

SEVERELY MOBILITY-DISABLED PEOPLE ASSESS THE QUALITY OF THEIR LIVES

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ABSTRACT. Thirty-six severely mobility-disabled subjects aged 24-52 years using a wheelchair and in need of daily assistance and 36 non-handicapped, matched control-subjects were interviewed. They were asked to rank 30 different abilities involving physical and mental functions, interpersonal and social relationships, and to rate their overall quality of life (QOL) on a 0-10 point scale. Among the severely mobility-disabled subjects the mean value of self-reported QOL was 8.0, which differs only slightly from 8.3 among the controls. The mean QOL among the disabled showed no significant difference regarding congenital/acquired and progressive/permanent disability. The 'abilities' ranked 1-9 were not directly related to mobility and corresponded among the disabled and non-handicapped. The functions lacked by the severely mobility-disabled persons were rated as less important by the disabled. The undiminished QOL is probably a result of personal adjustment, compensation by medical rehabilitation and society, as well as positive features of the disability.

Key words: physical disability, handicapped, movement disorder, quality of life, psychological adaption, activities of daily living

Medical rehabilitation and social compensation for the severely disabled people aim to make their lives as normal as possible as regards living accommodation, transport, employment, leisure, financial situation, etc. Beyond these vital provisions the attitudes towards the mobility-disabled are of great importance. Previously, attitudes have largely been characterized by keeping the disabled separate as a minority group that differed from others generating uncertainty and simultaneously feelings of pity. 'Normal' attitudes less distorted by prejudice are now developing in countries with a positive handicap-policy.

Many people with severe motor handicap have described a satisfactory psycho-social situation in spite of their disability. This study intends to investigate the quality of life (QOL) reported by severely mobility-disabled subjects as well as by non-handi-

capped subjects, plus their evaluation of the importance of different functions.

The phrase 'quality of life' (QOL) was minted in 1956 as a political slogan in the USA, and has featured in political discussions in Europe since the early seventies'. The interest in QOL within sociology and medicine probably represents a striving towards a comprehensive view of the individual and his/her situation. This is contrary to earlier studies where the standard of living was objectively measured by physical abilities, mental and physical health, and/or social activities and relations. In order to evaluate QOL, different methods have been used. In fundamental studies Andrews & Withey (1974); Allardt (1975) and Campbell et al. (1976) utilized both objective and subjective data, while Naess (1979) leaves it to the investigator to rate the QOL of the interviewed subject. Other important studies concerning QOL and values in life are those of Cantril (1965), using a 0-10 rating scale with over 23 000 people in 12 different countries, and the investigations of Flanagan (1982) who defined the main determinants of quality of life in three age groups of Americans. The determinants were found by using the 'critical incident technique'. The literature on QOL is rather extensive (for bibliography, see Kajandi, 1981) and will only be alluded to when of importance to this investigation.

Quality of life of patients with various chronic diseases has been the subject of individual studies. Lichtenhahn et al. (1977) interviewed 38 patients following kidney transplantation and found "a definite improvement of the quality of life". Malm et al. (1981) developed an instrument for measuring QOL and tested it on 30 patients with schizophrenia. Drettner & Ahlbom (1983) studied QOL in 52 patients with head and neck cancer and 104 control subjects. They found a very high correlation between poor prognosis and low health index/low quality of life, but cancer patients with a good

prognosis often reported better health, including quality of life, than the control subjects. Ahlsjö et al. (1984) studied quality of life in 96 patients two years after stroke. Their patients marked on a visual analogue scale their evaluation of quality of life before and after the stroke. Most of them had experienced a diminished QOL, and no improvement was observed during the 2 years.

The number of studies of QOL of physically disabled persons are few. In comparing questionnaires of 190 physically disabled persons (129 severely mobility-disabled) and 195 physically able-bodied persons, Cameron et al. (1973) found that there were no differences between the two groups in ratings of life satisfaction, frustration with life, or mood.

Weinberg & Williams (1978) questioned 88 physically disabled persons about the significance of their disability. Only 11% considered their disability to be 'a terrible thing' and only 7% considered it to be 'the worst thing that ever happened to them'. The majority of the respondents accepted their disability as a fact of life and/or an inconvenience. Weinberg (1984) in a personal interview asked 30 people with physical disability (23 with mobility impairment) the following question: "If there were a surgery available that was guaranteed to completely cure your disability (with no risk) would you be willing to undergo the surgery?" The result was that only about 50% chose surgery. Shontz (1977) has pointed out that a disability also can generate positive experiences.

Crewe (1980) in a study of 128 spinal cord injured persons from Minnesota showed that QOL may be lower for people with a disability than for the general population. The questions presented to the disabled and the non-disabled were, however, not identical. The same study suggested that disabled people who work are not necessarily healthier, less disabled or better off psychologically than those who do not work. Woodrich & Patterson (1983) questioned 251 persons with spinal cord injury in Florida about their acceptance of the disability and their results indicated that women and young people were significantly more ready to accept their disability. The findings further indicated that the duration of the disability and the educational level of the subjects were positively related to their acceptance of the disability. The severity of the disability was of no importance. Geisler et al. (1983) in a Canadian study of 1510 persons with spinal cord

injury found a suicide rate of 1.7–4.0 times the expected rate for the general population. Ray & West (1984) in a study found that among 17 paraplegics, 10 reported more positive feelings about themselves, 3 more negative feelings about themselves and 4 persons reported no change.

Hanson & Franklin (1976) asked 54 men with spinal cord injury to rank functional losses associated with their injuries. In addition staff members of the rehabilitation team caring for these patients were asked to give their opinion of the importance of these functional losses to their cord injured patients. The data indicated that contrary to the patients' ranking, the staff tended to overemphasize the importance of normal genital sexual functioning.

Berg et al. (1976), in an attempt to elicit values concerning loss of function, asked 150 health workers to assign weights from 0 to 10 for 50 abilities or functions. The highest average values were assigned in rank order to: being able to use one's mental abilities, to see, to think clearly, to love and be loved in return, to make decisions for oneself, to live at home, to walk, to maintain contact with family and friends and to talk.

Kottke (1982) in an article 'Philosophic Consideration of Quality of Life for the Disabled' considers the disabled "dependent upon the rehabilitation team to provide assistance and services to make it possible for him to achieve his optimal level of performance as the basis for the quality of his life".

Petersson & Rune (1983), using a method based on the theoretical thinking of Naess, investigated QOL among 25 severely mobility-disabled persons living in Uppsala in integrated dwellings with care available both day and night. The results indicated that the quality of life was rated above scale-mean on most variables. In an earlier study (Stensman, 1985) interviews with and tests on 133 persons with severe mobility-disability (67 needing daily assistance and a wheelchair) could not reveal any significant differences in psycho-social measures between the disabled groups and available data from reference groups. Half of them reported that the disability was of little or no importance in their lives.

In forming an impression of the significance of a motor handicap, autobiographies (Carlson, 1952; Viscardi, 1952; Eareckson, 1976; Segal, 1977) and biographies (about Douglas Bader, Brickhill, 1954 and an anonymous person with cerebral palsy (Mayhew, 1861) are important sources.

What is meant by quality of life?

The term 'quality of life' cannot be distinctly defined. In this study the term is understood as a keynote in an individual life, which is influenced by several functions including psychological and physical factors as well as relations to other people and society. This frame of reference is illustrated in Fig. 1, where basic standards of living and basic security have been marked as a prerequisite for QOL. The concepts of QOL and of 'overall life satisfaction' are almost congruous. Consequently QOL is something relative that the individual measures in relation to need and expectation.

Aims of the study

The purpose of the investigation has been to answer the following questions:

- * Does the quality of life reported by a severely mobility-disabled person differ from that of a non-handicapped person?
- * What factors influence the QOL of the severely mobility-disabled individual (age, sex, character of disability, degree of functional loss, education, intellectual ability, personality, mental disorders, having a hobby)?
- * Does the severely mobility-disabled person experience the lack of a function as more important than a non-handicapped person imagines it to be?

The study is in its character hypothesis generating and explorative.

MATERIAL

Thirty-six severely mobility-disabled people using a wheelchair and in need of daily assistance, living in the town of Uppsala (150 600 inhabitants, 2 500 km²) in Sweden, took part in the study. They form part of a group (from a register of wheelchair-owners and/or receivers of handicap allowance) in an earlier study (Stensman, 1985) in which there was no refusal to participate. In this study the following subjects from the original group of 67 were excluded: 21 not living in Uppsala, 2 with interpreters (due to severe dysarthria), 4 due to difficulties with concentration and/or dementia and 4 subjects who in the earlier study did not participate in tests, whose results are used in this study. As in the earlier study individuals with severe visual or auditory handicap, mental retardation, psoriasis, diabetes, schizophrenia etc were excluded. The 36 probands constitute a generally representative and homogenous group of severely mobility-disabled persons. All accepted participation in the study.

The age range was 24–52 years (mean 39.7 years, median 38.5). There were 16 women and 20 men. Table 1

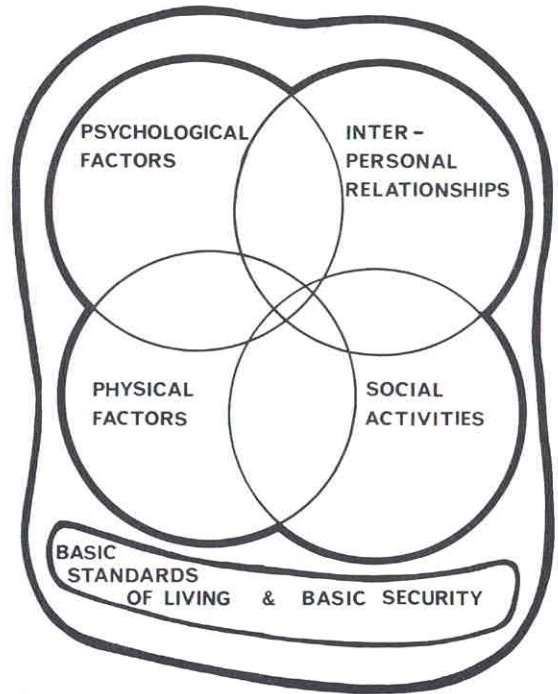


Fig. 1. Quality of life—a frame of reference.

shows the diagnoses and other characteristics of the 36 severely mobility-disabled subjects.

Those with a disability acquired after 7 years of age have had severe impairment for 5–40 years (mean 15.9 years; median 13 years). All subjects needed daily assistance according to Katz' ADL index (Activities of Daily Living) (Katz, 1963). This Index is based on an evaluation of the functional independence or dependence of patients in bathing, dressing, going to the toilet, transfer, continence and feeding. Rated on this index 11 subjects belonged to groups B, C, D (least dependent) and 25 belonged to groups E, F, G (most dependent).

Sixteen subjects lived alone, 16 with their spouses and 4 with their parents. 21 subjects lived in a service block offering special amenities for the disabled. 19 subjects were employed, 5 were studying and 12 were unemployed, neither did they study.

A control group of 36 subjects of the same sex, age, country of birth and living in the same town was selected from the computerized population register (which includes the total population of the town). Nobody in the control group was disabled in any way.

Eleven subjects in the control group (31%), who declined to participate or did not answer the letter inviting them to participate, were replaced by new subjects selected in the same way. Of these, a further 5 persons declined, making altogether 16 dropouts, who all were replaced. In the control group these 16 dropouts are compared with regard to sick leave and income, from available registers, with the 11 corresponding subjects who participated in the study:

	Participants	Dropouts
	n=10; 1 person had no income	n=15; 1 person had no income
<i>Sick leave</i>	0-106 days	0-24 days
83 01 01-	median 6 d	median 3 d
84 05 10	mean 24.1 d	mean 6.7 d
<i>Income</i>		
(estimated for 1984)	32 500-276 500 SEK median 89 800 SEK mean 100 670 SEK	10 000-117 000 SEK median 80 000 SEK mean 73 730 SEK

In summary the table shows that the participating controls had slightly higher incomes and a somewhat higher sick-leave absence than those who declined to participate as controls. The differences were small, however.

METHOD

The 72 probands were interviewed at their place of work or at home. To get a frame of reference and an 'introduction' to QOL, and at the same time a comprehension of the importance of different factors to the quality of life for all the probands, the subject was asked to rank order 30 cards (10.5×7.5 cm) on which 30 different functions (abilities) were printed. These functions are presented in Table II and are essentially derived from Berg et al. (1976). The functions (sometimes with slight modification) chosen from Berg et al. are marked with *, and those from the suggestions made by interviewees to Berg et al. with **. Questions marked with *** are those that were selected in the preparatory discussions with experienced colleagues regarding which functions to choose in this study. The functions chosen included all the abilities in the Katz ADL scale.

Functions considered but rejected were (marked as in Table II):

- To be able to make decisions for oneself*
- To be able to taste (and smell)*
- To be able to obtain an education*
- To be able to do things on the spur of the moment**

- To be able to create things***
- To feel secure from criminal and political violence***
- To be able to watch television***
- To be able to have a religious life***
- To be able to engage oneself in something***

This reduction was made to keep the number of cards manageable and to avoid including functions whose meaning was too diffuse or could not be ranked or compared with the other functions.

The probands were instructed to rank the cards from 1-30 and to 'weigh' the items on a scale from 0-10 in terms of their value to the quality and meaningfulness of life.

They were then asked to rate their overall quality of life during the last year (on the basis of their own assumptions, perceptions, goals and values) on a 0-10 point scale, where 0 corresponds to the lowest QOL and 10 to the highest.

In a semistructured interview the probands were asked about employment, education, civil status, chronic disease, pain and life-crises during the last year. The subjects with severe mobility-disability were asked to what extent the disability affected their QOL.

The investigation was preceded by a pilot study on 10 probands, five of whom had severe mobility-disability. These 10 subjects were not included in the final material.

STATISTICAL METHODS

When comparing ranks, weights and other quantitative variables the Wilcoxon rank sum test was used. Spearman's rank-order correlation was used as a measure of association.

RESULTS

A. Quality of life

The self-reported QOL of the 36 severely mobility-disabled subjects on a 0-10 point scale is shown in Fig. 2. The mean value was 8.0 (range 5-10). The

Table I. Main diagnoses and other characteristics of the 36 mobility-disabled persons

Diagnosis	Number (F/M)	Congenital or onset <7 y. age	Chronic progressive
Cerebral palsy	13 (7/6)	13	-
Contusio cerebri, seq	1 (0/1)	-	-
Multiple sclerosis	5 (1/4)	-	5
Hereditary ataxias	4 (2/2)	1	4
Spinal cord injury with quadriplegia	6 (1/5)	-	-
Other spinal disorders, seq	4 (3/1)	3	1
Muscular dystrophy	1 (1/0)	-	1
Rheumatoid arthritis	1 (1/0)	-	1
Congen. orthopedic disorder	1 (0/1)	1	-
	36 (16/20)	18	12

Table II. A list of thirty selected functions (printed on cards) ranked by the 72 subjects before evaluating quality of life

<i>Psychological functions</i>	<i>Interpersonal relationships</i>
To be able to (have):	To be able to (have):
use one's mental abilities*	close contact with family and friends*
feel pleasure*	love and be loved in return*
inner harmony***	sexual togetherness*
<i>Physical functions</i>	<i>Social activities</i>
To be able to:	To be able to:
see*	live at home (rather than
hear*	in an institution)*
read*	obtain a job*
talk*	live mainly on one's own salary***
be free from pain*	go to the cinema, restaurants, etc*
control one's bladder*	participate in sports**
control one's bowels*	be out in nature (open air)***
take a bath/shower on one's own***	travel**
get dressed on one's own*	blend in with the crowd**
go to the toilet on one's own***	
get in and out of bed*	
walk*	
get around in a wheelchair	
(if one cannot walk)***	
feed oneself*	
write or type*	
drive a car*	

* from Berg et al. (1976).

** suggestions from the interviewed subjects to Berg et al.

*** from the preparatory discussions for this study.

corresponding results in the matched control-group is shown in the same figure—the mean value of QOL was 8.3 (range 4–10), a difference which does not reach statistical significance.

Within each group no statistically significant differences were found in self-reported QOL with regard to:

- age (below/above median 38½ years)
- sex
- civil status (single/not single)
- education (above statutory education or not)
- employment (more than/less than 10 hours per week or no work)

Out of the total material of 72 subjects, 6 persons (4 severely mobility-disabled/2 controls) reported lifecrisis within the last year (separation, death of a close relative, etc) which influenced their QOL negatively. Likewise 9 subjects (7/2) reported chronic disease/s (different from their disability) within the last year, which influenced their QOL negatively.

Within the disabled group the mean value of self-

reported QOL for different characteristics of the disability were assessed for significant differences. Some of the characteristics of the disabilities—including diagnosis—are shown in Fig. 3. Comparison of means of self-reported QOL failed to yield statistically significant ($p < 0.05$) differences for the following characteristics:

- disability, congenital or acquired before the age of seven/acquired after the age of seven (Fig. 3B)
- progressive/permanent disability (Fig. 3C)
- functioning level according to Katz' ADL Index (Fig. 3D)
- moderate or severe pain/little or no pain

The 36 severely mobility-disabled subjects had taken part in a previous study (Stensman, 1985) about 3 years before this one. Data from that study showed no statistical correlation between self-reported QOL and:

- having a hobby (defined in the previous study)
- intellectual ability measured by testing (SPIQ)

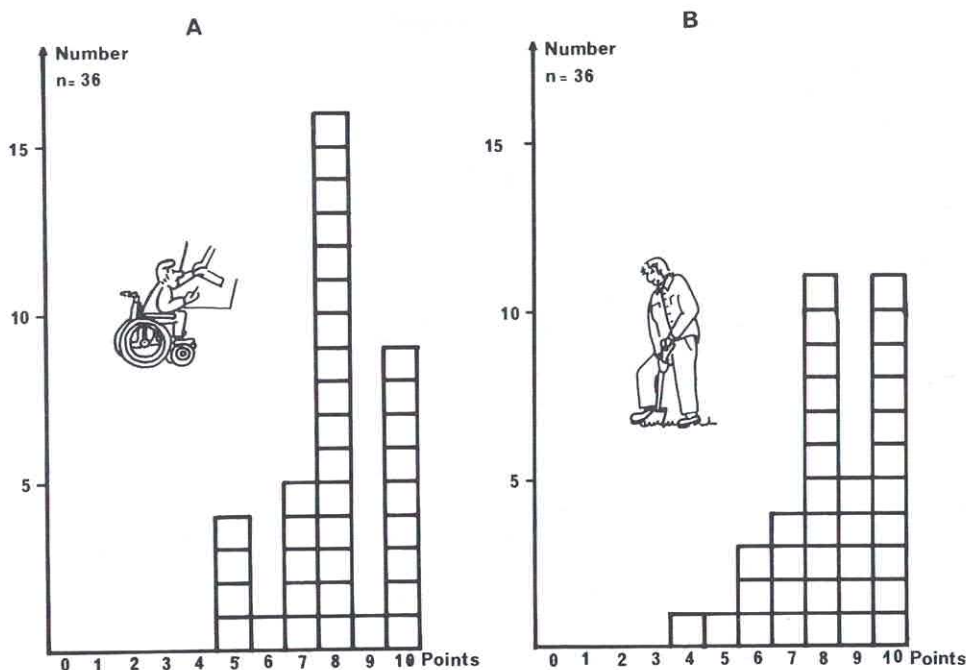


Fig. 2. Self-reported QOL on a 0-10 point scale for 36 subjects with severe mobility-disability (A) compared with 36 non-disabled controls (B).

- depressive trait measured by a personality inventory (GW-LI-SR), described in the previous study
- grade of neuroticism as measured by the Eysenck Personality Inventory

The 10 subjects who in the previous study had reported mental disorder at any time did not show any statistically significant difference in QOL values compared with those who had not reported mental disorder.

Severe mobility-disability was reported to exert an influence on the evaluated QOL as shown below:

highly negative	5 subjects
moderately negative	6 subjects
slightly negative	6 subjects
both negative and positive	13 subjects
moderately positive	1 subjects
no influence	5 subjects
	36

The influence of medical services, including technical aids, on the experience of the disability was

positive to 24 subjects, negative to 1 subject, both positive and negative to 3 subjects. No impact of these services on disability was reported in 8 subjects.

Those among the severely mobility-disabled subjects who had regular contact with the Department of Rehabilitation Medicine ($n=9$) had a lower mean value of QOL (6.6) than those subjects ($n=13$) with sporadic contact (QOL 8.6) or no contact ($n=14$), whose mean value of QOL was 8.2.

B. 'Functions'

The medians of individual rank-order and median 'weights' of the 30 functions evaluated by the 72 persons are presented in Table III.

There are only slight differences in the evaluation of the 30 functions between the mobility-disabled subjects and the non-disabled. The nine highest ranked functions were unrelated to mobility and given equal priority in both groups. The functions 'write or type' and 'get around in a wheelchair (if one cannot walk)' were valued higher by the disabled people, while 'walk', 'get dressed on one's

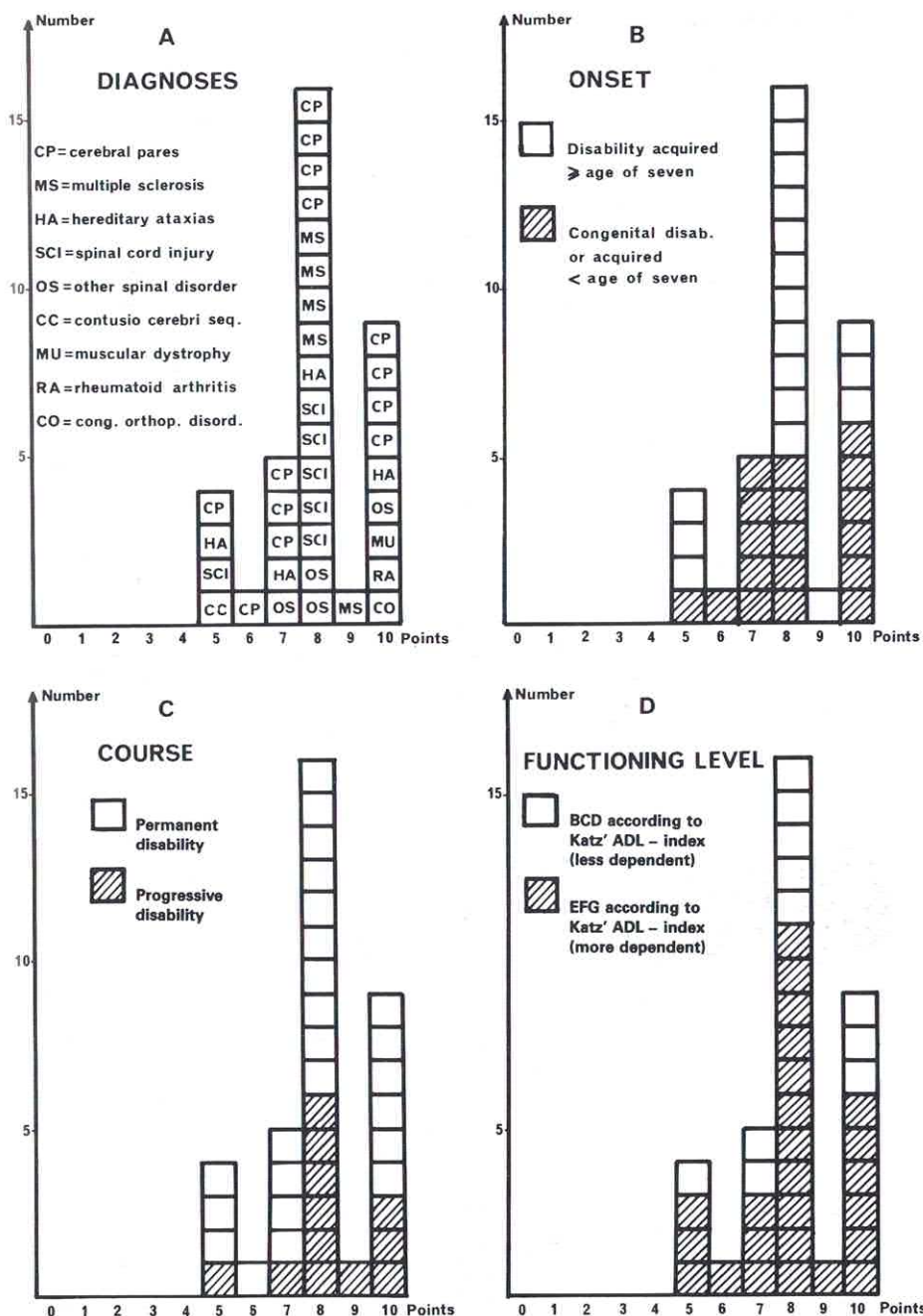


Fig. 3. The 36 subjects with severe mobility-disability, their self-reported QOL and (A) diagnoses, (B) onset of

disability, (C) course of disability, and (D) functioning level.

own' and 'get in and out of bed' were valued higher by the non-disabled subjects. The functions unrelated to mobility were ranked differently between the two groups with respect to 'obtain a job', 'travel' and 'go to the cinema, restaurants, etc', which

were all ranked higher by the severely mobility-disabled subjects. The function 'sexual togetherness' was given equal priority in both groups (rank-order 18 and 17 respectively).

The correlations between high score on the over-

Table III. Rank-order and 'weights' (medians, ranges and differences) attached to 30 functions by 36 severely mobility-disabled persons and 36 non-disabled controls

The ranges are presented only regarding rank-order. *Differences according to Wilcoxon rank sum test

Function and rank-number among mobility-disabled	Rank						Weights				
	Mobility-disabled		Controls				Rank-number	Diff.* <i>p</i>	Mobility-	Controls Median	Diff.* <i>p</i>
	Median	Range	Median	Range	Median	Median					
1 Love and be loved	4	1-21	7	1-25	6	NS	10	10	NS		
2 See	6	1-20	3	1-17	1	NS	10	10	NS		
3 Hear	6.5	1-27	7	2-25	5	NS	10	9	NS		
4 Inner harmony	7	1-25	6	1-22	4	NS	10	10	NS		
5 Talk	7.5	1-22	7.5	1-24	7	NS	10	10	NS		
6 Mental ability	8	1-24	5.5	1-25	3	NS	9.5	10	NS		
7 Feel pleasure	9	1-26	5.5	1-25	2	NS	9	10	NS		
8 Read	9	3-28	11	2-24	10	NS	9	8	NS		
9 Family and friends	9.5	1-22	9	1-22	9	NS	9	9	NS		
10 Live at home	10	1-28	14.5	1-29	15	NS	9	7	0.0181		
11 Write or type	11	3-27	18	4-28	19	0.0004	9	7	0.0003		
12 Obtain a job	13.5	2-27	20.5	3-26	23	0.0227	8	7	0.0061		
13 Use a wheelchair	13.5	6-25	18.5	5-29	20	0.0015	8.5	6.5	0.0006		
14 Free from pain	14.5	1-29	8	1-26	8	NS	8	9	NS		
15 Control bowels	15	2-30	14	5-26	14	NS	8	7.5	NS		
16 Feed oneself	15	2-27	13.5	3-25	12	NS	8	8	NS		
17 Control bladder	16.5	1-29	14	6-27	13	NS	7	7	NS		
18 Sexuality	18	3-29	15	4-29	16	NS	8	7	NS		
19 Toilet oneself	18.5	6-29	15	1-27	17	0.0140	7	7	NS		
20 Nature (open air)	20	1-28	24	8-29	24	0.0393	7	6	NS		
21 In and out of bed	21	9-30	19	5-28	22	0.0084	5.5	7	NS		
22 Travel	21	8-30	25.5	14-30	26	0.0082	6	5	0.0135		
23 Bath or shower	21.5	8-28	19	9-27	21	NS	6	5.5	NS		
24 Get dressed	22	6-29	17	6-26	18	0.0004	5	7	NS		
25 Cinema, etc	24.5	10-30	28.5	22-30	30	0.0001	5	4	0.0074		
26 Own salary	24.5	5-30	25	11-30	25	NS	6	5	NS		
27 Walk	24.5	2-30	11	1-24	11	0.0001	5	8.5	0.0001		
28 Blend in with crowd	26	5-30	28	5-30	28	NS	5	3.5	NS		
29 Sports	27	5-30	27.5	10-30	27	NS	5	4	NS		
30 Drive a car	28	12-30	28	20-30	29	NS	4	4	NS		

all QOL and high ranking of the specific functions were very weak. A positive correlation was found among the severely mobility-disabled for 'participating in sports' ($r=0.38$, $p=0.02$), and among the non-disabled with regard to 'to be free from pain' ($r=0.39$, $p=0.02$). A negative correlation between high score on the overall QOL was found among the non-disabled controls with regard to 'to be able to see' ($r=0.39$, $p=0.02$). These weak correlations are in agreement with other studies (Allardt, 1975; Campbell, 1976).

At the interviews all 72 subjects were asked if they missed any 'function', and 5 reported a lack of:

- to be able to experience success
- to be able to watch television
- to be able to have a religious/spiritual life (2 subjects)
- to be able to live in a world in peace

C. Re-interviews

Fourteen of the 36 severely mobility-disabled persons were re-interviewed 2-3 weeks after the first examination concerning their evaluation and ranking of the 30 functions and their overall QOL. The intention was to re-interview the 14 first interviewed, but for practical reasons slight deviations had to be done. The correlations between the rank-

ordering on the two different occasions were in most cases high: $r=0.98-0.56$ ($p<0.05$). The correlation for self-reported overall QOL was 0.97. Four variables (to be able to take a bath or shower on one's own, to be able to live at home rather than in an institution, to be able to control one's bowels, to be free from pain) showed no significant correlations ($r=0.42-0.47$). A longer interval between interviews might have altered the circumstances determining their individual judgements (Kammann et al., 1979).

Comments on the Method of Using Self-reported QOL

The subjective evaluation of QOL—a complex concept with limits difficult to define—may seem delicate for use in a scientific analysis. The way QOL is regarded in this study, however, it can only be evaluated by the individual—'everybody is the architect of his own fortunes'. In this connection attention should be focused on the relationship between objective and subjective measures, which in most studies is surprisingly weak. Allardt (1984) comments "the objective and subjective indicators measure different aspects of well-being, and it seems important in most situations to use both". Allardt further points out "the second major dilemma is whether one should focus mainly on material and impersonal needs or whether non-material and social needs should also be emphasized".

At the assessment of the results the following five factors should be taken into consideration.

1. Variation in evaluation depending on different backgrounds

People estimate QOL from different points of view. In Fig. 4 a model is presented illustrating the relationship between realization and expectation. The hypothesis is that people in the group with great expectations and a high degree of fulfilment score fairly high for QOL, as does the group with low expectations and a low degree of fulfilment. A higher score for QOL is to be expected in the group that has a high degree of fulfilment and low expectations, while the converse group, with a low degree of fulfilment and great expectations has a low score for QOL. A way to test this hypothesis would be to measure expectancy and satisfied realization simultaneously. This has not been done in the present study, nor has an attempt to objectively measure QOL been made. However, 16 of the probands in

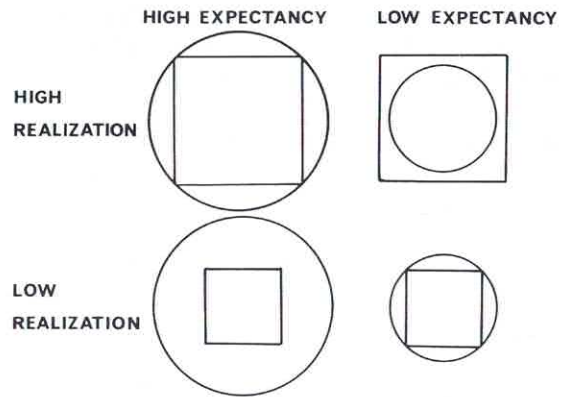


Fig. 4. Relationship between realization and expectancy. A model displaying the different backgrounds for estimating quality of life. The four extremes are presented. Realization: □. Expectancy: ○.

this investigation have participated in a previous study by Pettersson & Rune, 1983, where QOL was 'objectively' measured for occupants in a 24-hour-service house for people with severe mobility-disability. The method employed very closely resembled the one used by Siri Naess (1979). The results showed that QOL was not reduced among the severely motor handicapped subjects.

2. Tendency to overrate

Experience of using rating scales shows that most people utilize the positive part of a scale more frequently than the negative part. Boucher & Osgood (1969) have coined the phrase "the Polyanna hypothesis" about people's tendency to prefer the use of positive rather than negative concepts when evaluating words. In agreement with this is the high percentage of subjects who reported 'life as happy' (95% in Sweden), and 'life is easy' (76% in Sweden) in a comparative Scandinavian welfare study (Allardt, 1975). In the study by Campbell et al. (1976), the mean score for 'overall life satisfaction' was 5.5 on a 7-point scale, which would correspond to 7.9 on a 0-10 scale.

3. Influence by a temporary mood

Kammann et al. (1979) have pointed out in a study the importance of evaluating QOL over a long period of time. Their results show higher correlations at re-interview if the recording period used for the subjectively reported QOL is longer. In the present study the time frame was one year. Fourteen of the severely motor-handicapped persons were re-inter-

viewed 2–3 weeks after the first interview. Eleven persons reported the same QOL score and the other 3 reported differences of 1 point.

4. Influence by the interviewer

If the interviewer is an enthusiastic and happy person it is conceivable that this could influence the proband to give a more positive answer—and vice versa if the interviewer is disinterested or depressed. The problem is almost negligible in the present study, as it deals mainly with comparisons between groups that were interviewed by the same investigator.

Campbell et al. (1976) showed that weather conditions on the day of interview did not affect the responses. Temperature and humidity in the place where the interview took place, however, showed a relationship to the responses to the Index of Well-being.

5. Manipulated answers

Severely mobility-disabled subjects might manipulate their answers either in a positive direction (to show that disabled people can have good lives), or in a negative direction (to demonstrate the need for extra service etc. for the mobility-disabled). None of the probands reported any reflections of this kind. Similar manipulation would not be expected in the control group.

DISCUSSION

The severely mobility-disabled subjects partaking in this study are fairly representative of the rather homogeneous group of wheelchair users in need of daily assistance from another person. They constitute all people in the age range 24–52 within the described area, with a severe mobility-disability acquired at least 5 years before the investigation. Individuals with any other severe disability (blindness, mental retardation, dementia, very severe dysarthria, etc.) were excluded, as well as 4 subjects who did not participate in psychological tests in a previous study. Due to the size of the sample group the specific findings of the present investigation cannot lead to any general conclusions.

The results indicate that the QOL reported by the severely mobility-disabled subjects in the study does not differ significantly from that reported by the non-disabled controls. This confirms the find-

ings of Cameron (1973) and Weinberg (1984). In this context it should be emphasized that a severe mobility-disability is almost always an inconvenience and/or a cause of frustration. The undiminished QOL reported by the severely mobility-disabled subjects might be explained by an adjustment process, coping and/or that the disability had some positive consequences.

The adjustment to a disability, in addition to compensation by medical rehabilitation and society, in most cases implies a change of interest and/or a reduction of expectation on a level corresponding to the disability (cf. Fig. 4). It should be observed that for most disabled people, the remaining number of functions is large and that the non-disabled individuals normally use only a small fraction of all their abilities, and for different reasons have to adjust to present conditions.

Adjustment to a disability is a painful and difficult process, which takes a long time. Four of the eight subjects in this study who acquired their disability acutely (mostly spinal cord injury) reported that the time needed for adjustment was more than 4 years. A prospective study of individuals with acutely acquired mobility-disability is planned to examine the adjustment and change in QOL during the first 6 years of disability. The process of adapting to a disability has been described by Wright (1960), Kerr (1977) and Sjögren (1982), among others.

In the study reported by Weinberg & Williams (1978) approximately half of the group with severe mobility-disability thought that the disability offered them some advantage. The most frequently cited advantages were that the disability provided a "challenge, goal or purpose" and that it made a person more "sensitive, tolerant and patient". The present study confirms these findings. About half of the group with a severe mobility-disability experienced positive features of the disability like those described above, as well as "a less hectic life" and "more contact with other people". A disadvantage often stated was the dependence on others for practical help, which sometimes moreover was inadequate.

This adaptation to a disability is also described in the autobiographies and biographies mentioned above. Illustrative examples (Stensman, 1983) are for instance the cases of Sarah Bernhardt who continued as an actress in spite of losing her right leg—and not using a prosthesis, and President

Franklin D. Roosevelt, who suffered from a flaccid paraplegia as a result of poliomyelitis.

The predominantly negative attitudes that exist towards the disabled are a serious obstacle in attempting to achieve 'Full Participation and Equality' (the motto of the International Year of Disabled Persons, 1981). These attitudes have been studied by Titley (1969), English (1977) and Wright (1977). The non-disabled person who lacks knowledge about the situation for disabled people will often surround the disabled by myths. For instance, Shakespeare attributed physical deformities to Richard III, when he wanted to create a negative picture of this able-bodied king. Many non-disabled people tend to perceive a severe physical defect as a tragedy, failing to appreciate the impact of time and readjustment.

Attitudes towards disabled people are also influenced by 'spread' and 'spread phenomenon' (Wright, 1977). This refers to the tendency when perceiving one characteristic of a person to develop further impressions about that person. These tend to be positive or negative according to the attitude generated by the first impression created. Thus, if a person's appearance is viewed as displeasing or disturbing, then the observer's tendency may be to infer other negative attributes such as emotional instability or intellectual limitation.

In an earlier study with regard to psycho-social situations no important difference was found between severely mobility-disabled subjects and the reference groups (Stensman, 1985). The viewpoint sometimes stated, that severely mobility-disabled people make up a disproportionately large proportion of drug and alcohol abusers seems to be without foundation. Self-destructive behaviour, including suicide, needs further investigation. A lowering of QOL due to severe mobility-disability in these age groups has not been demonstrated in any study known to the author.

Evaluation of 'functions' not directly related to mobility showed very slight differences between the severely mobility-disabled subjects and the non-disabled. The findings are in accordance with the study of Berg et al. (1976), from which most of the 'functions' rated were selected. The evaluations also correspond to the findings of Allardt (1975) and Campbell et al. (1976) in which "being in good health and in good physical condition" and having "a good family (friends)" respectively were considered as most important for the feeling of well-being.

The hierarchy of needs enumerated by Maslow (1964) "primary physiological needs, security, affection and belonging, appreciation, personality development and longing for knowledge" are represented among the 30 'functions'. This hierarchy is most clearly demonstrated over the period of an individual's maturation, and is not easily applied to the present investigation, since the questions asked concern the present situation.

Three basic physical functions ('see', 'hear', 'talk') were ranked as the most important, together with interpersonal relationships and mental functions. Among the social functions, 'living at home' and 'obtain a job' were ranked as most important, especially among the mobility-disabled subjects. "Sexual togetherness" was ranked as moderately important and equally in both groups. This is in accordance with Hanson & Franklin (1976). In the study by Berg et al. (1976) 'sexual intercourse' was ranked 28th out of 50 and "have an orgasm" was ranked 34th out of 50. Abilities not related to mobility dominated the first third of the list of functions. This may be an important reason for the positive picture obtained of adjustment to severe mobility-disability.

The 'functions' which most of the severely mobility-disabled persons lacked ('to take a bath or a shower on one's own', 'getting dressed on one's own', 'go to the toilet on one's own', 'get in and out of bed' and 'to feed oneself') were rated as less important by the disabled, particularly those who lacked those functions. The hierarchy of these functions was in general found in the order described by Katz et al., e.g. taking a shower/bath was regarded as less important than feeding oneself. The ability 'to walk' was ranked very low (27th place) by the mobility-disabled, in contrast to the non-disabled (11th place). This implies that the real loss of a function was of less importance than the image of the same loss in the mind of a non-disabled person.

The findings in this study—equal QOL among severely mobility-disabled and non-disabled subjects—might be an expression of successful individual and social rehabilitation. This points to the need for a change in attitudes towards the disabled and an improvement of the total rehabilitation program. The 'pitying' mentality will hopefully be replaced by more 'normal' attitudes towards the severely mobility-disabled. In this context, television, films and literature—for adults and children—play an im-

portant role by showing and describing disabled people in 'non-disabled' situations (Staffilios-Rothschild, 1977). In rehabilitation medicine it seems very important that the patient with a severe mobility-disability and his/her relatives are advised by a person with a longstanding mobility-disability, to dispel anxiety for the future. Athletic activities—individual and team sports for physically disabled people—offer a threefold bonus through improved physical fitness, increased self-confidence and fellowship.

The results of this study may also have implications in the discussion of prenatal diagnostics, selective abortions and 'euthanasia', as well as follow-up information for the physicians who first treat the injury leading to the disability.

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