far from the truth. While leg/ foot effects have the highest incidence by a significant amount, the high incidence of upper body effects counters the stereotype.

A complicating factor in analysing the data in this question is that some people showed a lower rating for their current than their earlier condition. This is contrary to the experience of most Polio survivors. It is not possible to tell, however, whether these respondents were considering their condition through most of their life compared to their condition soon after the initial illness.

For most Polio survivors there are four phases:

- the initial illness and treatment which can last from a few months to several years and in which the symptoms are at the worst;
- the initial recovery when mobility is regained and symptoms generally decrease;
- the period of maximum recovery which can last 30 - 40 years and
- the onset of the late effects of Polio or Post Polio Syndrome.

It is possible that some respondents mis-read the question and referred to the improvement from the initial illness to the recovery phase.

PHYSICAL CONDITION

1a The late effects of Polio

Which parts of your body are affected by Polio?
Most polio survivors have more severe problems at the time of their initial illness. They then improve and are at their best some time later. Years later some develop additional difficulties. Show your condition **when you were at your best (maximum recovery)** and **now**.

1 - Slight Little effect on your activity
2 - Moderate Causes restriction in activity
3 - Severe Paralysis, non-functioning or very restricted activity

Trunk

	Maximum recovery					**Current**					**Deterioration**		
	1	2	3	Total	%	1	2	3	Total		No.	% *	%**
Head neck/ face	163	18	12	193	52	122	77	8	207	57	76	37	20
Chest	145	31	12	188	51	118	71	14	203	55	57	28	15
Back	140	59	26	225	60	54	138	54	246	66	130	53	35
Abdomen	122	45	29	196	53	91	83	33	207	56	57	28	15
Hips/ buttocks	123	64	38	225	60	51	149	60	250	67	121	48	33

Lower limbs

	Maximum recovery					Current					Deterioration		
	1	2	3	Total	%	1	2	3	Total		No.	% *	%**
L leg/ foot	112	88	75	275	74	53	139	101	293	79	115	39	31
R leg/ Foot	108	82	78	268	72	47	139	103	289	78	127	44	34

Upper limbs

	Maximum recovery					Current					Deterioration		
	1	2	3	Total	%	1	2	3	Total		No.	% *	%**
L shoulder	142	27	26	195	52	90	93	32	215	58	87	27	23
Left arm	139	30	27	196	53	95	99	29	213	57	79	37	21
Left hand	145	25	22	192	52	115	65	29	209	56	68	33	18
R shoulder	148	19	24	191	51	99	91	25	215	58	86	40	23
Right arm	149	17	22	188	51	95	85	21	201	54	83	41	22
Rt hand	144	14	21	179	48	102	77	18	197	53	74	38	20

* People who showed deterioration as % of those Indicating difficulties with that part of body

** People who showed deterioration as % of total respondents

b. The nature of the difficulties experienced

People affected by Polio experience a range of common difficulties.

It might be expected from the obvious physical deformities and disabilities and the extraordinary demands placed on the less affected limbs that a person would expect to experience muscle and joint pain, muscle fatigue, and proneness to falling. On contemplation it should also be expected that breathing difficulties would be likely for those who had been in iron lungs or needed breathing assistance during their initial illness.

What an 'outsider' might not realise is the range of other problems which are common among Polios and experienced well in excess of the normal occurrence in the population. These include sensitivity to cold, sleep problems (including sleep apnoea), swallowing difficulties and changes in the voice.

Table 1b shows the incidence of these problems among respondents. While calculations were not made of the number of responses made by respondents only 4 did not mark any of the difficulties and the sheer number of total responses is indicative of the fact than many respondents indicated that they experienced anything from four to all of the difficulties.

The problem possibly most commented on by those commented on by Polio survivors, apart perhaps from reduced mobility, is general fatigue. The term 'hitting the wall' is used to describe the intense fatigue experienced. This fatigue is of a different qualitative nature from that experienced by those with, for example, chronic fatigue syndrome.

The high incidence of this problem is illustrated in Table 1b with 81.5% of respondents indicating that they experience unusual tiredness.

The incidence of some medical conditions such as hiatus hernia is thought to be more common among Polio survivors but these were not included in the questionnaire. Another factor not assessed is severe difficulty with weight control which seems in excess of what might be expected just from reduced mobility.

Comments

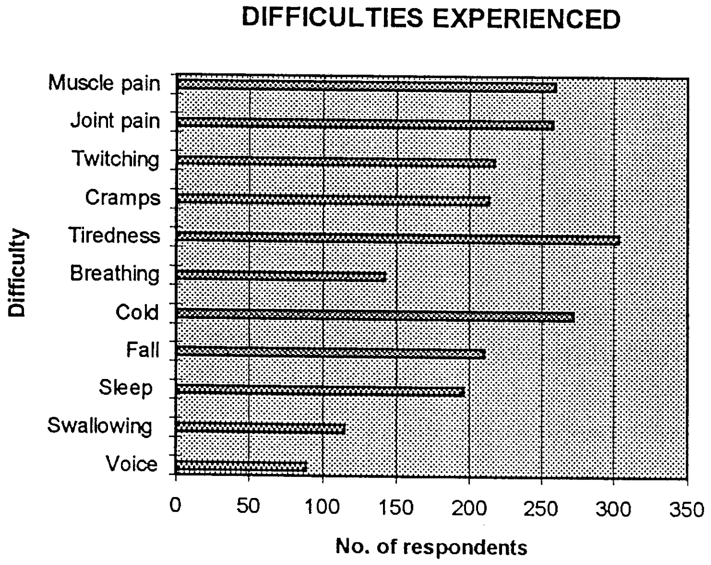
One person put three ticks against sensitivity to cold and another two and three ticks for tiredness, sensitivity cold and breathing difficulties
Hoarseness, loss of voice
Voice deeper, gave up choral society
Sciatica from worsening scoliosis

Table 1b: The nature of the difficulties experienced

Do you experience the following difficulties? Tick each which is appropriate.

Difficulty	Number of respondents	Percentage
Muscle pain	260	69.9
Joint pain	258	69.4
Muscle twitching	217	58.3
Muscle cramps	213	57.3
Unusual tiredness	303	81.5
Breathing difficulties	142	38.2
Sensitivity to cold	272	73.1
Tendency to fall	210	56.5
Sleep problems	196	52.7
Swallowing difficulties	115	30.9
Change in tone/quality/ loudness of voice	89	23.9
No response	4	1.1

Total respondents: 372



SECTION 2: MOBILITY AND AIDS

For the majority of Polio survivors who have lower limb damage the issue of mobility is an obvious one.

It is not as obvious, but equally as important an issue for those with back and arm difficulties, that walking may be difficult. Climbing stairs and boarding public transport vehicles can also be made more difficult for those with back and arm difficulties as it may not be possible to hold onto handrails and/or to carry bags while boarding.

Difficulties with transport are covered more fully in Section 8.

Table 2a provides an overview of mobility issues.

It is apparent from these figures that mobility is a major issue.

Just over 50% cannot even walk on level surfaces without difficulty and for 6% this activity, the easiest of all mobility activities for most people, is impossible.

Only around 16 - 17% are able to walk on uneven surfaces or climb stairs without difficulty and for around 13 - 14% these everyday activities are impossible. When one considers the number of buildings which have only stair access and that the majority of railway stations require at least one flight of stairs it is easy to see the severe restrictions on daily activities that mobility limitations can cause.

The questionnaire did not ask for additional information such as how steep the path is, how far one has to walk, how fast one can walk or how many stairs one can handle.

The matter of slippery surfaces is a factor which the Network raises when discussing building codes and access issues. These are readily negotiated by wheelchair users and therefore not considered as an access issue in many building code discussions but they are excessively dangerous and terrifying for many ambulatory mobility impaired people. This was another issue which was not included in the questionnaire.

Some of the comments added were:
Without difficulty only for short distances or time
But tire easily
Ramps difficult [and ramps are what are provided for disabled access]
Descending stairs is difficult
Stairs only if rail
Stairs and transport need care
Very short distances
I find ramps difficult, stairs I can manage

Table 2a: **Mobility**

1 - cause you no problem
2 - can be managed alone with difficulty
3 - can be managed with help of person/s
4 - are impossible for you

Activity	1	2	3	4	No Response
Walking - level surfaces	179	133	14	22	24
Walking - uneven surface	60	186	55	50	21
Climbing stairs	65	202	39	54	14
Boarding a bus/ train	107	126	38	73	28
No. of respondents: 372					

b. AIDS AND DEVICES

Paralysis, deformity and weakness resulting from Polio require people to use a variety of aids and devices in order to cope with everyday life, particularly with mobility.

Most Polio survivors were encouraged in the initial recovery phase to try to get rid of their devices - it was a sign of regaining 'normality' to discard wheelchairs, calipers and crutches. In hindsight it may be considered that this was inadvisable. For many people the increased wear and tear on, for example, the "good leg" may have been counter-productive, especially as it is now known that all parts of the body were affected even though only in some areas were the effects more obvious and more severe.

This philosophy of life is maintained by many Polio survivors and they are resisting the use of devices which would increase their ability to cope with the decreased mobility and increased fatigue of the late effects of Polio.

Table 2b shows the devices now used by respondents. While some added notes about the different usage at the time of the initial illness the question did not provide for obtaining information on this, nor on whether the devices have been more recently acquired because of new difficulties.

The numbers using devices is lower than might have been assumed from the percentage of members who attend Network functions who use aids but this may simply reflect the range of devices as the numbers are spread throughout the table. The number showing a nil response is only 21.5%.

It is a cause for concern that comments were added in a few instances to indicate that aids and devices are required but cannot be afforded. These comments related to, for example, scooters which can cost $3000 - $5000 but it is especially a concern when the comments relate to, for example, shoes which are expensive compared to those purchased by the general community but often 'only' around $500.'

Comments

Manual chair only if pushed
Crutches only when chair access is impossible
Mobility only when wearing caliper
Need crutches to walk at all but now shoulder problems mean no more crutches and little walking

Table 2b: **Aids and devices**

Indicate what aids and devices you use:
1 - all the time
2 - some of the time:

Device	1	2	Total	Device	1	2	Total
Special shoes	107	29	136	In-shoe orthosis	81	15	96
Ankle-foot orthosis	34	10	4	Walking stick(s)	69	72	141
Walking frame	14	6	20	Crutches	24	24	48
Knee brace/ bandage	15	21	36	Arm support	4	78	12
Caliper(s) / half	17	8	25	Caliper(s) / full	51	10	61
Corset (surgical)	20	8	28	Manual wheelchair	25	25	50
Electric wheelchair	14	8	22	Electric scooter	10	21	31
Breathing help (day)	3	6	9	Breathing help (night)	15	14	29
Iron lung	0	0	0	Nil			80
Total respondents: 372							

SECTION 3: HOME LIFE

Question 3 sought to elicit information on the extent to which the residual and late effects of Polio have limited respondents' ability to handle personal care and household tasks - those aspects of life which most people take for granted.

a. Personal care

The personal care section of the question suggests that it is only a relatively small proportion of the respondents who have very severe difficulties in these aspects of life as the number indicating that personal care tasks can be managed with help or are impossible for them is relatively low.

The number, however, who responded that these aspects of daily life are difficult for them (rating 2), combined with the ratings of 3 (can be managed with help) and 4 (are impossible for you), is indicative of the extent to which their disabilities impede normal life.

Around a quarter or all respondents cannot easily handle the daily essentials of getting dressed and getting in and out of bed. Over a third cannot easily handle the very personal activity of taking a bath or shower and significant numbers have difficulty with the toilet and with the basic communication tool of writing by hand.

The number who gave a rating of 2 or above is as follows:

- Getting dressed	95	25.5%
- Getting in and out of bed	94	25.3%
- Feeding oneself	22	5.9%
- Taking a bath or shower	137	36.8%
- Using the toilet	54	14.5%
- Writing by hand	63	16.9%

With both increasing age and any further difficulties from the late effects of Polio these people could well find their daily lives become very demanding. The increased time and effort involved when such tasks are demanding adds to the fatigue which is experienced by so many of these people.

It became apparent from comments written on some questionnaires that it would have been better to have separated taking a bath and taking a shower (eg bath - 4, shower - 2) and to ascertain whether the use of shower chairs were necessary. Many people with mobility disabilities cannot climb into a bath but can use the shower independently, especially if they use a chair and have special fittings. This information was not gathered in this question.

Comments

Bed has to be high, toilet built up and chair in shower
Need aids in bed, monkey bar, bed sticks and slide
Difficulty doing up button right shirt sleeve.

Table 3: HOME LIFE

a. Personal Care

Please indicate whether the following tasks:

1 - cause you no problem
2 - can be managed alone with difficulty
3 - can be managed with help
4 - are impossible for you

Activity	1	2	3	4	No response
Getting dressed	246	85	10	4	27
Getting in and out of bed	251	82	9	3	27
Feeding yourself	322	19	2	1	28
Taking a bath or shower	213	109	18	10	22
Using the toilet	290	46	5	3	28
Writing by hand	281	52	6	5	28
Total respondents: 372					

b. Household tasks

For all people who live alone or in any non-care situation it is generally essential to be able to handle everyday requirements of living such as cooking and most people prefer to do at least some of their household cleaning etc themselves, even if they have help for heavier tasks.

While the level of ratings 3 and 4 for light tasks and cooking are relatively low the number of responses at this level for heavier tasks is very high.

Nevertheless, the level of response with ratings of 2 - 4 combined for the most basic tasks of cooking, shopping, light household tasks and light gardening is reflective of the fact that most Polio survivors have difficulty with many of the daily tasks which most people take for granted.

The fact that over half indicated that they cannot handle shopping easily is highly significant.

Only 28 (7.5%) indicated that heavy household tasks cause them no problem and 27 heavy gardening.

The numbers who gave a rating of 2 or above are as follows:

- Light tasks	68	18.3%
- Heavy tasks	313	84.1%
- Light gardening	153	41.1%
- Heavy gardening	311	83.6%
- Cooking	91	24.5%
- Shopping	214	57.5%
- Car maintenance	167	44.9%

These issues have implications for services which are examined in Section 4.

The higher level of non-response in this question is distorting. In the case of 'light tasks' a page format factor may have been relevant but the non-response to the other items could reflect embarrassment or it could be that those who did not respond do not experience problems in this area. Another reason for non-response is that the person may consider the task irrelevant to them. They might not have a garden, There are also varying interpretations such as whether car maintenance means checking the oil or undertaking a full service.

Comments

Short time only on heavy tasks and *Limited time for each*
All relative to how tired I feel - sometimes too tired to cook and clean
Never tried heavy tasks

b. Household Tasks

Please indicate whether the following tasks:

1 - cause you no problem
2 - can be managed alone with difficulty
3 - can be managed with help
4 - are impossible for you

Activity	**1**	**2**	**3**	**4**	**No response**
Light tasks	191	50	12	6	113
Heavy tasks	28	85	64	164	31
Light gardening	151	80	26	47	68
Heavy gardening	27	78	47	186	34
Cooking	216	59	20	12	65
Shopping	130	113	69	32	28
Car maintenance	77	50	27	90	128
Total respondents 372					

SECTION 4: ACCOMMODATION

a. Housing

For any person with a mobility disability or with restrictions in handling household tasks, gardening and other practical tasks, housing is a major issue. Even something such as a small step can prevent a wheelchair user from accessing a house. Internal stairs may be prohibitive for an ambulant mobility impaired person. Kitchen design is particularly important for those who have difficulty lifting and holding utensils and bathrooms for those who, for example, cannot stand without their calipers.

It is apparent from the previous section that a significant number of Polio survivors have difficulty with personal care and household tasks.

Table 4a shows the housing situations for respondents.

The majority of respondents live in houses or units/ villas which would suggest that most have a reasonable level of independence, especially when the age of respondents is taken into account.

However around a third of respondents have required modifications to their homes. Very few have had financial assistance for undertaking their modifications which is just one more burden. A few commented that they needed modifications but could not afford them.

Around ten percent indicated that they have been restricted in obtaining accommodation by their disability. Comments indicated that stairs are the most significant issue in access but steep drive-ways and bathroom and kitchen accessibility were also regularly mentioned.

Comments

Putting off modifications
I do not like steep driveways and lots of stairs
Built house to suit needs
Modifications not done - lacking finance
Recently bought house with no steps
Need to find house with no steps and suitable bathroom and kitchen
Must be ground floor with no steps, ask landlord to alter. people don't like disabled
Seldom leave home for more than hour or two
Hostels prefer independent residents because of staff cut-backs
Doors, keys and taps are a problem
Accommodation restricted when travelling
Must be wheelchair accessible
Need unit with lift
Low set accommodation is more expensive
Must have at least one accessible entrance
I could not live upstairs or if a 1/16 ramp could not be installed
*Access and inte*rnal *space and width of doorways limit choices*

Table 4a: **HOUSING**

Do you live:

In a house
In a unit/ villa
In hostel with assistance
In a hostel - no assistance

	House	unit/ villa	hostel with assistance	hostel - no assistance	No response
Number	300	64	2	2	4

Do you live:

Alone
With family/friend(s)
In a care situation

Situation	Alone	With family/ friend(s)	In a care situation	No response
Number	73	264	14	21

Has your home needed modifications? Yes / No
If yes, were the modifications Minor/ Major

Modifications	Yes	No	Minor	Major	No response
Number	65	107	93	24	100

Did you have financial assistance for your modifications? Yes/ No

Assistance	Financial assistance	No assistance
Number	30	113

Has your disability restricted you in finding accommodation? Yes / No

Restricted	Yes	No	Not stated
Number	32	197	143

b. Assistance

The question asked whether people require and have various types of assistance. In addition to obtaining information on existing usage of services, the reasoning behind the question was that it could be deduced whether people lack access to assistance if they responded that they required assistance but did not have it.

A surprisingly small number of respondents indicated that they need meals on wheels and nursing assistance. The high number responding that they have live-in assistance and assistance with housework can be explained by the comments that assistance is provided by family members, especially spouses. There were a number of endearing comments such as *'my wife, my angel'*

When the responses shown in Section 3 are taken into account there must be concern that there is a great reliance on informal services. If the spouse dies or is less able to provide assistance because of ageing or illness then the Polio survivor may have difficulty coping with daily life under these circumstances.

Comments

Husband helps
Live in assistance is partner
Husband does housework
Unable to manage at all by myself
Cannot garden, need meals provided, help with housework, can't maintain upright position for long, shopping a problem
Care is wife
Assistance with housework is badly needed. My family help but visiting domestic help would be my greatest unfilled need.

Table 4b: Assistance

Do you require and do you have:

Live-in assistance
Meals On Wheels
Part-time assistance eg district nurse
Assistance with housework

Assistance	Require	Have	Lack
Live-in assistance	10	37	2
Meals On Wheels	2	9	0
Part-time assistance eg district nurse	9	11	5
Assistance with housework	49	106	14
Total respondents: 372			

SECTION 5: FINANCIAL MATTERS

The need to use aids and devices and the need for assistance with a range of aspects of life are likely to impose financial demands on Polio survivors. This question was designed to obtain information on the expenses which Polio survivors must meet and the financial assistance they receive.

Pharmaceutical and medical expenses

For many Polio survivors pharmaceutical and general medical expenses are not high. This probably reflects the fact that pharmaceutics are not a major factor in coping with the late effects of Polio. Definitions were not provided for what constituted "high", "medium" and "low" and the interpretations varied considerably. This may, to a large extent, reflect income and financial means.

For many respondents the reason for the low pharmaceutical and medical expenses is that health care cards cover or reduce their expenses as illustrated by comments such as 'costs would be high if I had to pay for them'.

Aids and devices

Anecdotal evidence would suggest that many Polio survivors face high costs in obtaining aids and devices. As with pharmaceutical and medical expenses definitions were not provided and the interpretations were more varied. A significant issue is the frequency of purchase.

Comments indicated that expenses may be very high when major purchases are required, for example a new wheelchair or scooter may cost up to $5,000 and ventilation equipment around $16,000 but these may not need to be replaced for many years. This made responding to the question difficult. Similarly shoes can cost perhaps $600 -$800 and calipers more but these are intermediate term purchases. One respondent commented that his/ her total in recent years was $17000 for chair, scooter and chair lift.

There were some comments which indicated that aids were made to last for many years, implying aids being used beyond their optimal usage.

While the number paying in excess of $1,000 per year is relatively low, for these people and those with high intermittent costs the expenses are personally significant.

On the other hand those who need oxygen have recurring high expenses.

A few respondents commented that the reason their costs are reduced is that their costs are partially met by, for example, Veterans' Affairs or that they have assistance from the PADP scheme or by medical insurance which is expensive.

Comments

New caliper $1,600 - repairs can be expensive - $200-$400
Full length caliper and sticks $1,500
Power chair cost $8,000
Total pharmaceutical costs 1996/97 financial year after rebates $3,350.
Costs low because do not buy new orthopaedic shoes every year
Replacement of ventilator every 10 years $16,000
Medical and pharmaceutical costs low but natural herbs, massage etc approx $100 per month
One off cost of respirator $8,000; $11000
Very different feet sizes - although I buy normal shoes I usually buy 2 pairs

FINANCIAL MATTERS

Are your medical and pharmaceutical costs generally?
High; Medium; Low
Give total amount if known (per month estimate)

Are the costs of your aids and appliances?
High; Medium; Low
Give total amount if known (per year estimate)

Pharmaceutical/ Medical costs	High	Med	Low	Nil or No Resp	Estimate (per month)		
					<$50	$50-$100	<$100
Number	53	115	177	27	92	32	31
Aids and appliances	High	Med	Low	Nil or No resp	Estimate (per year)		
					<$300	$300-1000	>$1000
Number	45	64	116	147	36	28	20

b. Financial assistance

Health care cards

The significant information gained from this question is that the only major source of financial assistance to deal with medical and aids costs is health care cards which many would be entitled to as age pensioners regardless of their disability. There are very few Polio survivors who have other forms of assistance.

Mobility allowance

An interesting phenomenon is the low incidence of Mobility Allowances. This allowance is available to those who are unable to use public transport and who are employed or doing significant hours of voluntary work. As can be seen in Sections 7 and 8 there are many Polio survivors who work and many who have difficulty with transport. It is apparent that there are many who either have not applied or have been rejected for the allowance. There are 12 people in full-time employment and 14 in part-time employment who rated use of public transport as 2 - 4, ie have difficulty with it, who do not have the Mobility Allowance.

Anecdotal information suggests that gaining the allowance is difficult and one respondent wrote:
Nearly impossible to get. Government very tight with mobility allowance.

Taxi allowance

A question was not included on taxi allowances and only one respondent added this in comments. These allowances provide for reduced costs for taxis for those who are unable to use other transport means.

Other assistance

The number of respondents who nominated any other sources of financial assistance is negligible.

b. Financial assistance

Do you have a Health Care Card?

Do you receive the Mobility Allowance?

Do you receive any financial assistance?
eg from Veteran's Affairs

Health Care Card	Yes	No	No resp			
Number		167	9			
Mobility Allowance		No	Taxi	No resp		
Number	34	321	1	16		
Other financial assistance	Yes	No	What DSP	VA	DSS	Other
Number	22	314	4	6	3	1
Total respondents: 372						

SECTION 6: RECREATION

Two aspects of recreation were assessed by this question - whether Polio survivors are restricted from participating in recreational activities and what activities they enjoy.

a. Restriction from activity

As might be expected for people with mobility and dexterity related physical disabilities, restriction from active or physical recreation and sport was a significant factor. The strength of this rating was particularly important with 84% of respondents indicating that they experience this restriction in their lives.

While the level of response was lower in relation to each of the other three types of activities they are also indicative of relevance to a large number of respondents. Practical tasks, as logic might suggest, had the second highest rate of restriction.

What might have not been anticipated was the fairly high level of restriction from social activities with 29% indicating that they experienced restriction from this type of activity. The importance of this is that lack of social activities can lead to isolation, lack of support to deal with the problems of one's disability and lack of informal practical support.

Comments

No interest or energy
Just coping from day to day
Walking if possible
Old time dancing - getting harder because of crook hip
Can't sit long enough for movies or long train trips
Line dancing when able
Handcrafts - still do but tire easily
No leisure
I still love walking but NOT as far as I used to
Restricted due to lack of accessible facilities
I have never contemplated sport so I don't even do regular exercise eg strengthening abdominal muscles for walking
I have had to give up walking for pleasure; I find social activities too tiring in the evening

RECREATION

Table 6a. **Restriction from activity**

Does your disability restrict you from participating in activities?

Active/ physical recreation/ sport
Practical tasks such as mechanics and woodwork
Handcrafts such as knitting, embroidery
Social activities

ACTIVITY	Number	Percent
Active/ physical	313	84.1
Practical tasks	165	44.4
Handcrafts	69	18.5
Social activities	107	28.8
No response	9	2.4
Total respondents: 372		

b. Leisure activities

Table 6b shows the range of activities pursued by respondents. As can be seen activities are many and varied, and not all are sedentary as some might expect from people with physical limitations. The frequency of reading and music as activities may simply reflect the general community situation or may be that these activities can be more readily pursued by those with physical limitations.

The comments were also varied and add to the total picture. Some people wrote that they had difficulty pursuing any activities because of their Polio-related problems.

Others wrote that they have had to give up activities because of their increasing problems or that their activities could only be intermittent according to their physical condition.

Yet some could nominate activities which are very physically demanding.

Table 6b: **Leisure activities**

What are your main leisure pursuits?

Activity	No.	Activity	No.
Reading	135	History/ genealogy/ research	4
Art/ Handcrafts	96	Scientific	4
Gardening/ horticulture / farming	56	Camping/ caravanning	4
Active sports	40	Sports administration	4
Family/ friends/ dining	34	Collecting (stamps. coins etc)	3
Television/ radio	33	Dancing	3
Swimming/ hydrotherapy	32	Adult education/ study	3
Music	31	None	3
Community work/ church activities	28	Spectator sport	2
Walking/ bushwalking	25	Thinking/ Meditation	2
Computer	21	Relaxing/ sedentary	2
Movies/ videos	20	Exercise	1
Mechanical/ technical	18	Current affairs	1
Writing	17	Study	1
Travel / touring	16	No response	63
Fishing	16		
Concerts/ theatre	14		
Cards/ bridge	13		
Singing/ choir / instrumental	10		
Driving/ outings	11		
Cooking	9		
Photography	7		
Crosswords/ puzzles	7		
Bingo/ backgammon/ mahjong	5		

SECTION 7: EMPLOYMENT

In the Australian community employment is a defining aspect of life. One's status and income are both inherently linked to one's employment. People with a disability are over-represented among those who are either not in the labour force or who are unemployed.

The aim of this question was to ascertain whether Polio survivors have been able to maintain employment or whether their employment has been affected by their Polio related difficulties.

The analysis is complicated by the fact that the age range is narrower than the general community and a higher proportion of Polio survivors are older and may well have retired as a normal matter of course. The older women among the respondents may also have been in the situation of not being involved in the paid workforce because it was less common for women to take paid employment outside the home in the times in which they were of working age.

Cross-referencing for age was not undertaken but would be possible from the raw data.

There are a number of issues which are apparent from the responses that are of major significance:

- Of the small group of people who indicated that they have never had paid employment the majority stated that this was for Polio-related reasons.
- Of those who have retired from work approximately half stated that this was for Polio-related reasons.
- Of those who are considering leaving work nearly three quarters stated that this is for Polio-related reasons. . Some comments also were inserted to indicate that they had reduced their hours of work or changed occupations for Polio-related reasons.

There are also other difficulties. One person wrote: *If in paid employment you lose benefits after one year. A high needs person might have to give up employment because of the cost of equipment replacement.*

In the Bunbury Group the only person who was employed was a semi-retired self-employed person.

Comments

Self-employed but have to do less; and not considering leaving work but do less
Had to cease full-time because of post-polio
Reduced hours because of tiredness
Gave up because of no help with equipment if you work
Couldn't go back to nursing;
Couldn't get into teachers' college
... not interested in me now - access problems due to wheelchair

Table 7: Employment

Are you currently in paid employment? Full-time / Part-time
Or are you currently seeking employment?
Have you ever had paid employment?
    If no, was this because of polio-related difficulties?
Have you retired from paid employment
    If yes, was this because of polio-related difficulties?
Are you considering leaving work?
    If yes, is this because of polio-related difficulties?

Currently in paid employment			
Yes	No	Seeking empl't	No response
114	245	4	13
Full-time	Part –time	Not stated	
66	44	4	
Ever had paid employment			
Yes	No	Polio related	No response
332	16	9	24
Retired from paid employment		Yes	Polio related
		208	98
Considering leaving work		Yes	Polio related
		37	29

Aspects of employment

Issues about the work situation were covered in the questions on lack of satisfaction and on discrimination. These questions elicited the following information:

- A small but not insignificant number (12%) indicated that their lack of satisfaction with work was for Polio-related reasons.
- A small number but not insignificant number (14%) indicated that they had suffered discrimination in obtaining or maintaining their employment.

Table 8b reflects these issues and also whether people are involved in home care and in voluntary work. The large number who undertake voluntary work is indicative of the fact that many Polio survivors have attempted to play their full part in the community despite their physical limitations. Some respondents commented that they had had to give up their voluntary activities due to their Polio related difficulties.

Table 8b

Do you undertake voluntary work?
Are you involved in home duties and/or caring?
If you have not been satisfied with your employment was this because of your disability?
Do you consider you have suffered from discrimination in obtaining/ retaining employment?

Voluntary work	Yes	No	No response
	139	144	89
Home duties	Yes	No	No response
	182	104	86
Not satisfied with employment	Polio related	Not Polio related	No response
	46	145	181
Suffered from discrimination	Yes	No	No response
	52	248	72

SECTION 8: TRANSPORT

For all people the ability to be mobile in order to access employment, services and social activities is important. In a country as large as Australia and with our major cities being large and spreading this takes on an extra significance. This question aimed to ascertain whether Polio survivors are restricted in their access to transport and in their ability to drive themselves.

Table 8 contains some highly significant figures:

- Only just over one third of respondents are able to travel by bus without problems and a slightly higher number are able to use trains or ferries without problems.
- For 20% of respondents buses are impossible even with help and trains and ferries are impossible for around 15%
- For a small number even travel in an ordinary car is not possible and for another group this can only be managed with help.
- For two people even travel in a special taxi is impossible and others need help for this special transport.

The limitations on the lives of these people must be enormous. One comment was *I no longer leave the house.*

An additional issue is the cost of transport. An item on car conversions and their costs was not included. Automatic transmission and power steering which are essential for many Polio survivors to be able to drive themselves now tend to be standard or optional without increased costs. This was not the case in earlier years and this change has been very beneficial to those who could not readily afford the additional cost. They are not, however, as common in older cars which may be all some people can afford.

The cost of taxis for those who cannot access public transport was addressed in Section 6.

Several respondents noted that a question was not included about air travel and supplied comments.

Transport is very difficult and expensive especially flying - lack of aid in boarding and disembarking aircraft.
I find airlines very helpful with airport wheelchairs
Cannot use toilet on planes

This is the section in which the most comments were added, a selection of which is shown.

Re public transport:

Cannot stand too long in public transport
Stairs at railway stations difficult and steep walk at ferry
Lack of toilets at railway stations difficult because of incontinence
Stairs a no-no hence trains and buses almost impossible
Public transport promises much, delivers little to disabled people
Buses difficult if not low floor / Cannot manage high step into buses
Would not work if it was necessary to use public transport
Train stations and ferry wharves are not always 'accessible' (steps and long ramps)
The stairs at railway stations are a problem and the steep walk up from local ferries as I get short of breath
Train travel is impossible mostly because of the many stairs and long distances to walk
Lack of public toilets at many suburban railway stations is in many ways fully as restrictive to someone with incontinence as lack of special access to those with limited mobility
I need to use hand grips to enter trains and buses

Re driving:

Short trips only - would not survive in city
Planning auto and power steering for next car
Power steering would be beneficial because of difficulty parking in tight spot
Need auto because manual made weak leg weaker or it became weaker
Use right leg for accelerator, left for brake
Major difficulty lifting legs into car
Transferring from wheelchair to car has become a major difficulty
Need auto but don't have due to lack of money
I need hand controls but can't afford them; I think all disabled people should get a car allowance, can't use most public transport
My car is my life line and I love it
Am considering 4WD - getting harder to lift myself up out of normal (low) sedans. Shoulders/ leg find the angles difficult but than I can't stand up to wash the thing
Have just become aware that power steering can be 'helpful' as my arms become weaker
Specially fitted front seat for greater space and easier control
Can't afford another car so have to make do without power steering
Can drive a manual but it's now too hard - too much work and very painful
My first two cars (manual) had special pedals for clutch and accelerator
Coping at the moment, use only locally. Disabled parking sticker helps with carrying
I can't drive any more/..... I no longer drive because sitting causes pain, leg cramps
In the interest of safety I gave up my licence / Cannot use left leg for gear change
No difficulty if parking available and walking level and accessible
Due to my recent weakness I now need power steering and brakes to drive safely
40 years ago I could not drive without expensive modifications. I have not tried since
When I can afford it I have to trade my present car for auto transmission as I now miss my gear changes
As I do not have proper co-ordination I do not drive very much
When having back problems everything I s *impossible, or almost, as I cannot walk*
Wheelchair cannot fit in car ../ ....Difficulty getting in and out of car
Power steering would be very beneficial as I have problem when parking in a tight spot
Never had confidence to drive due to polio effects

Table 8: TRANSPORT

Use this scale to indicate your ability to undertake these forms of travel:

1 causes you no problem
2 can be managed with difficulty
3 can be managed with help
4 is impossible for you

Activity	1	2	3	4	Not stated/ not applicable
Travel by bus	134	103	33	75	27
Travel by train/ferry	145	79	40	57	51
Travel by ordinary car/taxi	260	53	29	5	25
Travel by special taxi	122	13	16	2	219
Drive a modified car	97	12	3	25	235
Drive - non-modified car	201	38	2	47	84
Is it necessary to have automatic transmission			Yes	No	Not stated
			214	83	75
Is it necessary for your car to have power steering			Yes	No	Not stated
			155	137	80

SECTION 9: SERVICES

In this section respondents were asked to indicate which medical and para-medical services they have used.

In the interests of simplicity they were not asked about the frequency of their use of the services or of the time span involved. For example: Was their use mainly at the time of their initial illness? Is it now when their problems are increasing? or Has it been a regular usage throughout their lives?

Nor were they asked whether the usage was specifically related to the Polio-related difficulties

As with the general community, contact with general practitioners is almost universal. While comparative figures for the general community were not obtained, it would appear that the levels of usage of orthopaedic and rehabilitation specialists and of specialist physicians and neurologists are well above an expected community average.

Usage of those professionals who deal with mobility issues and physical aids is, not surprisingly, high with around two thirds having used physiotherapists and high usage of chiropractors, orthotists and bootmakers and, to a slightly lesser extent, occupational therapists.

The number contacting naturopaths and acupuncturists may suggest that Polio survivors do not consider they get the help they need from traditional medical services.

Only a relative small number have used counsellors. This may reflect the feeling expressed by many Polio survivors that only other Polios can understand their problems.

Under the heading of "other" the practitioners mentioned included osteopath, massage therapist, speech therapist, psychiatrist, urologist, heart specialist, hypertension specialist, rheumatologist, respiratory specialist specialising in sleep disorders and hydrotherapist

No attempt was made in this survey to address the issues regularly raised about the lack of understanding of the late effects of Polio among medical and para-medical professionals, nor of the availability of suitable services. These are major issues beyond the scope of this survey and have been considered as the topic for a separate project. There were, however, several respondents who added comments indicating that they have experienced a lack of understanding among the practitioners whom they have contacted.

GPs don't know enough to refer.
Mostly unaware or lack information on Post Polio Syndrome

Table 9: **Services**

Have you used the services of the following practitioners?

SERVICE	NUMBER	SERVICE	NUMBER
General practitioner	366	Orthopaedic specialist	205
Rehabilitation specialist	115	Neurologist	94
Specialist physician	163	Counsellor	32
Occupational therapist	80	Chiropractor	111
Physiotherapist	251	Naturopath	61
Podiatrist	132	Acupuncturist	84
Orthotist	112	Bootmaker	144
Other	38	Massage	6
Osteopath	5	Rheumatologist	2
Total number of respondents:372			

APPENDIX 1

HUNTER AREA POST-POLIO SUPPORT GROUP

SURVEY STATISTICS

AGE OF MEMBER

Age	Number	Percent
45 - 49	1	3
50 - 54	6	16
55 - 59	10	26
60 -64	4	11
65 - 69	8	21
70 - 74	6	16
75 - 80	3	8
Total	38	100

AGE CONTRACTED POLIO

Age	Number	Percent
0 - 4	17	45
5 - 9	10	26
10 - 14	4	11
15 - 20	2	5
20 +	2	5
No comment	3	8
Total	38	100

YEAR CONTRACTED POLIO

Year	Number	Percent
1920 -24	3	8
1025 -29	4	11
1930 -34	1	3
1935 -39	4	11
1940 -44	2	5
1945 -49	10	26
1050 -54	11	29
Total	38	100

DURATION OF HOSPITALISATION

Time	Number	Percent
0 - 3 mths	8	21
4 - 9 mths	6	16
10 - 18 mths	2	5
18 mths +	5	13
No comment	17	45
Total	38	100

DURATION OF SCHOOLING MISSED

Time	Number	Percent
1 - 12 mths	6	16
1 - 2 yrs	5	13
3 - 4 yrs	3	8
No comment	24	63
Total	38	100

DID POST-POLIO SYNDROME CAUSE EARLY RETIREMENT

	Number	Percent
Yes	11	29
No	16	42
Partly	3	8
No comment	8	21
Total	38	100

MOBILITY AIDS REQUIRED

	Number	Percent
Yes	17	45
No	17	45
No comment	4	11
Total	38	100

DOES SURVIVOR DRIVE

	Number	Percent
Yes	27	71
No	7	18
No comment	4	11
Total	38	100

HOUSE MODIFICATIONS

	Number	Percent
Yes	8	21
No	24	63
No comment	6	16
Total	38	100

CARER REQUIRED

	Number	Percent
Yes	28	74
No	5	
No comment		
Total	38	100