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DISTRESS IN EVERYDAY LIFE IN PEOPLE WITH POLIOMYELITIS SEQUELAE

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The prevalence of distress in aspects of perceived health and its relation to involvement of poliomyelitis sequelae were studied with the Nottingham Health Profile (NHP) in 113 outpatients (mean age 57 years). The leisure and employment situation was also recorded. Most distress was found in the NHP dimensions physical mobility, pain and energy, and least distress in social isolation. Most health-related problems were reported in housework, employment and leisure. Three-quarters of the persons were satisfied with their leisure, although many of them had problems. Fifty-nine per cent of the subjects of working age were in gainful employment, and no difference in employment rate due to the distribution of polio involvement was found. In comparison with norm values for the respective age groups, the subjects with poliomyelitis sequelae aged below 45 and 45–65 years had more distress in a larger number of NHP dimensions than older subjects.

Key words: activities of daily living, post-polio syndrome, rehabilitation, Nottingham Health Profile, leisure, employment.

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INTRODUCTION

It has been reported that 50–85% of the persons who suffered from poliomyelitis about 30–40 years ago are now experiencing new symptoms of increased muscle weakness, fatigue, pain and muscle atrophy (1–6). New or increased muscle weakness is a diagnostic criterion for post-polio syndrome (PPS) according to Gawne & Halstead (7). The new health problems affect the ability of people to manage activities of daily living (ADL), and disability and distress are reported (1, 7–10). The late effects of polio have been described as feelings of becoming disabled for a second time (9, 10). However, studies on psychological and emotional aspects have produced different results. Both high levels (11) and low levels (12, 13) of psychological distress and disturbances of mood (11) have been reported. A recent study by Kemp & Krause (14) showed slightly more depressed people among subjects with polio than in a non-disabled comparison group. Distress in physical and psychological functioning has been found to differ between persons with poliomyelitis sequelae with and without PPS (8, 15), whereas in another study a higher degree of distress was not related to somatic symptoms (12). Further knowledge of these matters would probably contribute to better understanding of these patients and improved intervention measures.

A previous paper reported on the involvement of polio and its relation to ability and perceived difficulty in five personal activities of daily life (P-ADL) (feeding, transfer, washing, dressing and bathing) and four instrumental activities of daily life (I-ADL) (cooking, transportation, shopping and cleaning) in a consecutive group of outpatients with poliomyelitis sequelae (16). The present paper describes the prevalence of distress as measured according to the Nottingham Health Profile (NHP) (17) in the same sample of outpatients with poliomyelitis sequelae.

NHP is a measure of distress in physical and psychological functioning related to chronic disease and major illnesses (18) The instrument has been used in studies with various physical disabilities and conditions (17, 19, 20) and has also been found to detect differences in perceived distress between persons with poliomyelitis sequelae with and without PPS (8, 15). The detailed aims of the present study were: (i) to investigate the prevalence of distress in aspects of perceived health; (ii) to analyse scores in NHP in relation to polio involvement and sociodemographic factors; and (iii) to place emphasis on the leisure and employment situation.

MATERIALS AND METHODS

Subjects

Between September 1994 and June 1996, 133 patients with poliomyelitis sequelae were admitted, either referred by their physician or self-referred, to the special polio unit at the Department of Rehabilitation Medicine, Sahlgrenska University Hospital, Göteborg. From this group 20 patients were excluded: (i) 13 patients with other diagnoses not related to their polio, such as inflammatory joint disease, cancer, post-traumatic stress disorder and solvent-related disorders, which could have considerable influence on their experiences of distress; and (ii) seven people who had not completed the NHP questionnaire owing to difficulties in understanding the questions (four people born in other countries) and for other reasons (three Swedish-born people). The remaining 113 patients (71 women, 42 men; mean age 57, range 15–84,

Table I. *Distribution of subjects into groups according to number of affected body parts and degree of polio involvement in the most afflicted part of the body*

	Afflicted body parts					
NRH post-polio classification	Group 1 (both legs, one or both arms)	Group 2 (both legs)	Group 3 (one leg, one or both arms)	Group 4 (one leg)	Group 5 (one or both arms)	Total
Class II (subclinical polio)	0	0	0	1	1	2
Class III (clinically stable polio)	0	3	0	8	1	12
Class IV (clinically unstable polio)	18	13	7	18	2	58
Class V (severely atrophic polio)	19	14	0	5	3	41
Total	37	30	7	32	7	113

median 59 years) were included in this study. At the time of the study, 14–82 years (mean 48, median 47 years) had elapsed since the onset of poliomyelitis. Of the total group, 88 (78%) subjects were Swedish born and 25 (22%) had been born elsewhere. The latter, multiethnic group was younger (mean 40, range 15–74, median 37 years) than the Swedish-born group (mean 62, range 39–84, median 63 years). The multiethnic group was highly heterogeneous, with 16 nationalities being represented (four Africans, three Americans, seven Europeans and 11 Asians) and at most three subjects from the same country. They had lived in Sweden for between 4 and 35 years. Forty-seven subjects were single, and 66 were married or cohabiting with a partner.

Ninety-seven per cent experienced some new health problems, and 86% had new or increased muscle weakness and fulfilled the criteria of PPS (7). (For a further description, see Ref. 16.)

The study was approved by the Ethics Committee of the Faculty of Medicine, Göteborg University, Sweden.

Procedures

Before the first outpatient appointment at the polio unit a questionnaire concerning demographics, age at polio onset, body part(s) affected, other diseases, new or increased health problems, and mobility assistive devices was mailed to the patients. The questionnaire was completed during the first visit to the physician. The subjects were interviewed in the clinic by an occupational therapist (A-LT-J) using a semistructured questionnaire on ADL, use of assistive devices, social conditions, housing conditions, vocational conditions and leisure activities. For a further description, see the previous paper (16), in which most of these data were reported.

Assessments

The National Rehabilitation Hospital (NRH) post-polio limb classification (7) was used to describe the progress and degree of polio involvement in each of the limbs and the trunk: class I, no clinical polio; class II, subclinical polio; class III, clinically stable polio (no new or increased muscle weakness); class IV, clinically unstable polio (increased muscle weakness); and class V, severely atrophic polio. The attending physician classified the patients on the basis of their medical history, physical examination and an electromyogram (EMG) in at least three to five relevant muscle groups.

The result of the post-polio limb classification was used to place the subjects in subgroups according to the number of affected body parts and degree of polio involvement in the most afflicted part of the body (Table I): subjects with both legs and one or both arms afflicted (group 1), subjects with both legs afflicted (group 2), subjects with one leg and one or both arms afflicted (group 3), subjects with one leg afflicted (group 4), and subjects with one or both arms afflicted (group 5). In some data analyses, the first four groups were combined: groups 1 + 2 and groups 3 + 4. This grouping was used since a difference was found between groups 1 + 2 and groups 3 + 4 in walking speed, a predictor of dependence in mobility-related activities in everyday life, in the previous study (16). Demographic information about subjects distributed into these groups showed a significantly higher mean age (60 years) in groups 1 + 2 compared with groups 3 + 4 (53 years) and significantly more foreign-born persons in groups 3 + 4 than in groups 1 + 2 (Table II).

The NHP (a self-administered questionnaire) in a validated Swedish version was used to describe physical, emotional and social aspects of perceived health (20, 21). NHP part I consists of 38 statements that reflect the subject's degree of discomfort or distress in six dimensions: energy, physical mobility, pain, sleep, emotion and social isolation. Subjects are required to indicate with yes/no answers what problems they are experiencing. Every answer is multiplied by a weight, and a score ranging from 0 to 100 can be calculated for each dimension; the higher the score in a dimension, the greater the number and severity of problems.

The second part (NHP II) contains seven yes/no statements referring to health-related problems within the domains of employment, housework, social life, family life, sexual life, leisure and holidays. Each statement is analysed separately, so that a single domain can be excluded.

The reliability and validity of the NHP questionnaire have been extensively documented in the U.K. (22) and in Sweden (20). The NHP item weights have also been closely replicated in other cultures (language groups) (18). The NHP questionnaire was given to the patient

Table II. *Demographic information on subjects distributed into groups used in the different analyses*

	Age group			Polio involvement		
	≤44	45–64	≥65	Groups 1 + 2	Groups 3 + 4	Group 5
Number	22	49	42	67	39	7
Mean age (years)	34	55	71	60	53	50
Gender[a]						
Women	11 (50)	28 (57)	32 (76)	44 (66)	21 (54)	6 (86)
Men	11 (50)	21 (43)	10 (24)	23 (34)	18 (46)	1 (14)
Nationality[a]						
Swedish-born	4 (18)	44 (90)	40 (95)	57 (85)	25 (64)	6 (86)
Foreign-born	18 (82)	5 (10)	2 (5)	10 (15)	14 (36)	1 (14)

[a] Data are shown as *n* (%).

and collected on the first appointment by the occupational therapist. The item on sexual life was excluded from the analysis owing to an error in printing the questionnaire, which resulted in some missing data. The responses to the NHP were compared with "norm" values, i.e. average scores in two samples of the population: (i) the WHO MONICA Project (monitoring of trends and determinants in cardiovascular disease) (23), a random sample comprising 1562 subjects (women and men) in four age groups, 25–34, 35–44, 45–54 and 55–64 years (Halling & Wiklund, unpublished data); and (ii) the longitudinal population study IVEG (the Intervention Study of the Elderly in Göteborg), a study among 76-year-old ambulant citizens (19).

Three subjects in the present study were younger than 25 years. Since their scores in NHP did not differ from scores in the youngest age group (≤44 years), they were included in that group and compared with the corresponding age groups from the WHO MONICA Project.

Subjects' vocational activities were classified according to the Swedish Classification of Occupations 1996 (SSYK 96) (24), which is a national adaptation of the International Standard Classification of Occupations (ISCO-88) (25). The classification organizes vocational activities into a hierarchical framework based on two main concepts: kind of work performed and skill (skill level and skill specialization). If subjects had problems at work they were asked to describe their difficulties. The subjects were also asked: "How do you get on at work?" Four alternatives on an ordinal scale were given: 1, very well; 2, rather well; 3, not very well; and 4, not at all.

Subjects were asked to describe their leisure activities, and whether and how they had changed their pattern of leisure activities as a result of new health problems. They were also asked to rate on a four-level ordinal scale how satisfied they were with their leisure: very satisfied, largely satisfied, rather dissatisfied and very dissatisfied. In some analyses the four-level scale was dichotomized, to separate those who were satisfied from those who were dissatisfied.

Statistics

The distribution of variables is given as means, median, S.D., ranges and percentiles. For comparison between independent groups the Mann–Whitney *U*-test was used. The χ^2-test and Fisher's exact test was applied to compare differences between proportions of groups. To facilitate comparison with norm values the mean was calculated for NHP part I and the Student's two-sample *t*-test was used. All hypothesis tests were two-tailed and performed at the $\alpha = 0.05$ level of significance. Multiple comparisons between independent groups was adjusted according to the Bonferroni–Holm stepwise method (26).

RESULTS

The NHP part I demonstrated that subjects reported most distress (highest median scores) in the dimensions of physical mobility, pain and energy and least distress in social isolation. Comparisons with norm values (Halling & Wiklund, unpublished data; 19) showed that women with polio in general had significantly higher distress scores in the dimensions of physical mobility and pain (Fig. 1). Women in the age group ≤44 years had significantly higher scores for distress than norm values even in the dimensions energy, sleep, emotion and social isolation. Men with polio in general had significantly higher scores for distress than the norm values in the dimension physical mobility. Men in age groups ≤44 and 45–64 years had significantly higher distress scores in the dimensions pain, sleep and emotion compared with norm values. Significant differences between the age groups with polio were only found in emotion: women ≤44 years reported more distress than women in the age group 45–64 years (Fig. 1) and men ≤44 years had higher scores for distress than men ≥65 years old (Fig. 1). No significant difference was found between women and men in any of the age groups in the dimensions in NHP part I.

Subjects in the multiethnic group had significantly higher distress scores in the dimensions of pain and emotion than Swedish-born subjects (Fig. 2). Four Swedish-born subjects included in the youngest age group (≤44 years) had similar or higher scores for distress than subjects in the multiethnic group.

When divided into groups according to polio involvement, subjects in group 1 + 2 (both legs affected) affirmed significantly more distress in physical mobility than subjects in groups 3 + 4 (one leg affected), whereas groups 3 + 4 showed higher scores (more distress) in emotion than groups 1 + 2, but this result was not significant after correction according to the Bonferroni–Holm method (Fig. 3). The subjects in group 5 showed high median scores for distress in energy, sleep and emotion (Fig. 3).

When divided into groups according to the post-polio classification, subjects in class IV (clinically unstable polio) showed higher scores (more distress) in pain and emotion than subjects who had severely atrophic polio (class V), but these results were not significant after correction according to the Bonferroni–Holm method.

In NHP part II, most health-related problems were reported in the domains housework (64%), employment (53% of the subjects of working age, i.e. 16–64 years, subjects with full disability pension and in education excluded) and leisure (50%) (Table III). Forty per cent reported problems with their holidays, whereas family life was least affected. Significant differences between the groups according to the polio involvement were only found in housework and family life. Housework caused problems for significantly more subjects with both legs affected (groups 1 + 2) than persons with one leg affected (groups 3 + 4). Subjects with one or both arms affected (group 5) reported significantly more health-related problems in family life than subjects in groups 1 + 2. More subjects in groups 3 + 4 affirmed problems in employment compared with subjects in groups 1 + 2, but the result was not significant after correction according to the Bonferroni–Holm method. No significant difference in NHP part II was found between women and men or between the multiethnic and the Swedish-born groups.

Comparisons with the norm values (Halling & Wiklund, unpublished data; 19) showed that significantly more women with polio affirmed problems in domains in daily activities, with the exception of the oldest age group (≥65 years), where no significant difference was found in family life (Fig. 4). Significantly more men with polio, irrespective of age group, stated problems in housework compared with norm values. Significantly more men with polio in the age groups ≤44 years and 45–64 years affirmed problems in leisure and holidays than male norm values. More men in the youngest age group (≤44 years) reported problems in the domains employment and social life compared with norm values (Fig. 4).

Table IV shows that subjects with problems in housework and holidays had significantly higher distress scores in the dimensions energy, physical mobility and pain than subjects without

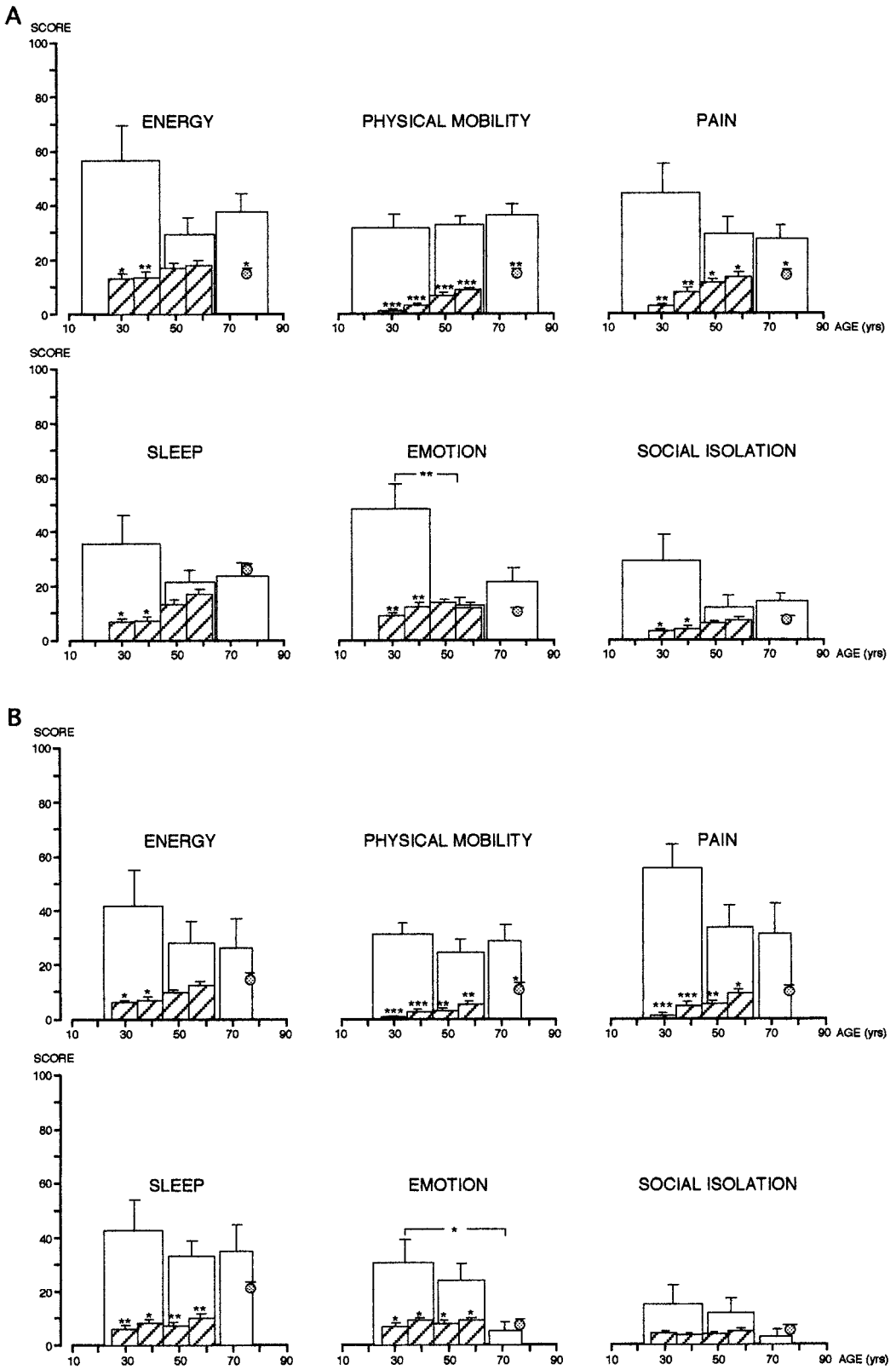

Fig. 1. Distribution of mean scores (out of 100) and s.e.m. in the six dimensions of Nottingham Health Profile (NHP) part I for three age groups (≤44, 45–64 and ≥65 years) of women (A) and men (B) with poliomyelitis sequelae (□) compared with norm values from two populations: (i) a random sample of the population (Halling & Wiklund, unpublished data) in age groups 25–34, 35–44, 45–54 and 55–64 years (▨); and (ii) a systematic selected sample of the population of 76-year-old ambulant persons (19) (●). After correction according to the Bonferroni–Holm method (29), * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

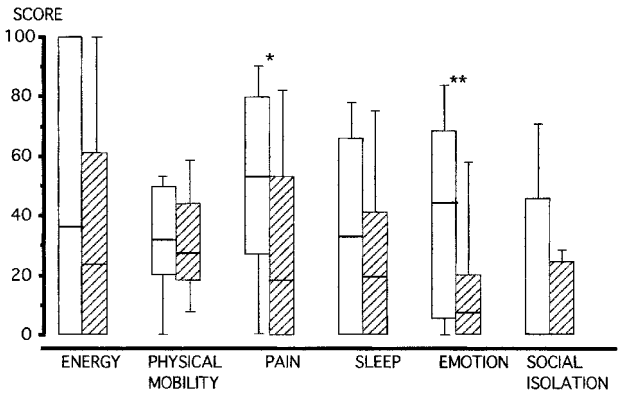

Fig. 2. Distribution of values of the Nottingham Health Profile (NHP) part I for the multiethnic ($n = 25$) (□) and the Swedish-born ($n = 88$) (▨) groups. Median values, 10th, 25th, 75th and 90th percentiles and significant differences between the groups are given. After correction according to the Bonferroni–Holm method (29), * $p < 0.05$, ** $p < 0.01$.

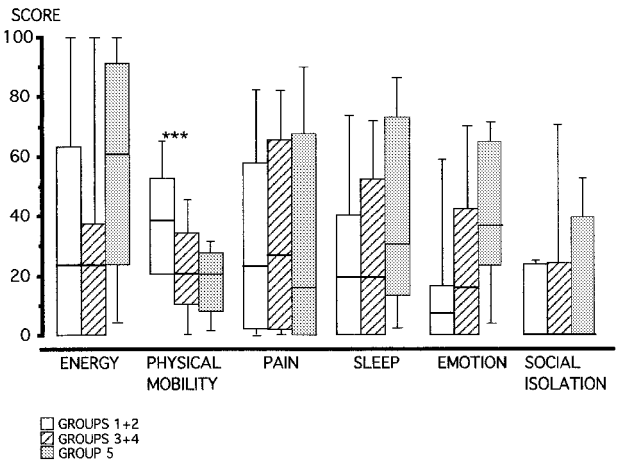

Fig. 3. Distribution of values of the Nottingham Health Profile (NHP) part I for groups with different numbers of afflicted body parts. Median values, 10th, 25th, 75th and 90th percentiles and significant differences between the groups are given ($n = 113$). After correction according to the Bonferroni–Holm method (29), *** $p < 0.001$.

such problems. Those who affirmed problems in social life scored more distress in energy, physical mobility, pain, emotional reactions and social isolation. Subjects with problems in family life indicated significantly higher distress scores in all dimensions, with the exception of physical mobility, compared with those who stated no problems. Higher distress scores in the dimensions energy, pain, emotional reactions and sleep were found in people who perceived problems in leisure compared with those who did not affirm such problems. However, subjects with problems in employment did not report more distress than subjects without such problems. When the multiethnic group was excluded some differences in distress levels between subjects with problems and those without were changed to non-significant differences, whereas others became significant.

Despite reported problems in the domain leisure, 75% of the subjects were satisfied (very satisfied 22% rather satisfied 53%), whereas 25% were dissatisfied (rather dissatisfied 15%, very dissatisfied 10%) with their leisure. No significant difference was found between women and men, between the multiethnic and Swedish-born groups, between groups with different involvement of polio, or between subjects who were single or were cohabiting with a partner. Seventy-two subjects (64%) reported that they had altered their leisure activities: reduced physical activities (23%), diminished social activities (5%), diminished the pattern of leisure activities (28%), developed/changed activities (6%) or reported a lack of activities (2% with disability pension). No significant difference in alteration was found between women and men or between subjects in the multiethnic and Swedish-born groups. Significantly more subjects in the oldest age group (≥65 years) had altered their leisure activities than younger subjects (≤44 years). Significantly more subjects in polio class IV (increased muscle weakness) reported

Table III. *Distribution of health-related problems in six domains of daily life according to NHP II for groups of subjects with different numbers of body parts afflicted by polio*

Domain of daily life	Groups 1 + 2 $n = 67$ n (%)	Groups 3 + 4 $n = 39$ n (%)	Group 5 $n = 7$ n (%)	Total $n = 113$ n (%)	Groups 1 + 2/3 + 4 p-Value	Groups 1 + 2/5 p-Value	Groups 3 + 4/5 p-Value
Employment	13 (38) ($n = 34$)	17 (71) ($n = 24$)	3 (75) ($n = 4$)	33 (53) ($n = 62$)	0.014	0.291	0.999
Housework	48 (73)	18 (46)	6 (86)	72 (64)	0.007*	0.668	0.098
Social life	22 (33)	12 (31)	2 (29)	36 (32)	0.826	0.999	0.999
Family life	9 (14)	7 (18)	5 (71)	21 (19)	0.581	0.003*	0.010
Leisure activities	33 (49)	20 (51)	4 (57)	57 (50)	0.840	0.999	0.999
Holidays	31 (46)	11 (29)	3 (43)	45 (40)	0.082	0.999	0.659

Comparisons between groups are given (p-value). For employment, subjects with full disability pension, subjects in education and subjects aged ≥65 are excluded.
Groups 1 + 2: subjects with both legs and probably one or both arms afflicted.
Groups 3 + 4: subjects with one leg and probably one or both arms afflicted.
Groups 5: subjects with one or both arms afflicted.
After correction according to the Bonferroni–Holm method (29), * $p < 0.05$.

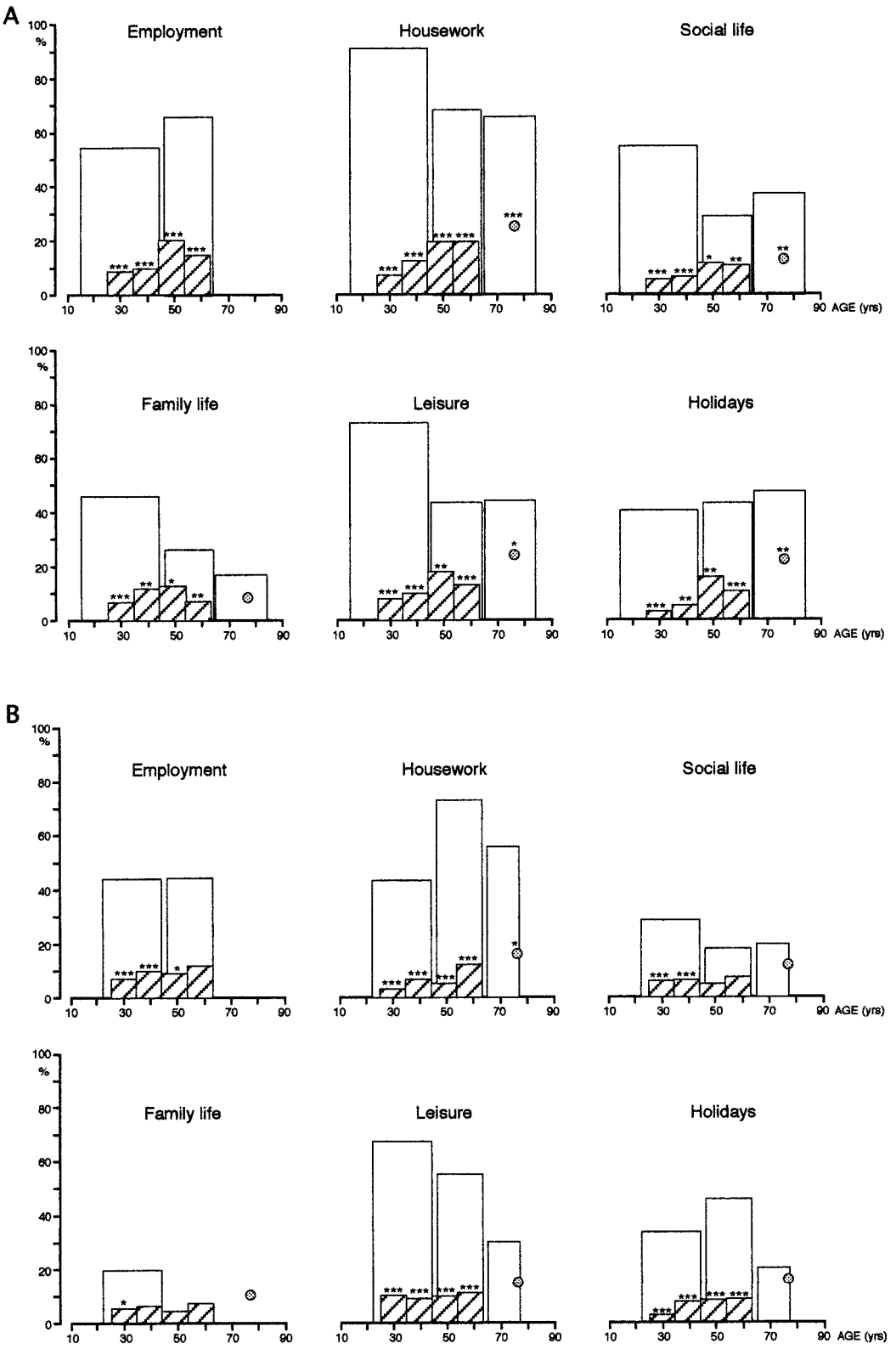

Fig. 4. Proportion (%) of women (A) and men (B) with poliomyelitis sequelae (≤44, 45–64 and ≥65 years) (□) affirming health-related problems in six domains in daily activities, Nottingham Health Profile (NHP) part II. Comparison with norm values from two populations: (i) a random sample of the population (Halling & Wiklund, unpublished data) in age groups 25–34, 35–44, 45–54 and 55–64 years (▨); and (ii) a systematic selected sample of the population of 76-year-old ambulant persons (19) (⊗). After correction according to the Bonferroni–Holm method (29), * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.

Table IV. *Median scores of the Nottingham Health Profile (NHP) part I (ranging from 1 to 100) related to proportions of subjects with and without problems in six domains of daily life (NHP II)*

	NHP I											
	Energy		Physical mobility		Pain		Emotional reactions		Sleep		Social isolation	
NHP II	Md	*p*	Md	*p*	Md	*p*	Md	*p*	Md	*p*	Md	*p*
Employment												
Problem ($n = 33$)	23.8	0.1875	31.7	0.0833	27.3	0.9660	16.3	0.5599	33.1	0.1379	0	0.6633
No problem ($n = 29$)	23.8		20.6		28.4		8.6		11.1		0	
Housework Problem ($n = 72$)	23.8	0.0002***	38.1	0.0001***	31.8	0.0066*[a]	11.9	0.1285	22.3	0.2753	0	0.0349
No problem ($n = 40$)	0		20.3		10.9		8.1		11.1		0	
Social life Problem ($n = 36$)	36.8	0.0052*	40.0	0.0007**	49.2	0.0008**	31.1	0.0050*	33.1	0.6684	22.9	0.0005**
No problem ($n = 77$)	23.8		24.5		18.5		7.7		19.6		0	
Family life Problem ($n = 21$)	60.6	0.0002***	34.7	0.2295	52.6	0.0049*	37.0	0.0001***	33.1	0.0095*	21.6	0.0025**
No problem ($n = 87$)	23.8		27.6		20.6		7.7		11.1		0	
Holidays Problem ($n = 45$)	23.8	0.0040*	41.5	0.0001***	29.4	0.0237*	16.3	0.0136[b]	33.1	0.1710	0	0.0142[b]
No problem ($n = 67$)	0		20.6		18.7		0		11.1		0	
Leisure Problem ($n = 57$)	36.8	0.0010**[a]	32.4	0.1528	45.9	0.0001***	16.7	0.0001***	33.1	0.0026**[a]	0	0.0692
No problem ($n = 56$)	11.9		27.6		8.2		0		11.1		0	

Comparisons between the proportions are given (*p*-value).
After correction according to the Bonferroni–Holm method (29), * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$.
[a] No significant difference when the multiethnic group was excluded.
[b] Significant difference when the multiethnic group was excluded.

that they had altered their leisure activities compared with subjects in polio class II + III (subclinical and clinically stable polio) and polio class V (severely atrophic polio).

Eighty subjects (71%) were at an occupationally active age (16–64 years), whereas 32 (28%) received a retirement pension and one person was younger than 16 years. Of the 80 subjects of working age 25 persons (31%) were in full-time employment, 22 (28%) worked part-time, nine (11%) had a job but were currently on the sick-list, six (7%) were unemployed, two (3%) were in education and 16 (20%) received a full disability pension. The most frequent vocational occupations were clerks (27%), professionals (20%), and technicians and associate professionals (13%). No significant difference in vocational occupations was found between groups that could be related to the number of afflicted body parts. Thirty subjects (54% of subjects in employment or on the sick-list) reported problems at work. The most common problems were tasks that involved standing/walking, lifting/carrying, monotonous work and outdoor work. Despite problems, 49 subjects (88%) answered that they got on well at work ("very well" 48%, "rather well" 40%), whereas three subjects answered "not very well" and one subject "not at all".

DISCUSSION

The results show that the prevalence of distress in people with poliomyelitis sequelae was highest in the physical health dimensions physical mobility, pain and energy, and lowest in social isolation. High scores for distress in that triad of dimensions were in agreement with other studies in people with poliomyelitis (8, 15, 27), even though one study (15) reported most distress in energy. However, the scores for distress in all dimensions except for social isolation were lower than those reported in a study in persons with arthrosis of the hip joint (20).

The present study was based on a consecutive clinical group. The subjects showed a wide range in age, involvement of polio, years since onset, experience of distress and ethnic composition. Therefore, with the number of subjects, there are limitations in the statistical analyses.

Not unexpectedly, most distress in the physical mobility dimension was found among subjects in groups 1 + 2 (both legs affected). However, distress in this dimension was not reflected in the psychological and social dimensions. The findings in the present study indicate that subjects with more involvement of polio were fairly well adapted to their disability. A large proportion (73%) of subjects in groups 1 + 2 had health-related problems in carrying out housework, but in the other domains, such as employment, social and family life and leisure, the proportions of subjects with problems were about the same as (or less than) in groups 3 + 4 (one leg affected) or group 5 (only affected in the upper extremities). Follow-up studies are needed to investigate how both age and polio involvement influence the prevalence of distress over time. In another study it was suggested that subjects seemed to be more distressed the closer they were to the onset of the stressor (13).

There were relatively few persons with only the upper extremities affected (group 5), as found in an earlier report

(7). As expected, the subjects had lower distress scores in physical mobility than subjects with both legs affected (groups 1 + 2). In the previous study on the same population (16), these subjects reported difficulties in several daily activities. Probable consequences were seen in the present study, since they reported high levels of distress in the emotional dimension and significantly more people experienced problems in family life compared with persons with polio involvement in their legs. These findings suggest that increasing muscle weakness in the upper extremities might influence activities and roles in daily life to a great extent and is probably more difficult to compensate for than weakness in the lower extremities. It would be advisable to perform a careful evaluation of the abilities and problems of this group in clinical practice.

Twenty-two per cent of the subjects were foreign born, compared with 9.7% (1996) in the total population in Sweden (28). Subjects in the multiethnic group reported higher distress scores in the dimensions pain and emotion than the Swedish-born subjects. This finding was in agreement with other reports that have shown increased self-rated poor health among immigrants compared with Swedes, as well as increased vulnerability to psychological distress and illness (29, 30). A number of factors (not investigated in the present study) may account for these differences, including the migration process, refugee status, low social class and poor social network (30).

The differences due to "ethnicity" raise the question that aspects other than consequences of poliomyelitis sequelae might be reflected in the results. The NHP questionnaire measures perceived distress, which is a subjective evaluation and related to values and expectations as well as social comparison. The reported distress in all of the subjects might therefore be influenced by individual living conditions and psychosocial stress, in addition to polio (31).

When comparing groups it is important to obtain norm values (31). The two random samples of the population (19, 23) which provided the norm values in the present study were not completely compatible with each other or with the present population. The age group ≥65 years (median 71 years) was compared with a 76-year-old population of women and men (19). This difference in age might imply some higher norm values, but since these norm values were based only on ambulant persons who were able to visit an outpatient clinic, the difference may be insignificant. The norm values provide information about age groups and gender, but no distinction is drawn between Swedish-born and foreign-born populations.

It has been suggested that women are more likely to mention problems and expose distress than men (17). However, this supposition was not supported by the findings in the present study, since no difference was found between women and men. Both women and men in the youngest group (≤44 years) reported higher levels of distress than norm values in all dimensions of NHP I, with the exception of the men's score for social isolation. This result may reflect the presence of the immigrant group, since they made up three-quarters of the youngest age group. However, there is a risk of overemphasizing this cultural interpretation. High levels of physical and emotional distress might also be associated with actual age and a perception of a disrupted life-course, because new health problems may prevent these people from having the kind of lifestyle that they had expected. Each stage in the normative life-course is accompanied by expectations and tasks (32). Subjects aged 44 years and younger were in a stage in their life-course (adolescence, work–marriage–family) which implied roles and patterns of activities that might be difficult to manage with a disability, particularly in a time of increasing disability. Previous studies have reported that people try to continue to fulfil goals and role expectations (32–34), which may result in a risk of overload and secondary pain (27).

Both women and men with polio, but particularly women, had problems in domains of daily life to a greater extent than the general population. This experience of problems was, however, not reflected in emotional distress either among women aged 45 years and over or among men in the oldest age group. Fewer differences between older persons with polio and the general population were seen in respect to both distress and perceived problems, which may reflect adaptation to disabilities. However, it might also indicate lower expectations due to acceptance of the life-course (retirement and old age) (32).

Leisure implies opportunities for enjoyment, recreation, personal growth, achievement and relaxation (35). A positive finding was therefore that the perception of problems in the domain of leisure did not amount to dissatisfaction. Despite reported problems by half of the subjects, three-quarters of the whole group were very satisfied or satisfied with their leisure. It is important not to draw causal conclusions from this study, but the results indicate that pain and lack of energy prevented leisure activities to a larger extent than physical mobility per se. More emotional distress was reported among subjects who affirmed problems in leisure. Among those who had altered their leisure activities some were satisfied and others were dissatisfied. In clinical practice, patients with polio are often recommended to save energy. When offering guidance on how to change their activities, it is important to remember that giving up activities might result in a feeling of frustration, whereas setting priorities, which involves consideration and choice, generally results in more positive feelings. It is also essential to compensate for lost activities in some way (34).

More than half (59%) of the subjects of working age were in gainful employment, compared with just over two-thirds (71%) of the population in Sweden (28). Full-time work was less common among the employed subjects in this study (53%) than in the total workforce (74%) (28). Those subjects who perceived health-related problems at work did not show higher levels of distress in any dimension of NHP than subjects without such problems. These findings and the fact that there was no difference in the employment rate between the groups due to polio involvement indicate that this was not a deciding factor. Problems at work might, however, be more common among subjects with one leg affected (groups 3 + 4). One reason for this might be that persons severely affected with polio had been

forced to choose or been encouraged to take up a suitable trade or profession earlier in life, whereas persons with less polio involvement had not needed such careful planning. The importance of finding a suitable vocational occupation with satisfactory accessibility and appropriate equipment should be emphasized in post-polio management.

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