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Comparison of health-related quality of life in three subgroups of spinal cord injury patients

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Health-related quality of life (HRQL) was evaluated in three subgroups of spinal cord injury (SCI) patients: (1) persons who had sustained a pediatric SCI (mean time from injury 20 years, age at injury 11.3 years, $n=36$), (2) newly injured patients at the beginning of acute rehabilitation (mean age 35.3 years, $n=31$), and (3) patients with a chronic SCI (mean time from injury 4.8 years, mean age at injury 35.2 years, $n=34$).

All the patients were clinically examined and structurally interviewed with a list of questions dealing with details of anamnestic information about injury, its treatment, possible complications and persons past and present psycho-social condition. HRQL was assessed by a generic fifteen-dimensional self-administered instrument (15D). The relative importance of the 15D dimensions and an overall judgement of health status were measured by a 0–100 visual analogue scale.

Average importance weights of the dimensions of moving and working differed significantly in the three subgroups. Patients with pediatric SCI assigned the lowest importance for moving. The newly injured patients highly valued working capability.

The HRQL scores of the patients who had sustained their injury in childhood were significantly higher than those of the newly injured patients or chronic patients. The tetraplegic patients estimated their HRQL significantly lower than patients with incomplete paraplegia.

Of the three subgroups studied, those with pediatric SCI were well adjusted on the basis of anamnestic information and scored high on HRQL when compared with the other two subgroups. Patients injured in adulthood rated their overall HRQL lower and were often unable to return to work. Patients injured in childhood expressed better performance in physical functions than patients who had sustained their injury in adulthood. The subgroups did not differ in psychological functions.

Keywords: health-related quality of life; spinal cord injuries; quality of life; pediatric spinal cord injury

Introduction

During the last decade health-related quality of life (HRQL) has been monitored in many outcome studies of spinal injuries.[1–4] Biologically-based methods of illustrating the results of health care interventions have been supplemented with self-assessment methods, although a generally accepted 'gold standard' for assessing HRQL and its variation in different illnesses, stages of adjustment or in the normal population does not exist. The relative importance of the dimensions of HRQL may vary in different illnesses and populations, and the values reflected in the relative importance may depend on age at and time elapsed since injury or illness. Therefore it may be necessary to measure not only how well persons are faring on each dimension but also the relative importance they assign to the dimensions.

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The purpose of this study, which is a part of a larger outcome study of pediatric spinal cord injury (SCI) patients, was to compare the HRQL in three subgroups of SCI-patients. The purpose was, further to study whether there are differences between the subgroups in the relative importance assigned by them to the dimensions of HRQL.

HRQL is defined in this study as: 'The level of well-being and satisfaction associated with an individual's life and how this is affected by disease, accidents and treatments'.[5]

Patients and methods

The first subgroup (Sgr.I, $n=36$) comprised of persons who had sustained a SCI in childhood and were adults at the time of examination. These patients were identified from the membership register of the Finnish Association of the Disabled, from the patient databases

of the Käpylä Rehabilitation Centre (Helsinki), the Orthopaedic Hospital, Orton (Helsinki) and the Children's Hospital (University of Helsinki). Of the 66 persons contacted, 47 agreed to participate and 46 returned the 15D questionnaire and another questionnaire mapping out the type of injury.

Of the 47 patients contacted 36 SCI patients who had sustained an SCI under the age of 17 years remained after attrition. The reasons for excluding 11 persons were (i) an insufficient severity of the SCI or a doubtful nature of the neurological lesion (eg meningomyelocele which were excluded from the study) ($n=3$), (ii) poor cooperation because of associated mental deficiency ($n=1$), (iii) unwillingness to travel or to take part in examinations in hospital ($n=6$) and (iv) death before examinations ($n=1$).

Two of the excluded patients were women. The mean age of excluded patients at injury was 10.1 years (SD 6.2, range at birth–16.5 years) and the mean age at entering the study 41 years (SD 14.4, range 18.2–60.5 years).

The second group consisted of newly paralysed patients who were examined before (Sgr.IIA; $n=31$) and after (Sgr.IIB; $n=31$) acute rehabilitation in the Käpylä Rehabilitation Centre. Their measurement results before rehabilitation (Sgr.IIA) were used in comparisons between the subgroups.

The third group (Sgr.III; $n=34$) comprised of SCI patients who attended a maintenance rehabilitation course in the same rehabilitation centre.

The total number of subjects was 101, of which 24 were women (24%). This distribution between sexes is usual in SCI populations.[6,7]

All patients were clinically examined and interviewed by using a structured questionnaire. The patient characteristics of the three subgroups are shown in Table 1.

The spinal lesions were classified by the type and completeness of the injury according to the standards of neurological classification of the SCI patients.[8]

The HRQL method

HRQL was measured by using the 15D.[9] The 15D questionnaire consists of 15 multiple choice questions each representing one health-related dimension. These are moving, seeing, hearing, breathing, sleeping, eating, communicating, urinary continence, working, social participation, mental functioning, pain, depression, distress and perceived health. The person ticks, for each dimension, the level that best describes her or his health status. For example, the levels of the dimension of moving are described in Table 2. In routine use, this questionnaire only requires completion by the subject.

The 15D score, representing the overall HRQL and ranging from 0 (being dead) to 1 (full HRQL) is calculated by combining the dimension importance weights and within-dimension level desirability values, elicited from subjects through a two-stage valuation

Table 1 Patient characteristics

	Sgr.I ($n=36$)	*Sgr.II* ($n=31$)	*Sgr.III* ($n=34$)
Women	11	6	7
Men	25	25	27
Mean age at injury (yrs)	11.3	35	35.2
Mean time from injury (yrs)	20	4 months	4.8
Mean age at examination (yrs)	31.3	35.3	40
Mean length of rehabilitation		4 months	25 days
Trauma/disease/iatrog.	30/5/1	31	28/6
Education			
Primary level	9	17	9
Secondary school	9	11	20
University	18	3	5
Economic resources			
Gainful occupation	24	2	–
Disability pension	12	29	34
Living arrangement			
Alone	19	13	13
With family	14	18	21
Car driving			
Yes/no	33/3	19/12	18/15
Classification of patients according to the level and completeness of the lesion			
Complete tetraplegia (ASIA A)	3	7	8
Complete paraplegia (ASIA A)	26	10	17
Incomplete tetraplegia	5	3	3
Incomplete paraplegia	2	11	6

procedure based on multi-attribute utility theory,[10,11] with the responses to the 15 questions as follows:

$$v_{iH} = \sum_{j=1}^{n} I_{ij}[W_{ij}(x_j)],$$

where I_{ij} = a positive constant for the jth dimension, representing the relative importance individual i attaches to it (j = 1,2, . . n), and W_{ij} (x_j = a numerical function on the jth dimension, representing the value individual i places on various levels of the dimension.[9]

To obtain the dimension importance weights the subjects indicate the relative position of each of the 15 dimensions on an adjacent ratio scale (0–100) by placing the dimension considered most important at

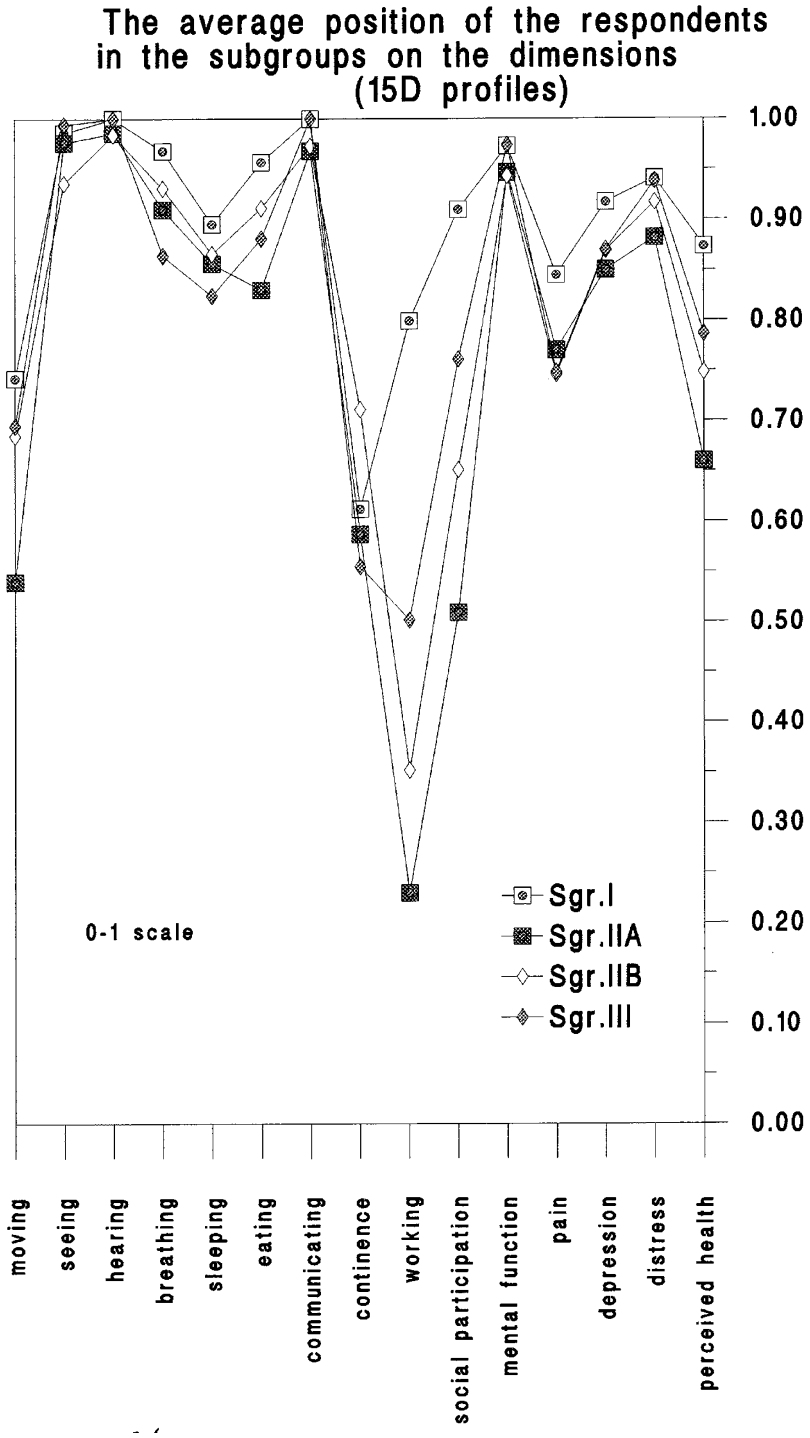

Figure 1 The average position of the respondents in the subgroups on the dimensions (15D profiles)

Table 2 The descriptions for levels of the moving dimension

1	()	I am able to move (walk) normally, i.e. without difficulties indoors, outdoors and on stairs
2	()	I am able to move (walk) without difficulties indoors, but outdoors and/or stairs with difficulties
3	()	I am able to move (walk) without help indoors (with or without appliances), but outdoors and/or stairs with help from others
4	()	I am able to move (walk) with help from others indoors also
5	()	I am completely bed-ridden and unable to move about; if helped, I may sit on a chair

100. The individual values given to a dimension by all the subjects are averaged and then transformed so that the sum of the 15 average importance weights equals 1.

The within-dimension discrete levels are valued similarly using a 0–100 ratio scale and placing the most desirable level at 100. The individual values given to the levels are then averaged and divided by 100.

A 15D profile was derived by averaging the levels ticked by the respondents on each dimension (Figure 1). The 15D profile indicates the group's average position on the dimensions.

The subjectively perceived overall health status was measured on a 0–100 visual analogue scale (VAS).

Statistical methods

A computer algorithm written on Excel 4.0 (Microsoft Corporation) was used to calculate the HRQL scores. The statistical analyses were carried out with Statgraphics (Statistical Graphics Corp.).

The relationship between HRQL scores and VAS scores was analysed by calculating the standard Pearson product moment coefficient of correlation. Analysis of variance (ANOVA) with the Tukey test was used to examine whether significant differences occurred between the subgroups in different variables of interest. ANOVA was also used to study the relationship between the severity of the neurologic impairment and the HRQL scores as well as to study the influence of gender on the scores.

The *t*-test for dependent samples was used to compare differences between the scores for newly injured patients before and after acute rehabilitation (Sgr.IIA *vs* Sgr.IIB).

Results

Average importance weights

The average importance weights reflect the relative importance of the dimensions as perceived by the subgroups. The results of ANOVA showed that the importance weights for the dimensions of 'moving' [df(2,99), F = 10.4986, $P < 0.0002$] and 'working' [df(2,99), F = 7.28487, $P < 0.002$] differed significantly between the three subgroups (Table 3). The Tukey post-hoc comparison test showed that for 'moving' the essential difference was between SCI-patients injured in childhood and those injured in adulthood ($P < 0.05$) with the pediatric SCI patients assigning a lower importance weight.

The average importance weight assigned by the newly injured patients (Sgr.IIA) for the dimension of 'working' was significantly higher than that elicited from Sgr.I and Sgr.III (Tukey test $P < 0.05$).

Apart from the dimensions of 'moving' and 'working', the average importance weights for the remaining dimensions did not differ significantly between the subgroups.

HRQL scores in the subgroups

The 15D scores calculated with group-specific importance weights were 0.906, 0.778 and 0.842 (Table 4), respectively. ANOVA showed a significant difference [df(2,98), F = 19.43671, $P < 0.0001$] between the groups. In the light of the post hoc test all the subgroups differed significantly ($P < 0.05$) from each other.

Before acute rehabilitation the HRQL score was 0.778 (Srg.IIA) and at the end it was 0.821 (Sgr.IIB). This change in the HRQL score during rehabilitation

Table 3 The average importance weights of the HRQL dimensions in different subgroups

Dimension	*sgr.I* ($n = 36$)	*Sgr.IIA* ($n = 31$)	*Sgr.III* ($n = 34$)	*Total sample* ($n = 101$)
Moving	0.056*	0.075	0.076	0.069
Seeing	0.077	0.075	0.079	0.078
Hearing	0.071	0.064	0.070	0.068
Breathing	0.087	0.080	0.088	0.085
Sleeping	0.064	0.068	0.064	0.065
Eating	0.067	0.068	0.070	0.068
Communicating	0.079	0.075	0.080	0.078
Continence	0.052	0.061	0.056	0.056
Working	0.048	0.064*	0.048	0.053
Social partip.	0.071	0.060	0.072	0.068
Mental function	0.093	0.083	0.092	0.090
Pain	0.061	0.057	0.059	0.059
Depression	0.053	0.050	0.042	0.049
Distress	0.058	0.055	0.049	0.054
Perceived health	0.065	0.066	0.055	0.062
Sum	1.000	1.000	1.000	1.000

Table 4 The average 15D HRQL scores in the subgroups

	Sgr.I ($n = 36$)	*Sgr.IIA* ($n = 31$)	*Sgr.IIB* ($n = 31$)	*Sgr.III* ($n = 34$)	*Total sample* ($n = 136$)
Mean	0.906	0.778	0.821	0.842	0.840
SD	0.058	0.096	0.091	0.100	0.098

is statistically significant ($P<0.01$, $n=31$, $t=-2.735$) (Table 4).

Gender did not have a significant effect on the HRQL scores in the subgroups [df(1,95), F = 0.76641, $P=0.39$]. The difference in the 15D scores between the patients with complete and incomplete lesions was significant [df(3,97), F = 4.08745, $P<0.01$] (ANOVA). There was also a statistically significant difference between tetraplegic and paraparetic patients, but not between patients with other types of neural lesion.

Average position of the respondents on the dimensions (15D profiles)

On average the newly injured patients (Sgr.IIA) performed poorest of the four subgroups on the dimension of moving [df(3,129), F = 5.55544, $P<0.00164$], while there was no significant difference in this respect between the subgroups I, IIB and III (Figure 1). The newly injured patients expressed also the lowest average level on the dimensions of working [df(3,129), F = 35.46618, $P=0.00001$], social participation [df(3,129), F = 16.61209, $P=0.00001$], eating [df(3,128), F = 2.74683, $P=0.045$] and perceived health [df(3,129), F = 7.45568, $P=0.00028$]. Subgroup I scored significantly better than the other subgroups on the dimension of working (Tukey 0.05).

In intergroup comparisons there was no significant difference in the average position between the subgroups on the dimensions of depression, distress, urinary continence, pain or mental function (Figure 1).

The VAS scores followed an identical pattern to the 15D scores [df(2,98) F = 24.64547, $P<0.0001$] (ANOVA). The average VAS scores were 82.3 (SD = 15.5), 47.3 (SD = 20.9) and 61.5 (SD = 23.9), respectively (Table 5). The subgroups differed significantly from each other ($P<0.05$). The difference between VAS scores before and after acute rehabilitation was not significant ($P<0.06$, $n=30$, $t=-1.926$) (Table 5).

In the whole sample (n = 101) the Pearson product moment correlation coefficient between the HRQL and VAS scores was highly significant (r = 0.68, $P=0.0$).

Discussion

This cross-sectional study shows that there is a considerable heterogeneity in the HRQL scores in various subgroups of SCI patients. However, subgroups I and III may not be representative samples of their underlying populations. The patients in subgroup I were volunteers from a larger random group of SCI patients with pediatric spine injury. The chronic SCI patients who came to the re-rehabilitation course as a part of life-time care were selected by the possible fact that employed and otherwise socially integrated persons are more seldomly accepted to re-rehabilitation than individuals in undesirable living situations. The considerably low employment status in the subgroup of chronic adult SCI patients (Sgr.III) in comparison to other reported employment studies reflects that kind of selectivity.[12]

The overall quality of life of SCI patients has been reported to be high already some years after injury, as measured by various self-assessment instruments and comparable in many respects to the scores of the population in general.[2,3,13]

This study showed a clear difference of HRQL between adults who had sustained an SCI in childhood and those paralysed in adulthood. A significant difference in the HRQL scores existed also between those who were starting their first rehabilitation period (Sgr.IIA) and those injured for a long time (Sgr.I and Sgr.III). A statistically significant difference was found in the HRQL scores before and after acute rehabilitation (Sgr.IIA and Sgr.IIB). This probably reflects a positive outcome of rehabilitation as assessed with the 15D. Here the result was evaluated at the group level, but the method can also help therapists to assess a single patient's progress during rehabilitation.

Psychosocial adjustment during the first two years after injury has been reported to be loaded with anxiety and depression and other longstanding psychological morbidity in approximately 30% of the cases.[14] In terms of depression and distress, the newly injured patients (Sgr.II) scored worst, while those injured in childhood scored best in our study, but there was no significant difference between the subgroups.

The patients with pediatric SCI were much better educated, were quite often in gainful occupation, drove cars, and had more family ties than the patients in the other two subgroups. In terms of social participation, subgroup I managed in social life markedly better than the other two subgroups. These results confirm the good psychosocial adjustment of those who were injured in childhood, but does not affirm that mood perturbations are more common in the axis of depression-distress during the first years after SCI.[3,14]

Overall HRQL has been shown to improve with years post injury and to correlate positively with the number of years of adjustment and with an age of under 20 years at injury.[15,16]

Conflicting results exist concerning the influence of the degree of disability and impairments on the HRQL in SCI-patients.[1,17]

Fuhrer *et al.*[17] found that life satisfaction was influenced, albeit indirectly, by selective aspects of patients' social role performance (handicap), but not by their degree of impairment or disability. Clayton and Chubon[1] found, in their study consisting of 100 SCI patients, that lower ratings of HRQL were associated with greater severity of disability. A

Table 5 The VAS scores in different subgroups

	Sgr.I ($n=36$)	*Sgr.IIA* ($n=31$)	*Sgr.IIB* ($n=31$)	*Sgr.III* ($n=34$)	*Total sample* ($n=132$)
Mean	82.3	47.3	55.3	61.5	61.7
SD	15.5	20.9	21.4	23.9	24.8

plausible explanation for this inconsistency may lie in the different approaches and instruments used to measure HRQL.

Lundqvist *et al*. studied 98 patients with traumatic SCI using the Sickness Impact Profile (SIP), Mood Adjective Check List and the Hospital Anxiety and Depression Scales.[3] All SCI groups exhibited clearly higher disability values in the physical-function categories of the SIP than did the control group. Severity of neurologic impairment correlated with physical dysfunction, but scores reflecting psychosocial function did not differ between the SCI patients and the control group.

In this study an association was found between the severity of disability and lower HRQL scores among the paraparetics versus other patients, but not between tetraplegics, paraplegics and tetraparetic patients. Gender did not seem to affect the outcome in any of the subgroups.

HRQL scores among SCI patients have been found to be high and comparable to those of the ablebodied population.[2,3,18] Previously the 15D has been applied to several patient groups.[6] For example, in a study of coronary artery bypass patients the average 15D score was 0.76 before and 0.87 one year after operation.[19] The coronary by-pass patients thus started off lower, but ended up higher than the SCI patients who were at entering a re-rehabilitation course 4 years after initial injury. The average HRQL score in a sample of adult Finnish general population ($n = 372$) under 47 years of age has been reported to be 0.929, SD = 0.083.[20] The average HRQL score of 0.906 (SD = 0.058) measured in the pediatric SCI patients (Sgr.I) is lower than the score of the general population.

The elevated HRQL scores in SCI population have been regarded as somewhat surprising and explained by a shifting of priorities because of the long-term physical disability. Whiteneck *et al*. concluded on the basis of their study that the SCI group not only ranked their needs differently, but also differed from the general population in how well they felt those needs were met. Those needs that were met least also seemed to be ranked relatively lower in importance.[13]

The general adjustment to disability appears to be conditioned by changes in living attitudes.[21] High HRQL scores and good psychosocial outcome suggest a successful adjustment process which may have been caused by changes in personal living attitudes.

The social importance weights of the 15D dimensions can be interpreted as reflecting subjective values (Table 3). The statistically significant differences in the importance weights for 'moving' and 'working' between the subgroups of SCI may be a result of transformation of these values or living attitudes. More research is needed to understand the psychology underlying the varying HRQL scores in the subgroups of SCI patients. Studies of psychiatric symptomatology and ego-defences especially may lead to a better understanding of the phenomena behind the HRQL scores.

Conclusions

A comparison of HRQL scores and importance weights using the 15D shows that the SCI patients who have sustained their injury in childhood are better adjusted and have higher HRQL scores than newly injured adult patients or adult SCI patients some years after the injury. A majority of patients with pediatric SCI had a gainful occupation or were studying whereas few of the patients with otherwise chronic SCI had returned to paid work.

Adult SCI patients were not significantly more depressed and distressed during the first years after injury than patients who had sustained their injury in childhood. Longstanding SCI may influence attitudes towards ability to move and work, which can be detected by quantifying the relative importance of various HRQL dimensions. More attention and resources are needed to investigate the social rehabilitation of adult patients when the rehabilitative goal is full integration to society.

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