

DISABILITY AND HANDICAP IN LATE POLIOMYELITIS

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ABSTRACT. The impact of long-standing polio sequelae in terms of disability and handicap was studied in 41 patients (17 men and 24 women, mean age 54 years). Twenty-nine (71%) of these met the criteria for post-polio syndrome. The Katz' ADL index, the Functional Status Questionnaire (FSQ), selected questions concerning social needs and support and the WHO ICIDH-Classification of handicaps were used. A substantial impact on intermediate (secondary or instrumental) ADL was a consistent finding, most severely affecting the quality of mobility. This emphasizes needs for individual rehabilitation services including transportation, walking and domestic aids.

Key words: disability, handicap, poliomyelitis, activities of daily living (ADL).

In recent years attention has been drawn to people who suffered poliomyelitis three or more decades ago (cf. 5, 7). Their main complaints are muscle weakness, muscle soreness and pain, unaccustomed fatigue and sleep disturbances. A consequence of muscular weakness and fatigue is fading in voluntary muscle contraction and loss of function.

The literature on clinical problems in persons with antecedent polio dealing especially with impairment has increased specially since 1985 (5). On the other hand the literature on disability and handicap concerning postpolio problems is still rather scarce.

For the purpose of describing the functional consequences of disease in this category of patients a broad study was undertaken of muscle structure and function as well as aspects on impairment, disability, handicap and need for social and medical support. The results from the studies of muscle structure and function, and impairment have been published elsewhere (2, 4).

In the study presented here, an attempt is made to compare different ratings of "disability" and "handicap" as those terms are defined in the International Classification of Impairments, Disabilities and

Handicaps (8); "... disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for human beings", and "... a handicap is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual".

We are aware of the problems that may arise in distinguishing between disability and handicap in the sense of the WHO ICIDH-Classification (cf. 3), but will here use "handicap" as an operational term with its different dimensions for classification.

In the present study possible consistencies are sought between several recognized methods of investigation thus creating a more reliable compilation of results. Functional consequences of concern in this study were impacts on primary ADL, secondary or instrumental ADL and social and emotional problems.

STUDY POPULATION

For the recruitment to this study an attempt was made to discover all polio survivors in the city of Gothenburg, Sweden, and in certain neighboring communities. Registrations of the diagnoses "poliomyelitis acuta" and "poliomyelitis sequelae" were sought at the Department for Contagious Diseases at The Östra Sjukhuset (earlier The Epidemics' Hospital), Gothenburg. Tracing backward was possible to the year 1950. In addition, membership registrations of the regional branches (for the Gothenburg Region) of "The Swedish National Association for the Disabled" and "The Swedish National Association of the Traffic Accident- and Polio-Disabled" were utilized.

Of 154 persons discovered, 68 survivors under the ordinary retirement age of 65 years were traced and 41 of these agreed to participate in our study. The upper age limit of the study population being 65 years, the lower limit was set at 40 years and other inclusion criteria were a long-standing polio condition of at least 25 years and residence in the city of Gothenburg or certain surrounding communities. The participants in the study were 17 men (aged 42-63, mean 53 years) and 24

women (aged 41–65, mean 55 years), the mean age of the group as a whole being 54 years.

The age at onset of polio ranged from a few months of age to 34 years, mean age 13 years. Duration from onset of polio ranged from 25 to 61 years with an average of 41 years. According to the patient history, the time of improvement from the impact of acute disease ranged from 1 to 18 years, on the average 4.5 years, to a functional recovery designated as "best function". By this expression we understand a state of neurologic and functional stability which was reached by all our patients, and with the exception of 6 subjects all had experienced this stability for more than 15 years. Twenty-nine of the patients in this study suffered "new" symptoms of muscle function deterioration identical to those suggested by Halsted (6) in his definition of the "post-polio syndrome": "1) a confirmed history of paralytic polio; 2) partial to fairly complete neurologic and functional recovery; 3) a period of neurologic and functional stability of at least 15 years' duration; 4) the onset of two or more of the following health problems since achieving a period of stability: unaccustomed fatigue, muscle and/or joint pain, new weakness in muscles previously affected and/or unaffected, functional loss, cold intolerance, new atrophy; 5) no other medical diagnosis to explain these health problems." The duration of these "new" symptoms varied from 1 to 30 years with an average of 10 years.

Seventy-five per cent of the subjects were married and shared housing and other living conditions with their spouse, the remaining persons lived alone as single, widow/er or divorced.

All measurements and evaluations of each individual subject in this study were performed on the same day. Informed consent was given by all subjects and the procedure was approved by the Ethical Committee of the Faculty of Medicine, Gothenburg University, Sweden.

METHODS

For the classification of disability and handicap, four instruments were used. 1) The Katz' ADL-index (10); 2) The Functional Status Questionnaire (9); 3) Selected questions of our own construction concerning functional recovery and ability, social conditions, needs and support; and 4) the WHO ICIDH-Classification of handicaps in ICIDH (8).

Details regarding these instruments are given in the following:

1) For the purposes of the study we used a Swedish version of the Katz' ADL-index (1) of primary activities of daily living which actually registers 5 activities and 1 function. The evaluation was performed by the same person, a senior physiotherapist, in all subjects.

2) The second instrument for grading consequences of disease used in this study was the Functional Status Questionnaire (FSQ), a brief, standardized, self-administered questionnaire designed to provide a comprehensive and feasible assessment of physical, psychological, social and role function in ambulatory patients (9). The FSQ comprises 34 core items scoring 6 summary scale scores and 6 single-item scores. Those 6 summary scales are placed within 3 categories: 1) Basic (primary) activities of daily living (ADL) and Intermediate (instrumental- or secondary-) ADL; 2) Mental

health (feeling of well-being) items from the Mental Health Inventory (MHI), a measure of psychological distress and well-being developed for use in general populations (12); and 3) Work performance, Social activity and Quality of interaction. The 6 single-item scores deal with: work situation, health status/bed confinement, sexual relationships, social activities and general life satisfaction. All items apply to the subjects' situation during the past month and numerical values are given according to difficulty in performance.

Scale scores (SS), are calculated according to:

$$SS = \frac{\left(\sum_{i=1}^n y_i \right) - n}{n} \times \frac{100}{k}$$

where

SS = transformed FSQ scale score

y_i = individual questionnaire response score

n = number of questions in the scale for which valid information is available

k = maximum minus minimum valid response score (the numerical values given in the 6 summary scales being 1 to 4 or 1 to 6 leaving k -values in the FSQ either 4–1=3 or 6–1=5).

Transformed scale values range from 0 to 100 with a score of 100 indicating maximum functional ability.

A Swedish version/translation of the questionnaire was made by a professional translator; the translation was reviewed and some minor modifications due to cultural and social differences between North America and Sweden were made by the authors together with one of the authors of the original description of the instrument (A. Jette).

Five categories of scale scores were used to calculate scale values and for evaluation of internal consistency reliability using the coefficient Cronbach's alpha, which ranges from 0 to 1 where 1 equals perfect reliability. These categories were: Primary ADL, Intermediate- (instrumental-) ADL, Mental function (well-being), Social activities and Quality of interaction. A sixth class, Work situation/performance was not possible to evaluate because of the low response rate. Analyses of construct validity between the 5 categories of scale scores and 3 "health related" variables of the single-item scores were performed as well as correlations between the 5 categories. The form was mailed to all subjects and returned anonymously after completion of the clinical examination. The return rate of successfully completed forms utilizable for evaluation was 35 (of 41 subjects in all) with the exception of the questions on "employment" (work situation/performance).

3) The questions regarding performance in everyday activities, social conditions, needs and support were constructed by us to be appropriate in this category of subjects. There were 37 questions in our form which was mailed to all subjects prior to physical examination and on that occasion the investigating physician reviewed the form together with the patients to clarify occasional doubts. The results of the 17 questions strictly concerning disability and handicap are presented here, while questions concerning impairment are to be published later and questions regarding social and material conditions are neglected in this study except for the demographic information above.

Table I. Gratings of polio subjects according to Katz' ADL index of primary (basic) activities of daily living

Primary ADL-activity	Number of subjects		
	Independent ^a	Partly dependent	Dependent
Bathing	32	3	4
Dressing	36	2	1
Going to the toilet	38	—	1
Transferring	38	—	1
Feeding	38	1	—
Continence (function)	39	—	—

^a Independent means without supervision, direction or active personal assistance.

4) The evaluation of handicaps according to the ICDH (8) was made for 5 of the 6 "key dimensions" defined as "survival roles", each with gradings from 0 to 8 as exemplified below:

Orientation handicap: Orientation to surroundings including reciprocation or interaction with surroundings (such as seeing, listening, smelling or touching), 0=fully oriented, 1=fully compensated, e.g. using appropriate spectacles, 8=unconscious.

Physical independence handicap: Independence in regard to aids and the assistance of others (self-care and other activities of daily living), 0=fully independent, 2=adapted independence, e.g. of modification or adaptation in the environment by a wheelchair or domestic adaptation, 8=intensive care dependence.

Mobility handicap: The individuals' abilities augmented, when appropriate, by a prosthesis or other physical aids, including a wheel-chair (all these should have been identified in categories 1 or 2 of Physical independence handicap), 0=fully mobile, 3=reduced mobility, such as inability to cope with public transportation in all circumstances or difficulty in getting to and from activities which are at some distance from the individual's dwelling, including the use of licensed handicap transport, 4=mobility restricted to neighborhood, 8=total restriction of mobility (confined to bed).

Occupation handicap: The ability to sustain appropriate occupation of time during the working day, 0=customarily occupied, 4=part-time retired, 5-6=full-time retirement, 0=unoccupiable.

Social integration handicap: Individuals' level of contact with a widening circle, from reference point of self, 0=socially integrated, 2=restricted participation—the individual does not participate in the full range of customary social activities, 4=difficulty in sustaining relation with secondary contacts, 8=socially isolated. The evaluation was performed by the examining physician at the time of the interview and physical examination.

Statistics

Conventional methods were used for descriptive statistics. Correlation analyses were made with Spearman's rank correlation test.

RESULTS

1) The polio survivors in this study demonstrated a high degree of independence in primary activities of daily living according to the Katz' ADL index as shown in Table I. Overall performance showed 32 fully independent subjects, 6 partly dependent and 1 dependent in these 6 primary activities.

2) The analysis of the FSQ showed considerable independence in Basic (primary) ADL as revealed in the question of the form dealing with personal care (eating, dressing and bathing), where 26 subjects had no difficulty, 8 had some difficulties and 1 did not perform for health reasons. Difficulties were more common in Intermediate (secondary or instrumental) ADL as shown in Table II. The subjects' feeling of well-being (Mental functions in the FSQ) is shown in Table III and displays minor or moderate disturbances. Participation in Social activities was fairly frequent among the polio subjects although more demanding activities, as taking care of others, demonstrated increased difficulties (Table IV).

Scale values for the 5 categories of scale scores were high or fairly high except for the category Intermediate (instrumental or secondary) ADL as shown in Fig. 1. The internal consistency reliability using the Cronbach's alpha coefficient was acceptable for all 5 categories of scale scores (Table V).

Restricted activity days (usual activities cut by at least one half) because of illness or injury during the past month were reported and 25 persons had no such day, 9 persons reported 2-8 days, 2 persons 10 days and 1 person 17 days of restricted activity. Examination of the frequency of social contacts showed that 25 persons had contacts every day or several times a

Table II. *Difficulty in carrying out intermediate (instrumental) ADL activities during the past month*

	Number of subjects				
	No difficulty	Some difficulty	Much difficulty	Refrained for health reasons	Refrained for other than health reasons
Walking several blocks	4	8	14	6	3
Walking one block or climbing one flight of stairs	9	16	6	2	2
Walking indoors	20	10	1	1	2
Doing light work around the house	6	16	10	2	1
Doing vigorous activities, running, lifting heavy objects etc.	1	2	12	16	4

week, 5 persons were in contact with friends or relatives once a week and 5 persons with less frequency although none less than once a month. No one reported total social isolation. Five subjects were very satisfied and 15 were satisfied with their health status but as many as 13 were not sure and 3 were dissatisfied.

To analyze construct validity, correlations were sought between the individual FSQ scale scores and 3 "health related" variables (Table VI) and showed significant correlations for Primary ADL, Intermediate ADL and Mental function to restricted activity days and health satisfaction. In addition, Social activities were significantly correlated to health satisfaction as well as to frequency of social contacts. The Quality of interaction scale score, however, did not correlate

significantly to any of the "health related" variables. Significant correlations were found between all scale score categories (Table VII) except for Quality of interaction which only correlated to Mental function (well-being).

3) As seen in Table VIII, 28 subjects had personal assistance in the household (spouses not counted) and 13 persons were independent. The type of help given was usually not regarding primary ADL activities as demonstrated in the Katz' ADL index. The most frequent tasks undertaken by the home assistant were "cleaning and similar arduous labor" in which help was given to 11 subjects. In addition, 7 subjects required shopping assistance together with "cleaning etc.". Only one person had shopping assistance as a

Table III. *Feeling of well-being (also called Mental functions) during the past month*

Mental functions	Number of subjects					
	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
Feeling nervous	–	–	4	3	10	19
Feeling calm and peaceful	10	13	4	4	5	–
Feeling downhearted and blue	–	–	2	8	11	15
Being a happy person	9	7	7	8	2	2
Irritable toward those around	–	–	–	6	10	20
Unreasonable demands on family or friends	–	–	–	6	7	23

Table IV. The usual difficulty with which social activities were carried out during the past month

Social activity	Number of subjects				
	No diffi- culty	Some diffi- culty	Much diffi- culty	Refrained for health reasons	Refrained for other than health reasons
Visiting with relatives or friends	23	7	4	1	—
Participating in community activities	22	6	5	1	2
Taking care of others such as family members	13	13	4	3	2

single dependent function and the remaining subjects reported various combinations of help requirements in "cleaning", "shopping", "cooking", and "personal hygiene and care".

Telephone use was performed with ease by all but one subject who reported slight difficulty in this function. Handwriting was easily performed for 38 persons, one had slight and another greater difficulty. Thirty-five persons could set a wrist-watch with ease, while the remaining 6 had slight or greater difficulty due to paralysis in hand muscles.

There were great problems in the use of public transportation and serious difficulties in standing up from a sitting position (Table IX). Only 9 persons never used transportation aids of any kind, while 27 reported constant use of such aids, walking sticks and/or crutches including braces/bandages being the most common, more or less utilized by 23 subjects. Nine persons used a wheel-chair and 7 of these re-

garded themselves as wheel-chair confined. Thirty of the subjects had a special handicap-transportation licence issued by The Public Transportation Company of the City of Gothenburg and Vicinity in cooperation with the Health Authorities of the region. Eight persons held a licence for transportation with specially equipped vehicles and not only for a taxi/limousine. Six persons with problems in using public transportations were identified as not having a handicap transportation licence.

Twenty-five of the polio subjects were employed at the time of this study and 18 of these had full-time jobs. The vast majority of the employed persons held occupations of administrative or white collar type and only about one fifth were blue collar workers. Retirement of the remaining 16 subjects was caused in all cases by the functional consequences of poliomyelitis. Their age at retirement was evenly distributed from the age of 20 and upwards. The employment

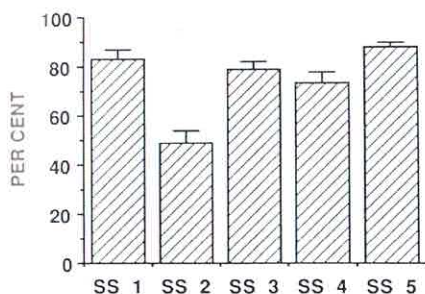


Fig. 1. Scale scores in percentage of maximum values (with SEM) for the categories: Primary (basic) ADL, SS1, Intermediate (secondary or instrumental) ADL, SS2, Mental function (well-being), SS3, Social activities, SS4, and Social interaction, SS5.

Table V. Internal consistency reliability of 5 categories of scale scores using the coefficient Cronbach's alpha

Scale score categories	Cronbach's alpha coefficient
Primary (basic) ADL	0.77
Intermediate (secondary or instrumental) ADL	0.87
Mental function (well-being)	0.88
Social activities	0.75
Quality of interaction	0.79

Table VI. Construct validity correlations between individual FSQ scales and three "health related" variables

Health related variables	FSQ scales: Construct validity correlations				
	Primary (basic) ADL	Inter-mediate (instrumental) ADL	Mental function (well-being)	Social activities	Quality of interaction
Restricted activity days	-0.42**	-0.44**	-0.32*	-0.18	-0.18
Frequency of social contact	0.02	0.08	0.29	0.35*	0.29
Health satisfaction	0.52***	0.47**	0.56***	0.47**	0.27

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

situation revealed by the FSQ showed that 11 of the employed persons needed special measures or equipment for maintaining normal working capacity.

4) Also the WHO ICDH-Classification of handicaps (Fig. 2) showed reduced Mobility in a high percentage of subjects, with substantial practical consequences. There was a high degree of Physical independence. Social integration showed a rather large variation between subjects. Spectacles were the sole reason for scoring 1 in Orientation handicap.

DISCUSSION

Recruitment to the study turned out to be more troublesome than expected. Not all polio survivors are members of organizations for the disabled and this especially applies to the younger subjects and those with minor sequelae who in many cases are not repre-

sented in hospital records. Extrapolations from an extensive epidemiological study in another region of Sweden (11) suggest that we have been in contact with roughly 50% of the population in question. The upper age limit was chosen to include people in professionally active ages and to limit the impact of aging processes. A polio history of at least 25 years was needed in order to allow for the development of a post-polio syndrome. Besides these criteria there was a requirement for inclusion for geographic reasons, i.e. the subjects' ordinary residence being the city of Gothenburg or certain neighboring communities sharing a common health administration and social insurance benefits.

Our methods differ with regard to the mode of assessment, which may explain some minor discrepancies in comparison between different instruments. Such discrepancies are, for example, less severe grad-

Table VII. Correlations between 5 FSQ-categories of scale scores

SS1 (Primary ADL), SS2 (Intermediate ADL), SS3 (Mental function), SS4 (Social activities), SS5 (Quality of interaction)

	FSQ categories of scale scores				
	SS1	SS2	SS3	SS4	SS5
SS1					
SS2	0.76***				
SS3	0.53***	0.37**			
SS4	0.55***	0.71***	0.34*		
SS5	0.16	0.07	0.76***	0.03	

* $p < 0.05$. ** $p < 0.01$. *** $p < 0.001$.

Table VIII. Dependency of personal assistance in the household for successful conduction of primary and secondary activities of daily living

Needs for personal assistance	Number of subjects
Independent	13
Monthly	6
Weekly	9
2-3 times/week	4
Less than 2 hours/day	5
2-6 hours/day	3
More than 6 hours/day	1

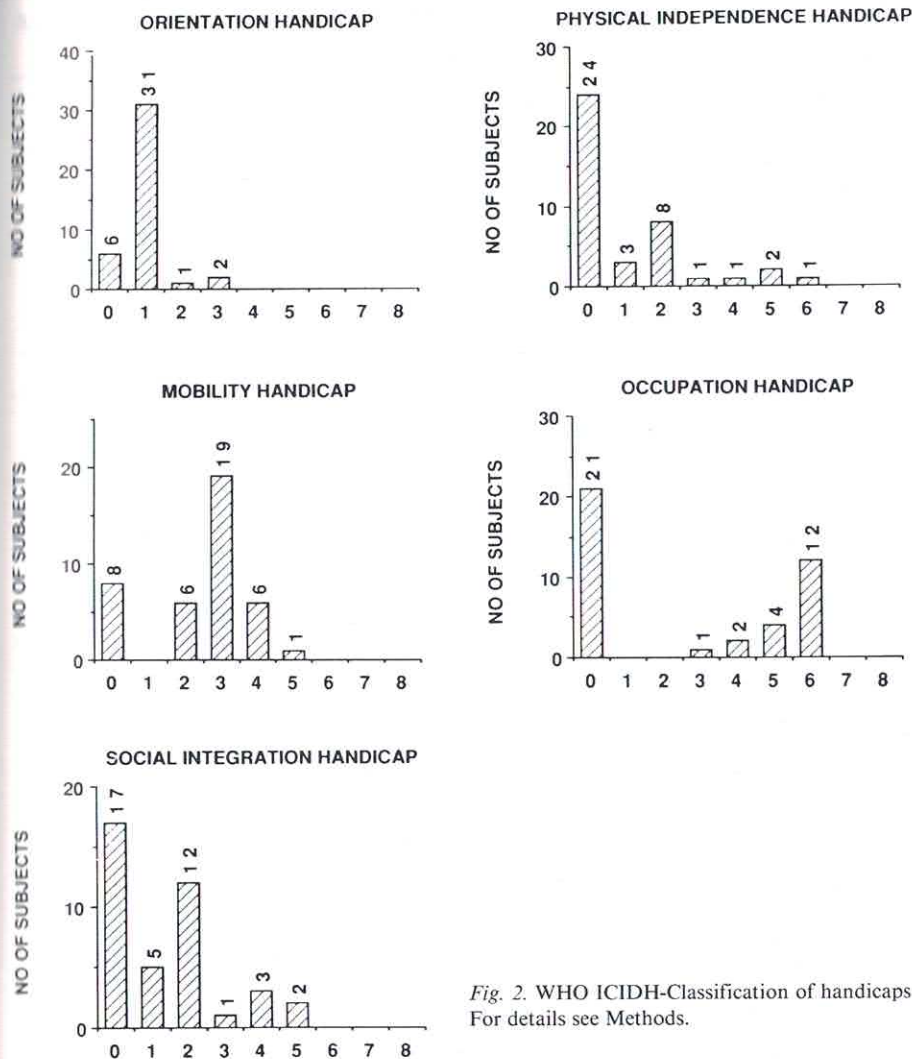


Fig. 2. WHO ICIDH-Classification of handicaps in grades from 0 to 8. For details see Methods.

ings in Physical independence and Mobility handicap than in corresponding selected questions or in the FSQ. The use of a combination of a self-administered health status questionnaire, observer-administered assessments and medical investigations was meant to add plurality to the study. The study design also allows comparison between the different modes of assessment. However, as the FSQ was administered anonymously, correlations could not be sought to other results. Reliability and construct validity in the FSQ was tested in our subjects as done in the original publication (9) in a group of ambulatory patients with different diagnoses. The internal consistency reliability (Cronbach's alpha) showed high and acceptable

values, well above those reported by Jette et al. (9) except for primary ADL. The test of construct validity showed expected correlations between most FSQ scale scores and "health related" variables. However, frequency of social contacts correlated only to Social activities. Thus, in this group of persons the frequency of social contacts does not relate to the degree of disability. All FSQ scale scores showed high intercorrelations except for Quality of interaction which only correlated to well-being. Similarly, quality of interaction did not show significant correlations to the "health-related" variables and may thus relate to other role aspects than the rest of the FSQ instrument. In summary, the FSQ seems to be an acceptable instru-

Table IX. The secondary-ADL activity "mobility" analyzed through the functions of standing up, transfer outdoors and the use of public transportation

	Performance of subjects (number)		
	Performed easily	Performed with difficulty and/or assistance	Incapacity
Standing up	19	15	7
Transfer to outdoor activities	31	6	4
Use of public transportation	5	21	15

ment also in testing polio patients, leaving the usefulness for individual comparisons over time unanswered.

The results of the present study within the functional groups, Primary ADL, Intermediate ADL, Working situation and Social contacts, allow some common conclusions: A generally small impact was found in the Primary ADL outcome scales, the Katz' ADL index, certain questions in the particularly selected questions form and items of the same category in the FSQ.

The Intermediate ADL gradings were certain questions in the selected questions' form, the WHO ICDH-Classification of handicaps (Mobility handicap), and parts of the FSQ. They showed the most severe functional consequences in this group of polio survivors. The quality of mobility is in general dramatically affected and creates needs for transportation aids including accessibility to public transportation means. However, only 2 of 10 persons who were mobility-restricted to their homes were limited because of architectural barriers. Thus, the reason for their restricted mobility must be sought in interpersonal factors. The apparent discrepancy between outcomes in the Physical independence-scale and Mobility-scale in the ICDH is due to the definition of the gradings. If a disability can be compensated for by adequate measures it is defined as aided or adapted independence (grade 1 or 2).

The present working situation demonstrates that the most disabled people have had their greatest difficulties in maintaining occupational activity. Thus, the 16 retired subjects all attributed the functional consequences to their polio. Those who were still working held occupations with minimal physical requirements.

The frequency of social contacts did not depend on the degree of disability within the ADL categories. Thus, the Social activities and Quality of interaction as evaluated by the FSQ as well as the Social integration in the H-code of the ICDH were in general well maintained and this might be interpreted as good coping ability in the polio subjects.

As regards the possibly increasing impact of a long-standing polio condition there might be new risks for social isolation, which should be considered in a follow-up study on post-polio problems. Perception of the health situation seems to be somewhat uncertain as 13 subjects were not sure and 3 were dissatisfied. Whether this may reflect the future health situation also remains to be studied.

The present study demonstrates that emphasis must be put upon sensitivity and empathy towards new health problems and concerns in subjects suffering from late sequelae of poliomyelitis. It also highlights needs for rehabilitation services, including transportation, walking and domestic aids besides individual physical measures.

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