PAPER

Perceived health in a population based sample of victims of the 1956 polio epidemic in the Netherlands

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Objective: To investigate perceived health and its relation to residual paresis from polio, late onset neuromuscular symptoms following poliomyelitis (LSP), and sex, in a population based sample of polio survivors.

Methods: 350 subjects traced from the notification records of the Dutch 1956 polio epidemic received a mailed questionnaire on residual polio paresis and new neuromuscular symptoms. Perceived health was measured using the Nottingham health profile. Respondents with new muscle weakness and new neuromuscular symptoms were considered as cases with LSP.

Results: Health problems were perceived by 151 of the 260 respondents. Respondents with residual paresis had significantly more health problems than clinically recovered respondents for the Nottingham health profile category of physical mobility. The perceived health of respondents with LSP (45.5%) was significantly worse than that of respondents without LSP for all the health profile categories. Among the respondents with LSP, health status did not differ between those with residual paresis and those who had recovered, except for physical mobility. Female respondents with LSP reported worse health status than male respondents with regard to physical mobility and social isolation.

Conclusions: In this population based sample, health problems were frequently reported. They were mainly related to late onset neuromuscular symptoms following poliomyelitis, which were perceived by a substantial proportion of all polio survivors—not only subjects with polio residuals but also individuals who (subjectively) had recovered from polio.

Population based clinimetric studies may provide useful information on the magnitude and distribution of perceived health problems in former polio patients. Perceived health status, or health related quality of life (HRQL), refers to subjective health problems, which include physical, emotional, and social functioning. HRQL can be used to measure the impact of chronic disease.¹ The many HRQL measurement instruments that are available differ considerably with regard to the areas of functioning they measure.² The Nottingham health profile, which was originally designed for use in population surveys, is a widely used, validated, generic, self administered questionnaire which measures perceived health status in six categories: physical mobility, energy, pain, social isolation, emotional reactions, and sleep.³ It has been used for measuring selected groups of polio patients, but not in population based studies.^{4–6}

New neuromuscular symptoms, many years after the acute poliomyelitis episode, are experienced by many former polio patients.^{7–10} These new neuromuscular symptoms are termed the postpoliomyelitis syndrome if new muscle weakness is among the symptoms and if other medical conditions that might explain the symptoms have been excluded.¹¹ More neutral terms such as “late onset neuromuscular symptoms following poliomyelitis” (LSP) must be used as a descriptor for these new neuromuscular symptoms if other causes were not excluded.¹² Patients with new neuromuscular symptoms often experience a decline in their physical abilities and an increase in disability and handicaps; their perceived health status according to the Nottingham health profile is worse than that of former polio patients with stable functioning.^{4–5 10} Although it is known that new neuromuscular symptoms may develop in patients with minor residual paresis, and even in patients with non-paralytic polio,^{8 13} differences in perceived health status between patients with residual paresis and those with little or no residual paresis have not been studied. Furthermore, it has been observed that there is a predominance of female patients

among polio patients attending polio clinics.^{14 15} However, population based studies disagree on whether female sex is a risk factor for the development of new neuromuscular symptoms.^{8 10} It is conceivable that the difference in the use of health care services between male and female polio patients is partly due to sex differences in perceived health status.^{14 15} However, differences in perceived health status between male and female former polio patients have not yet been studied.

Our aim in the present study was to investigate perceived health status in a representative sample of polio survivors and its relation with residual impairments from polio, late onset neuromuscular symptoms following poliomyelitis, and the sex of the respondents.

METHODS

Subjects

In 1956, 1784 cases of paralytic polio were notified to the Inspectorate for Health Care of the Dutch Ministry of Health. The male/female ratio was 1.2. The only records that have been preserved are those of the 564 cases registered in the provinces of Noord-Brabant and Limburg. Of these, 23 had died and 191 could not be traced. The sample therefore included the remaining 350 persons.¹⁰ As the identity of these individuals had been revealed to the authorities because of mandatory health regulations, the Inspectorate of Health allowed us to contact them only once, for privacy reasons. No reminders or telephone calls were allowed in cases of non-response.

The study was approved by the medical ethics committee of the Academic Medical Centre, and by the Inspectorate for Health Care of the Ministry of Health, and written informed consent was obtained from all participants.

Questionnaire

A questionnaire and the Nottingham health profile part I were mailed in 1995 to all subjects who had been traced. The questionnaire contained “yes” or “no” questions regarding the

severity of the acute polio episode, the residual pareses after recovery from polio, and questions regarding impairments, disabilities, and handicaps, during the stable period and at the present time. For the stable period, the questions referred to the situation in 1975, a period during which all subjects had reached adulthood, making recollection more reliable. The questionnaire did not contain any questions on comorbidity.

A Dutch validated version of the Nottingham health profile was used, consisting of 38 yes/no questions about six categories of normal living (the number of questions is given in parentheses): physical mobility (8), energy (3), pain (8), social isolation (5), emotional reactions (9), and sleep (5).¹⁶ For the Nottingham health profile, a total score was calculated by counting the number of questions with yes answers and calculating sum scores for each category by dividing the number of yes answers by the total number of questions in that category and multiplying the result by 100. This resulted in scores for the Nottingham health profile categories that ranged from 0 (no complaints) to 100 (answered yes to all questions).

Data analysis

For the purpose of this study, the questions from the questionnaire which provided information about residual pareses from polio and about currently experienced or increased muscle weakness and neuromuscular symptoms were used for the analysis.

As the respondents did not undergo a physical examination, the assessment of whether they might have late onset neuromuscular symptoms following poliomyelitis (LSP) had to be made on the basis of the self reported symptoms. Correct identification of cases may be hampered if new symptoms are of a non-specific nature.^{17,18} However, new muscle weakness is usually accompanied by other neuromuscular symptoms.^{7-10,14,15} Therefore, respondents were only considered as cases of LSP if they reported new muscle weakness, together with at least one other new or currently increased neuromuscular symptom, compared with 1975. These neuromuscular symptoms were fatigue, muscle pain, muscle cramps, muscle twitches, joint pain, and cold intolerance.

For the statistical analyses we used the SPSS statistical software package (SPSS 10.0.5; SPSS Inc, Chicago, Illinois, USA). Dichotomised variables were analysed with the χ^2 test. Ordinal data and non-normally distributed data were analysed by the Mann-Whitney U test, with correction for ties. An α level of $p < 0.05$ was used for all tests of significance.

RESULTS

Study population

The sample of 350 subjects had a mean (SD) age of 44.6 (7.0) years (range 39 to 79) and a male/female ratio of 1.3. Seventy four per cent of these subjects responded ($n = 260$). The mean age of the respondents was 44.4 (6.7) years (range 39 to 77). The female response rate was 79% and the male response rate, 70%. The respondents, 137 men and 123 women (male/female ratio 1.1), had contracted paralytic poliomyelitis at a mean age of 5.4 (6.7) years (range 0 to 38).

No information about residual paresis in the stable period was available for 29 respondents. The majority of these respondents either denied ($n = 19$) or could not recall ($n = 8$) having had polio, and had therefore only answered the questions about their present status. Two respondents did not answer the question about residual paresis. Residual paresis of bulbar muscles, trunk muscles, or extremities in the stable period was reported by 144 (62%) of the 231 respondents who had answered these questions. No residual paresis of any extremity was reported by 50% of the respondents, while 35% had residual paresis of one extremity, 12% of two extremities, 2% of three extremities, and 1% of all extremities.

The age at the acute polio episode, the presence of residual paresis, and the number of extremities with residual paresis did not differ between male and female respondents.

Perceived health status

In 38 cases (15%) the total Nottingham health profile score and a varying number of category scores could not be calculated owing to missing values. The percentage of missing values per item ranged from 0.8% to 5.4%. The median total Nottingham health profile score (with 25th and 75th centile scores in parentheses) was 2 (0;7); in 151 respondents (68% of valid cases) the total score was above zero and the median total score of these subjects was 5 (2;10). There were 11 respondents who scored above zero in all categories. The percentages of respondents who scored above zero—indicating that they perceived health problems in that category—were 49% for physical mobility, 32% for energy, 35% for pain, 13% for social isolation, 40% for emotional reactions, and 34% for sleep. For each profile category, the distributions of scores were skewed, with a decrease in numbers towards higher scores (fig 1).

Perceived health status and residual paresis

Information about residual paresis was available from 231 respondents. The physical mobility score of the Nottingham health profile was significantly higher for respondents reporting residual paresis from polio during the stable period than for respondents with no residual paresis. No differences were found for any other category, and the median value for all the other categories was zero for both groups (table 1).

Perceived health status and late symptoms of polio

In three respondents (two male, one female) the presence of LSP could not be determined as they had not answered the question on whether or not their neuromuscular symptoms were increasing. New muscle weakness was reported by 135 respondents and new neuromuscular symptoms by 159; both were strongly associated (χ^2 test, $p < 0.001$). LSP was experienced by 117 (45.5%) of the 257 respondents, and the prevalence did not differ between male (46%) and female respondents (45%). LSP was experienced by 73 respondents with residual paresis (51%), and by 33 with no residual paresis (38%) (NS).

The scores for all Nottingham health profile categories were significantly higher in respondents with LSP than in those without LSP (table 2). In respondents with LSP, the highest median scores were found for the categories of physical mobility, energy, and pain. Among the respondents with LSP, those with residual paresis from polio scored significantly higher than those reporting no residual paresis from polio only for physical mobility (table 3).

Perceived health status and sex

Female respondents scored significantly higher than male respondents in the categories physical mobility ($p = 0.02$), energy ($p = 0.006$), and social isolation ($p = 0.007$) (fig 1). In the subgroup of respondents with LSP, the female respondents had significantly higher scores in the categories of physical mobility and social isolation than the male respondents (table 4). The score for the category of energy was higher for female respondents with LSP than for male respondents, although this difference was not significant ($p = 0.06$).

DISCUSSION

In this study of a population based sample of polio survivors, the majority (151) of the 260 respondents perceived health problems, as measured by the Nottingham health profile, 39 years after acute paralytic poliomyelitis. Given the fact that we were not allowed to follow up the non-responders, the response rate of 74% was high. Judged by age the respondents

Figure 1 Histogram of Nottingham health profile scores for all respondents and for male and female respondents.

seemed to be representative of the sample studied, although the response rate was somewhat lower for men than for women.

Although a reference sample of the general population was not available for a comparison, it seems unlikely that the perceived health status in the study population had not worsened. Only 32% of the respondents scored zero on all items, which is less than the 35% and 60%, respectively, of respondents with a total Nottingham health profile score of zero found in community surveys of adults of all ages,^{19–20} and also less than the reported 46% of middle aged to elderly people with a total Nottingham health profile score of zero.²¹ From the category scores it appears that the smaller percentage of respondents with a total score of zero in the study population reflects the larger number of respondents with scores above zero in the categories of physical mobility, energy, and pain in comparison with general community population samples, which reported zero scores in these categories in

approximately 80% of the respondents.^{19–21–22} In studies of patients with postpoliomyelitis syndrome, these Nottingham health profile categories have also shown the highest problem scores.^{4–5} For each of the other three categories—social isolation, emotional reactions, and pain—the percentage of respondents with zero scores was within the range reported in those studies. Furthermore, it must be acknowledged that the ability of the Nottingham health profile to detect low levels of ill health may be limited compared with other clinimetric scales,^{21–23} and the Nottingham instrument measures a limited number of areas of functioning.^{24–25} Moreover, it may underestimate problems in some subjects, for example if a person is wheelchair bound.

The Nottingham health profile was incompletely answered by 15% of the respondents—a surprisingly high proportion given that the questionnaire is supposed to be simple and easily understood.²⁵ Missing values may in part reflect the method of data collection, as our missing value rates were

Table 1 Perceived health in respondents with residual paresis from polio and respondents with no residual paresis

NHP category	Residual paresis		No residual paresis		p Value
	(N=144)	n	(N=87)	n	
Physical mobility	12.5 (0;31.3)	137	0 (0; 12.5)	85	<0.001
Energy	0 (0;33.3)	136	0 (0; 33.3)	85	0.52
Pain	0 (0;37.5)	133	0 (0; 12.5)	82	0.07
Social isolation	0 (0; 0)	137	0 (0; 0)	83	0.51
Emotional reactions	0 (0;11.1)	131	0 (0; 11.1)	82	0.48
Sleep	0 (0; 20)	136	0 (0; 20)	83	0.77

Values are median (25th and 75th centile scores). Total number of respondents (N) and number who responded per category (n).
NHP, Nottingham health profile.

Table 2 Perceived health in respondents with and without late onset neuromuscular symptoms following poliomyelitis (LSP)

NHP category	LSP		No LSP		p Value
	(N=117)	n	(N=140)	n	
Physical mobility	25 (0;37.5)	112	0 (0; 12.5)	133	<0.001
Energy	33.3 (0;66.7)	112	0 (0; 0)	132	<0.001
Pain	25 (0;62.5)	110	0 (0; 0)	127	<0.001
Social isolation	0 (0; 0)	112	0 (0; 0)	132	0.02
Emotional reactions	11.1 (0;22.2)	104	0 (0; 11.1)	132	<0.001
Sleep	0 (0; 20)	109	0 (0; 0)	132	<0.001

Values are median (25th and 75th centile scores); total number of respondents (N) and number who responded per category (n).
NHP, Nottingham health profile.

Table 3 Perceived health for respondents with late onset neuromuscular symptoms of polio (LSP) and residual paresis and for respondents with LSP and no residual paresis

NHP category	LSP and residual paresis		LSP and no residual paresis		p Value
	(N=73)	n	(N=33)	n	
Physical mobility	25 (12.5; 50)	70	12.5 (0; 25)	32	0.01
Energy	0 (0;66.7)	69	33.3 (0;66.7)	33	0.64
Pain	25 (0;68.8)	69	12.5 (0; 50)	32	0.29
Social isolation	0 (0; 0)	70	0 (0; 15)	32	0.25
Emotional reactions	11.1 (0;22.2)	65	11.1 (0;27.8)	29	0.97
Sleep	0 (0; 20)	69	20 (0; 20)	31	0.21

Values are median (25th and 75th centile scores); total number of respondents (N) and number who responded per category (n).
NHP, Nottingham health profile.

comparable with those from another study using a mailed questionnaire.²² It may also be that the Nottingham health profile is not that simple to answer, because people sometimes have difficulty in answering questions that require only a yes or a no, as has been observed by interviewers.¹⁹ Although one can only speculate, it seems likely that the missing values in the study bias the results towards an underestimation of health problems, because it may be expected that some questions were left unanswered when subjects doubted whether the problem was fully applicable to them.

Health status was further examined for different subgroups of respondents. In accordance with the expectation, respondents with physical limitations from residual polio paresis scored higher for physical mobility. However, pain or lack of energy were unrelated to the polio residuals, and the polio residuals did not influence social functioning, emotional reactions, or sleep. The study population was also divided with respect to new neuromuscular symptoms. The health status of respondents with LSP was highly significantly worse for all Nottingham health profile categories in comparison with the

health status of those who did not complain about new neuromuscular symptoms, including muscle weakness. The areas of functioning, physical mobility, energy, and pain were the most compromised among the LSP respondents, which is in accordance with the results from hospital based studies of former polio patients with new neuromuscular symptoms.^{4,5} Major psychopathology has not been found among polio patients with new symptoms.^{26,27} However, although the scores for the Nottingham health profile categories of social isolation, emotional reactions, and sleep—which relate to aspects of psychological and social functioning—were generally low, they were significantly higher for the respondents with LSP than for those without LSP. This might be related to emotional distress resulting from increasing disabilities but could also be a result of uncertainty about the possible effects of their former illness in this population based study group.^{28,29}

Some selection bias may be assumed owing to the non-specific nature of symptoms, which are also found in the general population, though they were far more frequent among the polio subjects.¹⁸ However, in contrast to the sample

Table 4 Perceived health for male and female respondents with late onset neuromuscular symptoms following poliomyelitis (LSP)

NHP category	Female subjects with LSP		Male subjects with LSP		p Value
	(N=55)	n	(N=62)	n	
Physical mobility	25 (12.5; 50)	51	12.5 (0;37.5)	61	0.03
Energy	33.3 (0;66.7)	52	0 (0;66.7)	60	0.06
Pain	25 (0;62.5)	51	12.5 (0;62.5)	59	0.88
Social isolation	0 (0; 20)	53	0 (0; 0)	59	0.005
Emotional reactions	11.1 (0;22.2)	48	11.1 (0;22.2)	56	0.93
Sleep	0 (0; 20)	51	20 (0; 20)	58	0.93

Values are median (25th and 75th centile scores); total number of respondents (N) and number who responded per category (n).
NHP, Nottingham health profile.

studied by Rekand *et al*,¹⁸ the sample in the present study was younger, with 90% of the respondents being under 49 years of age. This probably reduces selection bias, as the prevalence of symptoms in the general population will increase with age, and the same holds true for bias from comorbidity. Furthermore, to reduce selection bias from non-specific symptoms, only respondents with both new muscle weakness and new or increasing neuromuscular symptoms were considered as cases of LSP.

It must be emphasised that our aim was to compare the health status of polio survivors with and without LSP and not to determine the exact prevalence of LSP or postpoliomyelitis syndrome. Interestingly, both respondents with polio residuals and respondents who claimed full recovery reported LSP, which is in agreement with previous results.¹⁸ Not only did a percentage of the recovered respondents report new neuromuscular symptoms, but the impact of these in terms of perceived health problems was comparable to that of new symptoms in the respondents with residual paresis. This was true for all categories except physical mobility, which was primarily related to the presence of residual paresis itself. This finding needs to be interpreted with care as our respondents were not examined physically. It is well known that some polio patients tend to minimise their symptoms and therefore limited residuals may not have been reported.³⁰ Furthermore, polio residuals may be present in apparently fully recovered muscle groups, as determined by manual strength testing,³¹ and residuals may only be recognised with imaging techniques.³² Nevertheless, LSP can also be expected among former polio subjects with no or limited polio residuals, which is supported by reports of subjects with postpoliomyelitis syndrome with a history of remote paralytic poliomyelitis, or even following non-paralytic polio.³³

Although health problems were related to new neuromuscular symptoms, no conclusions can be drawn from our study about whether these symptoms signify progressive loss of muscle strength. In a prospective study by Windebank *et al*,³⁴ of a population based sample of 50 previous polio subjects, no deterioration in muscle strength or performance was found when subjects were re-examined after five years. At baseline, new neuromuscular complaints were experienced by 32 subjects and new muscle weakness by 22, and it was supposed that overuse of weakened muscles was an important factor in the development of new symptoms.⁷ However, after five years these symptoms could be attributed to an alternative cause, such as degenerative joint disease, in two thirds of their symptomatic subjects, and symptoms remained unexplained in only 10 individuals.³⁴ It therefore seems likely that in a proportion of the respondents in our study, the new neuromuscular symptoms do not indicate a progressive strength loss but "secondary" disorders such as degenerative joint disease or other wear and tear pathology of the locomotor system. However, an insidious progressive strength loss may be occurring in some subjects which may only be detected over a period of

many years.³⁵ Thus it would be interesting to follow up a large unselected group of polio subjects prospectively with annual measurements, in order to investigate the influence of new symptoms, comorbidity, and aging on functional status.

More male than female polio victims were reported in 1956, which is in accordance with other observations of a higher incidence of polio in men than in women.^{36, 37} Although the response rate of the male subjects was somewhat lower than the female response rate, no differences were found in the prevalence of new muscle weakness between men and women in the present sample of polio survivors.¹⁰ Interestingly, the perceived health of the women appeared to be significantly worse in the Nottingham health profile categories of physical mobility, energy, and social isolation. Sex differences in the Nottingham health profile scores were also found for respondents with LSP. Why substantially greater numbers of female patients with postpoliomyelitis syndrome consult polio clinics remains puzzling. It may partly reflect a sex difference in problem perception, or it may be that women are more prepared to face the consequences of the new symptoms.

Conclusions

This is the first study to investigate the health status of a population based sample of polio subjects with a generic validated questionnaire, the Nottingham health profile. Perceived health problems were often reported and the areas in which problems were perceived were in agreement with those of polio patients attending health care facilities. Health problems were mainly related to the presence of late onset neuromuscular symptoms following poliomyelitis. New health problems may be expected among polio survivors with new neuromuscular symptoms, not only in subjects with residual paresis but also in those who appear to have made a good recovery.

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