Survey of the Late Effects of Polio in Lothian

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CONTENTS

1. SUMMARY

The Edinburgh Branch of the British Polio Fellowship (BPF) expressed the concern of members that the medical and related professions often appeared unfamiliar with the late consequences of polio and that services were not meeting their needs. In an attempt to determine the number of people affected and the nature of their experience, this postal survey was done in 1998.

A set of questionnaires were sent to 221 people, in Edinburgh and the Lothians, who had been identified as suffering polio in the past from those known to the BPF and hospital records. There were 125 replies which constituted the study population: 60% were female; the median age was 59 years; and the median time since original diagnosis was 51 years.

Common symptoms were: cold intolerance (70%); fatigue (66%); increased weakness in previously affected muscles (67%); new weakness in unaffected muscles (60%); muscle pain (64%); joint pain (61%); and joint stiffness (64%). These symptoms were often of recent onset. Other complaints included sleep disturbance (63%); exertional breathlessness (56%); headaches (33%); and swallowing difficulty (18%).

In terms of disability: 78% had difficulty with stairs; 72% with walking and 70% with bending. This was reflected in over a third reporting difficulty getting outdoors without help. Motor problems affecting upper limbs were present in over half the subjects. Daily activities were restricted because of severe pain in 38%. Over half (55%) the study population described difficulty living alone. The major factors restricting the lives of the subjects were physical problems, lack of energy and pain.

During the preceding 5 years, contact with health services were: hospital clinic 62%; physiotherapy 46%; occupational therapy 29%; speech therapy 2%; orthotics 40%; and wheelchair service 42%. The majority described satisfaction with these services but further study is warranted.

A conservative estimate is that there are about 300 people in Edinburgh and the Lothians with the range of difficulties demonstrated in this study and we suggest that special provision is made for them.

2. INTRODUCTION

2.1 Background & General Aim of the Survey

The Edinburgh Branch of the British Polio Fellowship (BPF) made representations to Lothian Health Board and at public meetings of Edinburgh Healthcare NHS Trust (EHT) expressing the concerns of members regarding the lack of specialist advice for health and related issues. People who had been affected by polio in childhood or early adulthood in the epidemic of the past reported a number of common symptoms and functional difficulties which had become apparent in their later years. In contrast to the expert advice available to them when initially affected by polio, many found that most health and related professionals (e.g. doctors, surgeons, therapists and social workers) appeared to have no or inadequate knowledge of the late effects of the condition.

They expressed a desire for a specialist service designed to address these issues. However little was known of the size or exact nature of the difficulties experienced and of how widespread was the dissatisfaction with current services.

The Rehabilitation Studies Unit (RSU) agreed to assist with a postal survey to try to determine the frequency and nature of symptoms and their consequences and the experience of use of health services by people with polio in Lothian.

2.2 Rationale Behind Survey Design

Poliomyelitis was a major cause of mortality and morbidity in Scotland until the introduction of effective vaccination in the mid 1950s. Those who survived the acute infection often endured a challenging and prolonged period of rehabilitation initially with considerable contact with health and related services at that time. These people, some 40 or more years on, describe a variety of symptoms and functional problems which may be referred to as the late effects or consequences of polio (Dalakas, 1995; Halstead & Grimby, 1995). These symptoms include new respiratory, neurological, musculoskeletal and other complaints. The term post-polio syndrome (PPS) has been adopted by some to cover all these features (Leboeuf, 1990) while others have recommended that it be restricted to those who have a progressive muscular weakness developing at least 15

years after reaching maximum recovery from the initial infection (Dalakas et al, 1986; Kidd et al, 1997). It is debatable as to whether there is a distinct clinical entity or whether there are a range of syndromes (Halstead & Grimby, 1995).

The literature on late consequences of poliomyelitis has increased considerably in the last 10-15 years, particularly following the first international conference on the subject in the U.S.A. in 1984 (Halstead & Wiechers, 1985). It is worth noting that some late symptoms have been recognised for over a century (Agre et al, 1989). Particular attention has been focused on the respiratory system with reports of recurrent chest infections, breathlessness and sleep apnoea (Lane et al,1974; Howard et al, 1988; Kidd et al, 1996); the neuromuscular system with muscle weakness, wasting fasciculation and a disorder like motor neurone disease involving both limb and bulbar muscles (Zilkha, 1962; Mulder et al,1972; Howard et al, 1988); and skeletal disorders such as fractures, joint and back pain (Cosgrove et al, 1987; Kidd et al, 1997). In addition there have been descriptions of headaches, mental confusion, irritability and sleep disturbances often related to respiratory changes (Howard et al, 1988; Kidd et al, 1997). Prominent complaints associated with the above symptoms are fatigue and weight loss. A frequent complaint is of cold intolerance especially in the affected limb.

In designing the symptom questionnaire the desire for a comprehensive approach had to be balanced with avoiding such a long list of possible symptoms as to dissuade individuals to complete it. Care was also taken to try to avoid invoking unnecessary anxiety in subjects who might be unaware of some of the potential symptoms. The Edinburgh branch of the BPF were most helpful in both suggesting and modifying this questionnaire.

As important as identifying the common symptoms or impairments it is essential to consider the functional consequences in terms of disability. The Office of Population Consensus and Surveys (OPCS) Questionnaire, used for a national survey of disability in the UK (Martin et al, 1988), has been recommended for community surveys aimed at establishing the prevalence of disability (Wade, 1992).

In addition to determining any disturbances of daily activities that may result from a disabling disorder, it is important to try to gauge how the individual views its effect on their health status. The Short Form Health Survey (Ware & Sherbourne, 1992), usually

referred to as the Short Form 36 or SF-36, is one of the most reliable and widely used instruments designed for this purpose (Jenkinson et al, 1996). The use of SF-36 would also allow the possibility of comparison of the post-polio population with other diagnostic groups and the general population.

The final component of the survey was devised to get information regarding contact with hospital or general practice based services in the preceding 5 years with some details of relative satisfaction with the services. Subjects were also asked to identify services that they had not had access to but with which they would have liked to have been able to have contact. The choice of which services to address was determined largely on the advice of the BPF.

3. METHODOLOGY

3.1 Study Population

The principal source of subjects for the questionnaires was the BPF, Edinburgh Branch which services Edinburgh and the Lothians but also has membership from Fife, the Borders and elsewhere. It was decided to limit the survey to those from Lothian (i.e. with an EH postcode).

In addition patients known to the Wheelchair Service and neurorehabilitation clinics of the Rehabilitation Directorate, Edinburgh Healthcare NHS Trust were included.

3.2 Questionnaires

Each subject was sent a letter informing them of the nature of the study assuring them of the confidentiality of the data collection and handling; a set of questionnaires and an SAE for return of completed questionnaires. Copies of the letter and questionnaires are included in Appendix 1.
The four questionnaires were as follows:

i) Symptoms Questionnaire
ii) OPCS Disability Questionnaire
iii) SF-36
iv) Use of Services Questionnaire

Only a single mailing was done on the grounds that the questionnaires were unsolicited and were sent to individuals who might have had minimal contact with services and might, therefore, object to repeat mailings.

All data were number coded and dealt with under the regulations of the Data Protection Act.

4. RESULTS

4.1 Response Rate

A total list of 221 people were sent the questionnaires and 142 (64%) were returned. Of these, seventeen were returned unanswered: in 11 cases the person was no longer at that address; 3 people had died; in two cases there was a note from a friend or relative to say that the individual could not complete it and in one instance the diagnosis of polio was incorrect.

Thus the final study population was 125.

Of these one individual only answered the symptom questionnaire and one other answered the other three questionnaires but omitted the symptom questionnaire.

4.2 Demographics

Of the 125 subjects: 75(60%) were female and 50(40%) were male.

The median age was 59 years; (mean 61; range 40-91 years). The median time since original diagnosis of polio was 51 years; (mean 54; range 23-89 years).

Thirty six (29%) of the subjects were currently attending a hospital clinic. This included orthotic clinics and in some cases was not related directly to polio but to other medical or surgical conditions.

4.3 Symptoms [Symptom Questionnaire]

Tables detailing the frequency of each symptom are included in Appendix 2. Only one individual, a 56 year old woman who had suffered polio at the age of 10 years, reported having none of the symptoms listed.

The following summarises the main findings.

i) *Respiratory*

Thirty seven people (30%) reported suffering a chest infection for which they had received antibiotics in the preceding year. In 14 cases (11%) there had been recurrent chest infections. Although recurrent chest infections were most common in those aged 70-79 years with five in this decade; two people aged 40-49 years, four aged 50-59 years and three aged 60-69 years also noted repeat episodes of chest infection treated by antibiotics.

Shortness of breath in bed, or rest dyspnoea, occurred in 19 (15%) while exertional dyspnoea was present in 70 (56%). Eight of the 19 with rest dyspnoea and 24 of the 70 with exertional dyspnoea stated that these symptoms had been present for less than five years.

ii) *Falls & Fractures*

In the preceding year 51 people (41%) reported a fall and in 35 this had occurred on more than one occasion. Fractures had been suffered by 13 (10%) of the study population and seven individuals had had fractures more than once. Other minor injuries as a result of falls were reported by 34 people and this was a recurrent problem for 19 of these.

Falls were distributed throughout the age range of 42 to 91 years. According to the following decades the number reporting falls were: 40-49 years: 12; 50-59 years: 13; 60-69 years: 10; 70-79 years: 12; 80-89 years: 3; 90-99 years: 1.

iii) *Musculoskeletal*

Table 4.1 summarises the frequency of musculoskeletal symptoms. Increased muscle weakness in affected muscles was noted in two thirds of patients (67%) and almost as many (60%) described weakness in unaffected muscles. Twitching or flickering in the muscles, cramps and other muscle pains were also common, occurring in almost half the population (42%, 45% & 49% respectively). If one considers the number of individuals who had either cramp or other muscle pain the total was 80 (or 64%) of the 125 respondents.

Joint pain; joint stiffness; and decreased range of joint movement affected almost two thirds (61%, 64% and 63% respectively) with increased joint instability in just over half the population (52%). As can be seen from Table 4.1 these symptoms were all reported as of relatively recent onset in a significant proportion of those who recorded the duration of their symptoms.

Table 4.1: Duration of musculoskeletal symptoms (n =125)

SYMPTOM	<5 years	6-20 years	>20 years	Unspecified	Total
Increased weakness	42	20	6	16	84
Weak previously unaffected muscle	38	18	5	14	75
Twitch/flicker	23	10	6	13	52
Cramp	20	6	11	19	56
Other pain	22	16	4	19	61
Joint pain	33	21	8	14	76
Stiffness	39	18	7	16	80
Reduced range	35	20	6	18	79
Joint instability	30	13	6	16	65
Back Pain	31	21	13	11	76
Neck pain	29	12	3	6	50

Back pain occurred in 61% and, again, in a substantial number 31 (48%) of the 65 who stated how long they had had the symptom, it had only been present for less than five years. Although neck pain was slightly less common, affecting 40% of respondents, it was also often a problem of recent onset.

iv) *Sleep*

Difficulty getting to sleep, initial insomnia, was recorded in 43 (34%); frequent waking, sleep fragmentation in 56 (45%); and early morning waking in 58 (46%) of the respondents. A total of 79 people (63%) described having one or more pattern of sleep disturbance. Although in some people such problems had been present for over 20 years,

disturbance of sleep pattern had been present for less than five years in 46 (55%) of those who specified the duration of the symptom.

v) *Confusion, Irritability and Headache*

Only 11 people (9%) were aware of episodes of mental confusion. However only four of these individuals were aged over 70 years; four were between 40 and 49 years of age and the remaining three between 50 and 69 years. Five of the 11 said it had been present for less than five years.

Irritability was present in 37 (30%) and reported as a recent problem in half (18) of these, only being described as present for more than 20 years in four people.

Forty one (33%) described headaches. Twenty respondents failed to indicate how long this symptom had been present but 11 indicated that it had been for less than five years; six for between 6 and 20 years and four for longer than this. The frequency and time of day of headaches is summarised in Table 4.2.

Table 4.2 : Pattern of headaches (n=41)

How often	**Daily**	**> 2 per week**	**weekly**	**1-4 per month**	**> 4 per month**
	5	9	5	17	5

Time	**Morning**	**Evening**	**During night**	**Anytime**
	5	2	0	34

It should be pointed out that the Symptom Questionnaire contained an error in that the final question regarding frequency of headaches should have been "<4" rather than ">4" attacks per month. The results are given as reported in the questionnaires returned.

vi) *Speech & Swallowing*

Six individuals (5%) had noted speech changes and in three this had been present for less than five years. Swallowing difficulty or choking was, however, reported by 23 (18%) and, in the nine of the 16 who specified the duration of these symptoms, they had been present for less than five years.

vii) *Weight Loss*

Fourteen (11%) report weight loss. This had been noted over the preceding year by three individuals and for one to five years in a further five.

viii) *Cold Intolerance*

The most commonly reported symptom, present in 87 (70%) of respondents was intolerance of cold in affected limb(s). The great majority of those in this group who indicated the duration, 58 (91%) of 64, had suffered this for over 5 years.

ix) *Fatigue*

Another very frequent symptom was fatigue present in 83 (66%). There was a relatively even distribution between those identifying it as a recent as opposed to a longer standing symptom with 26 noting it for less than five years, 27 for more than five years and 30 not specifying the duration.

4.4 Disability [OPCS Disability Questionnaire]

The frequency of reported activity of daily living difficulties using the postal questionnaire devised by the OPCS is shown in full in Appendix 2 and is repeated in part in Tables 4.3 to 4.5 in this section. Abbreviations used in both sets of tables are given in full in the questionnaires included in Appendix 1.

As is evident from Table 4.3, motor disabilities were very common with 78% reporting difficulty with stairs; 72% with walking; 70% with bending; 54% describing falls or balance difficulties; 45% with reaching and stretching and 32% with manual dexterity tasks. Over a third (38%) noted difficulty going outside the house or garden without help.

Table 4.3: Section A of OPCS Disability Questionnaire (n=125)

Activity	Difficulty reported
Walking ¼ mile on level	90 (72%)
Walking up & down steps	98 (78%)
Bending & straightening up	88 (70%)
Falling/keeping balance	67 (54%)
Reaching & stretching	56 (45%)
Holding, gripping & turning	40 (32%)
Recognizing friend across road	10 (8%)
Reading newsprint	12 (10%)
Hearing	19 (15%)
Noises in head or ears	22 (18%)
Going outside house/garden	48 (38%)
Following conversation with background noise	30 (24%)

Sections B & C of the OPCS Disability Questionnaire address health problems and disabilities and, therefore, overlap to an extent with the Symptom Questionnaire. The results of this part are summarised in Table 4.4.

The report of 35 people troubled with severe and frequent bouts of breathlessness, wheezing or coughing limiting daily activities should be considered in relation to the 69 who reported some exertional dyspnoea. Similarly eating difficulty is reported in eight while 23 had some swallowing difficulty or choking. It would be anticipated that figures for significant disability would be lower than those for the occurrence of symptoms.

Severe pain or irritation limited daily activities in over a third of people and just less than a third described such limitations due to scar, blemish or deformity. Although 21% stated that severe depression or anxiety were long term health problems only 5% had consulted a psychiatrist or other specialist for such problems in the preceding year.

More than half of the population reported difficulty living alone [69(55%)] and limitations to the type of work they could do [67(54%)].

Sixteen percent of the population were attending day centres while 15% said they had attended a special school.

Table 4.4: Sections B & C of OPCS Disability Questionnaire (n=125)

Health Problems or Disabilities	Present
Severe bouts of breathlessness, wheeze, cough	35 (28%)
Eating, drinking, digestion	8 (6%)
Severe pain or irritation	48 (38%)
Scar, blemish or deformity	37 (30%)
Lack of bladder control	18 (14%)
Lack of bowel control	13 (10%)
Fit or convulsion	7 (6%)
Difficulty being understood	7 (6%)
Difficulty understanding others	8 (6%)
Frequent confusion/disorientation	8 (6%)
Severe depression/anxiety	26 (21%)
Difficulty getting on with people	8 (6%)
Mental handicap/learning difficulty	1 (1%)
Mental illness/phobia	4 (3%)

4.5 Health Status [SF-36]

The SF-36 which, as its title suggests, consists of 36 questions provides eight dimensions of health: physical functioning; role limitation due to physical problems; role limitation due to emotional problems; social functioning; mental health; vitality/energy; body pain; and general perception of health. Analysis was done according to the Guidelines provided by the Medical Outcomes Trust (1993). Raw scores are transformed into scaled scores ranging from 0 to 100, where higher score indicates better health.

Table 4.6: SF- 36 Results (mean values)

	Total Polio group (n=124)	Normative data (n=2489)	Polio age 55-64 (n=37)	Normative 55-64 (n=1237)
Physical function	26.2	78.3	27.3	78.0
Role-physical	41.4	71.9	35.6	78.3
Role emotional	67.6	76.3	78.1	84.8
Social function	62.7	71.9	63.6	86.6
Mental health	71.2	69.9	70.1	76.1
Vitality/energy	42.2	54.0	40.6	60.9
Body pain	45.0	69.8	41.3	76.8
General health	50.6	60.8	49.0	68.3

Table 4.6 presents the results for the full study population compared to normative data for people with long standing illness of all ages and for polio patients aged 55-64 compared with normative data for this age group.

In both groups mental health means for the polio subjects was not dissimilar to the comparable general populations and will not be discussed further. In ranking order from lowest to highest scores the pattern is the same for both groups for the five lowest: physical function, physical role, vitality, body pain and general health. The differences are considerable for all of these items. There is also evidence of reduced emotional role and social function in both groups.

4.6 Use of Services

i) *Contact with Services*

In order of frequency contact had been with hospital clinic, physiotherapy, wheelchair service, orthotist, occupational therapist and speech and language therapy. It is notable that less than a third had contact with occupational therapy. Despite the reported occurrence of swallowing difficulty or choking in 23 people only two had seen a speech & language therapist.

Table 4.7 summarises the contact subjects had had with the various services in the preceding five years and indicates whether they were satisfied (strongly agree + agree) or not satisfied (disagree + strongly disagree) with the service received.

Table 4.7: Contact with services and agreement re satisfaction *

	No. using	Strongly agree	Agree	Disagree	Strongly disagree
Hospital clinic	78	21	44	10	2
Occupational Therapy	36	10	18	4	3
Physiotherapy	57	21	25	7	3
Speech Therapy	2	0	1	0	0
Orthotics	50	17	20	1	10
Wheelchair	52	25	22	3	2

* Not all respondents who had contact with a service rated their degree of satisfaction with it

With regard to relative satisfaction with the services received: 84% were satisfied with hospital clinic; 90% with the wheelchair service; 82% with physiotherapy; 77% with orthotics and 73% with occupational therapy.

EXKATOM

80%

ii) *General Practitioner Contact*

123 of the 125 answered the question on frequency of contact with their GP in the preceding year. Forty two people (34%) had seen their GP once or twice, 33 (27%) three to six times; 38 (31%) more than six times; while ten (8%) had had no contact.

iii) *Services Desired*

Only 42 people responded to the request to indicate services which they had not had access to but felt they would like to have.

In order of frequency (number and percentage) were as follows: hospital specialist 22 (18%); physiotherapist 11 (9%); wheelchair service 9 (7%); orthotist 8 (6%); occupational therapist 5 (4%); employment 5 (4%); housing 3 (2%).

5. DISCUSSION

This survey has confirmed a high level of impairment, disability and handicap in people in Lothian who had suffered poliomyelitis earlier in their life. It was designed as a preliminary investigation into the subject and cannot be regarded as more than this. Before discussing in more detail the four areas addressed by the questionnaires, a few points will be made with regard to the study design.

5.1 Study Design

Community surveys are best done on the basis of interview using skilled interviewers whenever possible rather than by self-administered postal questionnaire (Abramson, 1979). However the use of a postal survey was appropriate to capture as many subjects as possible and to do this project without substantial funding. The cost of interviewing over a hundred individuals to cover the wide range of issues to be addressed would have been considerable. This is not to suggest that such expenditure on a further more detailed study is not warranted, indeed we would suggest that the results of this survey support the need for further work.

How representative is the study population of the total number of people with previous polio in Lothian? The short answer to this is that it almost certainly is not. However the aim of the study was to determine the numbers of people in Lothian who might need medical or related services rather than to perform an epidemiological survey per se. It could be suggested that people who join the BPF are more likely to be those who have some ongoing difficulties related to their polio and those who volunteered to complete questionnaires might contain a higher proportion of people with difficulties than those who did not volunteer. The use of a listing of wheelchair users should inevitably include people with mobility problems while those attending a neurorehabilitation clinic are likely to have motor problems. It is accepted, therefore, that people with non-locomotor complaints may be underrepresented as may those with no significant problems. Further comments on the epidemiology of polio in Lothian are presented at the end of the Discussion.

How accurate were the responses? Self-administered questionnaires rely on a certain level of education and skill on the part of the respondent (Abramson, 1979). They are

always subject to the error of a respondent misreading or misunderstanding questions. The population included a high proportion of elderly people, some of whom may have answered inaccurately due to concomitant visual or mental problems.

Were all problems reported directly related to the effects of polio? Clearly people of middle age or older who have had polio in the past are susceptible to the same diseases as the rest of the population of these ages. In fact small numbers of individuals commented that they were attending clinics or had disabilities due to heart attacks, stroke, rheumatoid arthritis and accidental injuries such as burns. Those volunteering such histories, however, were few in number and again it would require an interview follow-up to determine the incidence of significant con-current illnesses unrelated to polio.

5.2 Common Symptoms

The difficulties relating to selection of a study population are common to most published studies on the late consequences of poliomyelitis. In a recent review article Thorsteinsson (1997) reported common new health complaints as fatigue, weakness in both previously affected and unaffected muscles, muscle and joint pain, cold intolerance and atrophy. To illustrate this she cited four major references (Halstead & Rossi, 1985; Halstead & Rossi, 1987; Agre et al, 1989 ; Lonnberg, 1993). Foremost among these is possibly the report of Lonnberg from Denmark which was based on a population of 3,607.

Table 5: Common symptoms (expressed as percentages)

Complaint	Halstead (1985) n=539	Halstead (1987) n=132	Agre (1989) n=79	Lonnberg (1992) n=3607	Present study (1998) n=125
Fatigue	87	89	86	62	66
Weakness affected muscles	87	69	80	54	67
Weakness unaffected muscles	77	50	53	33	60
Muscle pain	80	71	86	39	64
Joint pain	79	71	77	51	61
Cold intolerance	-	29	56	42	70

Table 5 is drawn from Thorsteinsson's report with the inclusion of our findings. It must be emphasized that our figures represent the total percentages of those reporting the symptom, rather than only those describing it as a new complaint. This is at least partially justified by the fact that many of our subjects did not specify the duration of their symptoms.

Fatigue

Peter Field (1995) published a questionnaire study by mailing it with the BPF magazine and handing it to individuals at rehabilitation centres. Of a total of 1220 he was able to analyse responses from 1212. The demographic characteristics were not dissimilar to the present study in that the average age was 60 years [*cf* mean 61; median 59 years] with 65% female [*cf* 60%]. He reports low stamina or high fatigue in 66% and, giving quotations from individuals, he describes overwhelming fatigue as the most common and often the most debilitating symptom. In the present study a number of individuals annotated their questionnaires with comments regarding being extremely tired or exhausted all the time. Others have identified fatigue as one of the more common principal reasons for polio patients being seen in medical clinics (Agre, 1995). The sudden onset of an "extraordinary sense of fatigue", some 28 years after he first contracted polio, was the first late symptom identified in himself by Dr L Halstead, a leading figure in polio research (Gould, 1995)

Cold Intolerance

This was the most commonly reported symptom by our subjects although in over half it was of longstanding. It has been associated with increased muscle weakness, skin discolouration and burning pain and to increase with aging (Frick & Bruno, 1986).

Muscle Weakness

The frequency with which people reported increasing weakness in previously affected muscles or new weakness in previously unaffected muscles would suggest a need for neurological review to determine the nature of this phenomenon. There is a considerable literature detailing neurophysiological and other investigations of people reporting this symptom (Windebank et al, 1996; Trojan & Cashman, 1997). There is an emerging

concensus that the development of new muscular weakness does not constitute a form of motor neurone disease (Kidd et al, 1997).

Respiratory & Related Symptoms

In the study population respiratory symptomatology was not unduly common but is probably higher than it would be in an age matched population. Thus although recurrent chest infections requiring treatment might be anticipated in an elderly population, the median age of the study population was 59 years.

Respiratory insufficiency is a recognized complication of longstanding polio due to chest wall deformity, scoliosis, muscle weakness and other factors (Howard et al, 1988, Kidd et al, 1996). This is associated with headaches particularly on waking, disturbed sleep and daytime hypersomnolence, episodic confusion etc (Laurie et al, 1984). Sleep disturbances were common in the study population but varied in nature.

Although only 11 admitted to confusion, seven of these were under 70 years of age and there is the possibility that this related to sleep apnoea. It would be valuable to consider a specific interview-based study of respiratory and associated symptoms in a cohort of post-polio patients.

Swallowing Problems

While swallowing difficulties are not among the more common symptoms in people with previous polio, they were reported by 18% of our study population. This is the same finding as Coelho and Ferranti (1991) who reported dysphagia in 18% of 220 polio survivors sent a questionnaire. A number of studies have demonstrated that, even when clinically there is no complaint of swallowing difficulties, many polio survivors have abnormalities on videofluoroscopy (Sonies, 1995)

Mood Disorders

Depression and anxiety are common complaints in the general population and the nature of the questions in this study were insufficiently precise to give a clear indication of the frequency of these problems. However 21% described severe depression or anxiety

interfering with daily activities on the OPCS questionnaire. Kemp et al (1997) found "probable major depression" in 6% and "significant depressive symptomatology" in 22% of 173 post polio patients but this was not significantly greater than in an age-matched control group. In a population based study postpolio patients were not prone to depression (Windebank, 1991).

Einarsson and Grimby (1990) used the Functional Status Questionnaire in 41 polio survivors to record feelings of well being and reported minimal disturbance. The SF36 results would suggest that psychological problems were not prominent in the study population.

5.3 Disability & Health Status

The frequency of severe physical disability and associated perceived health status in the study population is striking. The level of motor disabilities, particularly with regard to lower limb function and mobility is high, in keeping with the reports of others (Grimby, 1995). Although this may reflect the use of wheelchair client lists to recruit patients, the polio population represent a significant number of people, many still in employment who require walking aids or wheelchairs to get about. These physical problems contribute very significantly to the disadvantage, or handicap, experienced by these people.

5.4 Services

The nature of the hospital clinic was not specified in the questionnaire on services and although about two thirds of those responding had been to a clinic and most were satisfied with the service provided limited conclusions can be made from this. Fifty seven people had had physiotherapy although ten felt it was unsatisfactory. This warrants further study into the nature of the individual treatment offered in relation to specific patients.

Such comments are even more pertinent to orthotics. It is worth noting that 11 of the 50 patients expressed dissatisfaction with the service provided, and ten of these indicated marked dissatisfaction. Appropriate lower limb orthotic prescription has been shown to be effective in improving mobility and decreasing fatigue in many cases (Cosgrove et al,

1987; Waring et al, 1989). A detailed investigation of the orthotic requirements of this subgroup would be valuable to see if it is possible to improve patient satisfaction.

In our original discussions with the committee of the Edinburgh Branch of the BPF they indicated that many of their members had described medical and related personnel as admitting to their ignorance of the natural history of polio and lack of experience of the condition. It is conceivable that subjects in this study reported a satisfactory level of service despite being disappointed at the lack of expertise in those seeing them. By its nature the questionnaire did not address the post-polio person's reaction to clinic visits. Maynard (1995) has highlighted the danger of physicians communicating helplessness in the face of post-polio sequelae which may transmit a sense of hopelessness to the patient.

The response to the question as to what services people would like was slightly disappointing as many left it blank. This may relate to the wording of the question. In particular it might have been better to simply ask which services people considered should be available rather than asking which services they had not had but would like to have. It may also reflect a lack of knowledge of what the services might have to offer or a previous experience which suggested that they were ineffective.

5.5 Epidemiology of Polio

It seems appropriate to add a final comment on the potential size of the likely population of polio survivors in Lothian. An extensive literature search has failed to reveal any figures as to the numbers of people who suffered polio in the past and are still alive today in the U.K. population. Halstead (1995) estimates 640,000 such people in the U.S.A. Based on an approximate population in that country of 240 million this would suggest a prevalence of 270 per 100,000. The reported prevalence in Norway is 250 per 100,000 (Gilhus, 1998). Assuming an approximate prevalence of 200 per 100,000 in Lothian whose population is almost three quarters of a million, this would lead to an estimate of about 1,500 people who had suffered polio in the past.

De Visser (1994) states that in this country epidemiological data about the frequency of the post-polio syndrome are based on estimates from U.S. studies which vary between 22 and 87%. Gilhus suggested that 15% of polio survivors in Norway suffered from

post-polio syndrome. Taking a conservative figure of 20% and assuming that there are 1,500 polio survivors in Lothian would suggest about 300 people in the area who may be suffering the late effects of polio. Considering the limitations of our study design described above this appears a reasonable estimate. Taking account of the fact that the population of polio survivors is ageing it would be wise to plan for a larger number than this encountering problems and requiring services in a few years time.

6. CONCLUSIONS

- Half of the study population were under 59 years of age so that it would be incorrect to consider the population of people with post-polio symptoms as in the geriatric age group.

- The commonest symptoms were cold intolerance, increased muscle weakness, muscle pain, fatigue and joint pain. It is particularly notable that these symptoms, with the exception of the first, were often of recent onset (i.e. within the last five years)

- Pain is worthy of emphasis as a symptom, being commonly reported in the back and neck as well as in muscles and joints. It was also identified as a major source of limitation in daily activities.

- Lower limb motor disabilities were extremely common with about 3/4 unable to walk a quarter of a mile or go up and down steps. Over 1/3 need help to leave their home or garden.

- Motor disabilities of the upper limb were also common, affecting 1/3 to 1/2 of the population.

- Physical disabilities, fatigue and pain are the principal causes of handicap in this population rather than mental or social factors.

- Although those accessing health and related services generally reported them as satisfactory, there are no grounds for complacency and this area warrants further study.

- The findings are similar to reports from England, the U.S.A and Scandinavia.

- This study, although population based, was not designed to provide an accurate figure for the size of the post-polio population in Lothian. However, based on studies from other Western countries and our findings, we suggest that there may be approximately 1,500 polio survivors, at least 300 of whom are likely to experience significant health problems.

7. RECOMMENDATIONS

1. There is a need for a more detailed interview based survey BUT this should not delay attention being paid to a number of identified issues.

2. The large number of people with later onset muscle symptoms supports the case for a clinic including neurology, neurophysiology and physiotherapy resources to investigate the nature of these changes and offer expert advice on management.

3. The frequency of severe pain in muscles and joints and the prominence of these symptoms as a contributory factor to disability and handicap would suggest the need for access to specialist pain services.

4. While a smaller proportion of the study population reported respiratory difficulties of late onset, this may reflect study design and the symptoms in those who did have respiratory and related symptoms were sufficiently severe to suggest that access to respiratory services be facilitated.

5. There should be further more detailed study of the accessability of services such as orthotics, remedial therapies and wheelchair provision.

6. The findings of this report have implications for social services, housing, transport and other agencies with responsibilities for people with predominantly physical disability.

7. There are sufficient people with major impairments, disabilities and handicap in Lothian to warrant consideration being given to establishing a "one-stop shop" where they can be assessed for their health and related needs and be directed to appropriate specific services.

8. The size and nature of the late consequences of polio warrant specific attention being given to it in the training of health and related professions.

8. ACKNOWLEDGEMENTS

Sincere thanks are given to all the respondents who completed the questionnaires making this report possible. We hope they feel their efforts are rewarded in the results. This survey would not have been instituted without the initiation of the committee of the BPF, Edinburgh Branch; they provided invaluable assistance in the design of the questionnaire and made available their membership lists.

The authors are grateful to Mrs C. Dowell of the Mobility Service for providing patient listings of wheelchair users. We are particularly indebted to Dr J Hunter and Dr SJ Smith for their constructive comments in the preparation of the manuscript and to Miss R. Goodman and Ms Marion Paton for typing and assistance with publication.

Edinburgh Healthcare NHS Trust covered the costs of postage and stationery and supported the staff time necessary for the completion of the study.

Dr. Hellawell is employed by the University of Edinburgh on funding from the Association of British Insurers.

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APPENDIX 1: Postal Questionnaires

REHABILITATION STUDIES UNIT

The University of Edinburgh
Charles Bell Pavilion
Astley Ainslie Hospital
Grange Loan
Edinburgh EH9 2HL

Fax 0131 537 9030
Telephone 0131 537 9000
extension 49076

Dear Sir/Madam,

Questionnaires regarding Late Effects of Polio

Firstly please excuse the impersonal form of address and if you have not been informed in advance, please excuse the unsolicited nature of this letter.

The Edinburgh Branch of the British Polio Fellowship (BPF) has highlighted the fact that a number of members who suffered polio in their childhood or early adulthood are now encountering difficulties accessing health services or when they do receiving services which meet their needs.

It would be of considerable assistance in trying to overcome these difficulties if as many people who have had polio complete the enclosed questionnaires - even if they have no active problems or need of services. Although you are asked to provide your name and other personal details let me assure you that information will be kept in strict medical confidence by the researchers - and results will not be presented to anyone in a way that will allow individuals to be identified.

Your name and address has been obtained from the BPF or from your recent contact with a part of the health service but information obtained from the questionnaires will not be divulged to either of these sources.

The questionnaires are colour coded to assist in data analysis and address topics such as symptoms, disabilities and use of services. Although they may appear daunting, and at times questions appear inappropriate, we hope you will be able to complete them all and thank you in anticipation.

Yours sincerely

Dr B Pentland
Head of Rehabilitation Services

NAME : MAIDEN NAME
ADDRESS

DATE OF BIRTH
GENERAL PRACTITIONER (NAME & ADDRESS)

AGE/DATE WHEN POLIO DIAGNOSED:

HOSPITAL(S) ATTENDED

DO YOU CURRENTLY ATTEND ANY HOSPITAL CLINIC OR OUT-PATIENT SERVICE YES ☐ NO ☐

IF YES - PLEASE STATE WHERE YOU ATTEND

1) SYMPTOM QUESTIONNAIRE

THE FOLLOWING SYMPTOMS HAVE BEEN REPORTED BY SOME PEOPLE WHO HAVE HAD POLIO IN THE PAST. YOU MAY NEVER EXPERIENCE THEM. PLEASE FEEL FREE TO ADD DESCRIPTIONS OF ANY SYMPTOMS IN THE SPACES PROVIDED.

- In the last 12 months have you experienced any of the following?
  - Chest infection for which antibiotics were prescribed YES ☐ NO ☐ MORE THAN ONCE ☐
  - Fall YES ☐ NO ☐ MORE THAN ONCE ☐
  - Fracture as a result of a fall YES ☐ NO ☐ MORE THAN ONCE ☐
  - Other minor injuries as a result of a fall YES ☐ NO ☐ MORE THAN ONCE ☐

- Do you experience (or have recently experienced) any of the following? (Please estimate how long you have done so)
  - Muscles
    - Increased weakness in previously affected muscles YES ☐ NO ☐ HOW LONG _____
    - Weakness in unaffected muscles YES ☐ NO ☐ HOW LONG _____
    - Twitching or flickering in muscles YES ☐ NO ☐ HOW LONG _____
    - Cramps YES ☐ NO ☐ HOW LONG _____
    - Other muscle pain YES ☐ NO ☐ HOW LONG _____

    (Please describe other muscle pain:) _____

    _____

    _____

  - Joints
    - Pain (other than after a fall or injury) YES ☐ NO ☐ HOW LONG _____
    - Increased stiffness YES ☐ NO ☐ HOW LONG _____
    - Reduced range of movement YES ☐ NO ☐ HOW LONG _____
    - Increased joint instability YES ☐ NO ☐ HOW LONG _____

  - Pain
    - Back pain YES ☐ NO ☐ HOW LONG _____
    - Neck pain YES ☐ NO ☐ HOW LONG _____

- Breathlessness

  - Shortness of breath in bed YES ☐ NO ☐ HOW LONG _____
  - Shortness of breath on exertion YES ☐ NO ☐ HOW LONG _____

  (Please indicate the type of activity likely to make you breathless - e.g. climbing stairs, using wheelchair, etc.):

  _____

  _____

  _____

- Sleep disturbance

  - Difficulty getting to sleep YES ☐ NO ☐ HOW LONG _____
  - Frequent waking YES ☐ NO ☐ HOW LONG _____
  - Early morning waking YES ☐ NO ☐ HOW LONG _____

  (If these terms do not accurately fit your symptoms, please describe): _____

  _____

  _____

- Episodes of mental confusion YES ☐ NO ☐ HOW LONG _____

- Increased irritability with others YES ☐ NO ☐ HOW LONG _____

- Headaches YES ☐ NO ☐ HOW LONG _____

  If yes, how often do they occur?

  Daily ☐ 2 or more per week ☐ Weekly ☐ 1-4 per month ☐ More than 4 per month ☐

  When do they occur?

  Morning ☐ Evening ☐ During the night ☐ Anytime ☐

- Swallowing difficulty or choking YES ☐ NO ☐ HOW LONG _____

  If yes, how often? _____

- Speech changes YES ☐ NO ☐ HOW LONG _____

- Weight loss YES ☐ NO ☐ HOW LONG _____

- Intolerance of cold in affected limb(s) YES ☐ NO ☐ HOW LONG _____

- Fatigue YES ☐ NO ☐ HOW LONG _____

(Please describe fatigue symptoms): _____

_____

_____

_____

_____

2) USE OF SERVICES

1) PLEASE INDICATE WHETHER OR NOT YOU HAVE HAD CONTACT WITH ANY OF THE FOLLOWING SERVICES IN THE LAST 5 YEARS AND INDICATE YOUR LEVEL OF SATISFACTION WITH THE SERVICE PROVIDED BY ANSWERING THE FOLLOWING QUESTIONS.

Service	Contact in last 5 years		I am satisfied with the treatment/service provided			
a) Hospital clinic	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
b) Occupational Therapy	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
c) Physiotherapy	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
d) Speech and Language Therapy	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
e) Orthotics (calipers, braces, etc)	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐
f) Wheelchair	YES ☐	NO ☐	Strongly Agree ☐	Agree ☐	Disagree ☐	Strongly disagree ☐

2) CAN YOU INDICATE THE NUMBER OF TIMES YOU HAVE SEEN YOUR OWN DOCTOR (GP) IN THE LAST YEAR?

☐ 0 ☐ 1-2 ☐ 3-6 ☐ more than 6

3) PLEASE INDICATE BELOW ANY OF THE FOLLOWING SERVICES WHICH YOU HAVE NOT HAD ACCESS TO BUT YOU FEEL YOU WOULD LIKE TO HAVE (tick as many as applies)

☐ Hospital specialist
☐ Physiotherapist
☐ Occupational Therapist
☐ Speech Therapist
☐ Orthotist (re: calipers, braces, etc)
☐ Wheelchairs
☐ Employment
☐ Housing

3) ADL QUESTIONNAIRE

A. Do you have the following difficulties due to long-term health problems or disabilities, either physical or mental?

a) Difficulty walking for a quarter of a mile on the level? YES ☐ NO ☐
b) Great difficulty walking up or down steps or stairs? YES ☐ NO ☐
c) Difficulty bending down and straightening up, even when holding on to something? YES ☐ NO ☐
d) Falling, or having great difficulty keeping balance? YES ☐ NO ☐
e) Difficulty using arms to reach and stretch for things? YES ☐ NO ☐
f) Great difficulty holding, gripping or turning things? YES ☐ NO ☐
g) Difficulty recognizing a friend across the road, even if glasses or contact lenses are worn? YES ☐ NO ☐
h) Difficulty reading ordinary newspaper print, even if glasses or contact lenses are worn? YES ☐ NO ☐
i) Difficulty hearing someone talk in a quiet room? YES ☐ NO ☐
j) Suffering severely from noises in the head or ears? YES ☐ NO ☐
k) Difficulty going outside the house or garden without help? YES ☐ NO ☐
l) Great difficulty following a conversation if there is background noise, for example a TV, radio, or children playing? YES ☐ NO ☐

B. Are you affected by the following health problems or disabilities?

a) Severe and frequent bouts of breathlessness, wheezing or coughing which limit daily activities? YES ☐ NO ☐
b) Severe difficulties with eating, drinking or digestion which limit daily activities? YES ☐ NO ☐
c) Severe pain or irritation which limits daily activities? YES ☐ NO ☐
d) A scar, blemish, or deformity which limits daily activities? YES ☐ NO ☐
e) Lack of control of bladder at least once a day or night? YES ☐ NO ☐
f) Lack of control of bowels at least once a month? YES ☐ NO ☐

C. Have you had the following long-term health problems or disabilities?

a) A fit or convulsion in the past two years? YES ☐ NO ☐
b) Difficulty in being understood by others? YES ☐ NO ☐
c) Difficulty understanding what others say or what they mean? YES ☐ NO ☐
d) Frequently getting confused or disorientated? YES ☐ NO ☐
e) Severe depression or anxiety? YES ☐ NO ☐
f) Difficulty getting on with people, so that family work or leisure is severely affected? YES ☐ NO ☐
g) Mental handicap or other severe learning difficulties? YES ☐ NO ☐
h) Mental illness or phobias which limit daily activities? YES ☐ NO ☐

D. In the last twelve months have you seen a psychiatrist or other specialist because of a mental, nervous, or emotional problem?

YES ☐ NO ☐

E. In the last twelve months have you attended a day centre, taken sheltered work, or lived in sheltered housing because of a health problem or disability?

YES ☐ NO ☐

F. Did you attend a special school because of a long-term health problem or disability?

YES ☐ NO ☐

G. Do any of the following statements apply to you, of a long-term health problem or disability:

a) I would find it difficult to live alone without help? YES ☐ NO ☐
b) I am dependent on life-sustaining equipment? YES ☐ NO ☐
c) I am limited in the type or amount of paid work I can do? YES ☐ NO ☐

SF-36 Health Survey

INSTRUCTIONS: This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities.

Answer every question by marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is:

(Please tick one)

- Excellent ☐
- Very good ☐
- Good ☐
- Fair ☐
- Poor ☐

2. <u>Compared to one year ago</u>, how would you rate your health in general, <u>now</u> ?

(Please tick one)

- Much better now than one year ago ☐
- Somewhat better now than one year ago ☐
- About the same as one year ago ☐
- Somewhat worse now than one year ago ☐
- Much worse now than one year ago ☐

3. The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

(Please tick one box on each line)

	ACTIVITIES	Yes, limited a lot	Yes, limited a little	No, not limited at all
a.	**Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	☐	☐	☐
b.	**Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, playing golf	☐	☐	☐
c.	Lifting or carrying groceries	☐	☐	☐
d.	Climbing **several** flights of stairs	☐	☐	☐
e.	Climbing **one** flight of stairs	☐	☐	☐
f.	Bending, kneeling, or stooping	☐	☐	☐
g.	Walking **more than a mile**	☐	☐	☐
h.	Walking **half a mile**	☐	☐	☐
i.	Walking **one hundred yards**	☐	☐	☐
j.	Bathing or dressing	☐	☐	☐

4. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

(Answer Yes or No to each question)

		YES	NO
a.	Cut down on the **amount of time** you spent on work or other activities	☐	☐
b.	**Accomplished less** than you would like	☐	☐
c.	Were limited in the **kind** of work or other activities	☐	☐
d.	Had **difficulty** performing the work or other activities (for example, it took extra effort)	☐	☐

5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

(Answer Yes or No to each question)

		YES	NO
a.	Cut down on the **amount of time** you spent on work or other activities	☐	☐
b.	**Accomplished less** than you would like	☐	☐
c.	Didn't do work or other activities as **carefully** as usual	☐	☐

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours, or groups?

(Please tick one)

Not at all	☐
Slightly	☐
Moderately	☐
Quite a bit	☐
Extremely	☐

7. How much bodily pain have you had during the past 4 weeks?

(Please tick one)

- None ☐
- Very Mild ☐
- Mild ☐
- Moderate ☐
- Severe ☐
- Very Severe ☐

8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

(Please tick one)

- Not at all ☐
- A little bit ☐
- Moderately ☐
- Quite a bit ☐
- Extremely ☐

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks -

(Please tick one box on each line)

		All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a.	Did you feel full of life?	☐	☐	☐	☐	☐	☐
b.	Have you been a very nervous person?	☐	☐	☐	☐	☐	☐
c.	Have you felt so down in the dumps that nothing could cheer you up?	☐	☐	☐	☐	☐	☐
d.	Have you felt calm and peaceful?	☐	☐	☐	☐	☐	☐
e.	Did you have a lot of energy?	☐	☐	☐	☐	☐	☐
f.	Have you felt downhearted and low?	☐	☐	☐	☐	☐	☐
g.	Did you feel worn out?	☐	☐	☐	☐	☐	☐
h.	Have you been a happy person?	☐	☐	☐	☐	☐	☐
i.	Did you feel tired?	☐	☐	☐	☐	☐	☐

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc)?

(Please tick one)

All of the time	☐
Most of the time	☐
Some of the time	☐
A little of the time	☐
None of the time	☐

11. How TRUE or FALSE is each of the following statements for you?

(Please tick one box on each line)

		Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a.	I seem to get ill a little easier than other people	☐	☐	☐	☐	☐
b.	I am as healthy as anybody I know	☐	☐	☐	☐	☐
c.	I expect my health to get worse	☐	☐	☐	☐	☐
d.	My health is excellent	☐	☐	☐	☐	☐

APPENDIX 2 : Questionnaire Results

QUESTIONNAIRE RESULTS

SYMPTOMS

In the last 12 months have you experienced any of the following?

	Yes	> Once	No	No answer
Chest infection	37	14	79	8
Fall	51	35	66	8
Fracture	13	7	100	11
Minor injury	34	19	81	10

Do you experience (or have recently experienced) any of the following?

	Yes	No	No answer
Increased weakness in previously affected muscles	84	33	8
Weakness in unaffected muscles	75	38	12
Twitching or flickering in muscles	52	60	12
Cramps	56	54	15
Other muscle pain	61	48	15
Joint pain (other than after a fall or injury)	76	31	18
Increased joint stiffness	80	29	15
Reduced range of joint movement	79	30	15
Increased joint instability	65	41	18
Back pain	76	39	10
Neck pain	50	59	15
Shortness of breath in bed	19	89	16
Shortness of breath on exertion	70	48	7
Difficulty getting to sleep	43	71	11
Frequent waking	56	55	13
Early morning waking	58	51	16
Episodes of mental confusion	11	107	6
Increased irritability with others	37	83	5
Headaches	41	81	3
Swallowing difficulty or choking	23	94	7
Speech changes	6	107	11
Weight loss	14	104	6
Intolerance of cold in affected limb(s)	87	31	7
Fatigue	83	34	8

OPCS

	Yes	No	No answer
A: *Difficulty walking ¼ mile on the level*	90	30	5
Great difficulty walking up or down stairs	98	22	5
Difficulty bending down & straightening up	88	33	4
Falling, or having great difficulty keeping balance	67	49	9
Difficulty using arms to reach and stretch for things	56	61	8
Great difficulty holding, gripping / turning things	40	75	10
Difficulty recognizing a friend across the road	10	108	7
Difficulty reading ordinary newspaper print	12	107	6
Difficulty hearing someone talk in a quiet room	19	101	5
Suffering severely from noises in the head or ears	22	89	14
Difficulty going outside house or garden without help	48	64	13
Great difficulty following convers. with background noise	30	89	6
B: *Severe & frequent bouts breathlessness, wheeze, cough*	35	87	3
Severe difficulties eating, drinking, digestion	8	113	4
Severe pain, irritation	48	73	4
A scar, blemish or deformity	37	81	7
Lack of control of bladder at least x1/day or night	18	104	3
Lack of control of bowels at least x1/month	13	108	3
C: *A fit or convulsion in past 2 years*	7	114	4
Difficulty in being understood by others	7	115	3
Difficulty understanding what others say / what they mean	8	113	4
Frequently getting confused / disorientated	8	114	3
Severe depression or anxiety	26	94	5
Difficulty getting on with people	8	113	4
Mental handicap / other severe learning difficulties	1	121	3
Mental illness or phobias	4	118	3
D: *In last 12 months have you seen psychiatrist?*	6	117	2
E: *In last 12 moths: day centre, sheltered work/housing?*	20	103	2
F: *Did you attend special school?*	19	101	5
G: *I would find it difficult to live alone without help*	69	49	7
I am dependent on life-sustaining equipment	7	102	16
I am limited in the type/ amount of paid work I can do	67	39	19