

HEALTH-RELATED QUALITY OF LIFE IN PERSONS WITH TRAUMATIC SPINAL CORD LESION IN HELSINKI

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Objective: To estimate the health-related quality of life (HRQoL) of persons with spinal cord lesion.

Design: The study design was cross-sectional.

Subjects: All adult citizens in Helsinki with traumatic spinal cord lesion were identified. The final study group comprised 117 subjects, corresponding to a participation rate of 77%.

Methods: HRQoL was assessed by a generic 15-dimensional self-administered instrument (15D). Clinical examination was based on the manual of the American Spinal Injury Association. Examinations were performed on all subjects by the same experienced physician and physiotherapist.

Results: The average 15D score of the study group was significantly lower ($p < 0.001$) than that measured in the age-matched general population sample. Subjects with spinal cord lesion had significantly more problems due to the neurological lesion but also on the dimensions of sleeping, discomfort and symptoms and vitality. In regression analysis of the study group the only variable explaining HRQoL was the neurological level of the lesion. Spinal cord lesion caused more depression and distress in persons with motor incomplete lesion than those with motor complete lesion.

Conclusion: Persons with spinal cord lesion had lower HRQoL than the population in general. The results indicate that spinal cord lesion may cause problems in the areas of sleeping, discomfort and symptoms or vitality, in particular. More attention should be paid to finding ways of improving the situation of persons with motor incomplete lesion, especially in terms of psychological function.

Key words: spinal cord injury, health-related quality of life, 15D, prevalence.

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INTRODUCTION

The outcomes of spinal cord injury can be assessed in several ways, such as physiological function as well as social and psychological adjustment. Recently there has also been a growing

interest in evaluating a person's well being after diseases or disabilities. The instruments measuring well being may address different concepts, such as life satisfaction or quality of life (QoL), which may cause problems when comparing results.

Likewise, measuring health-related quality of life (HRQoL) has become a necessary and useful approach to evaluating the effectiveness and efficiency of healthcare interventions. HRQoL can be defined as a multidimensional concept that includes the physical, psychological and social functioning associated with an illness or its treatment (1). Because of severe impairment, extended life spans and ageing, the importance of measuring HRQoL should also be underlined as an outcome parameter after initial rehabilitation and in follow-up programmes developed for persons with spinal cord lesion (SCL) (2, 3).

Several instruments can be used for measuring HRQoL among persons with SCL (4). A full picture of outcomes requires comparison of similarities and differences between those with SCL and their non-SCL counterparts, using the same tools. Generic instruments allow comparison of different diseases and conditions, which condition-specific instruments do not allow (4).

The results for HRQoL in persons with SCL are somewhat contradictory (5, 6). The findings concerning the impact of severity of injury have not been consistent. Evans et al. (7) found that severity of injury was associated with QoL, with more severe injuries correlating with poorer QoL. On the other hand, Westgren & Levi (8) found no difference in QoL, with the exception of physical function, in subgroups according to the extent of lesion.

It has also been reported that HRQoL improves with the time since injury (8, 9). However, Post et al. (10) found no specific relationship between time since injury and life satisfaction. Persons who had sustained their injury in childhood seemed to be better adjusted in terms of HRQoL than those injured as adults (11). Several studies have failed to find a correlation between QoL and current age (5, 12). On the other hand, Post et al. reported that there were relationships between life satisfaction and age, but they were more pronounced in the population group than in the group of person with SCL (10).

It has been proposed that the inconsistency of these results may lie in the different approaches and instruments used to measure QoL (13). Also, in order to integrate QoL assessment with rehabilitation, analysis between the concepts and theories of QoL and rehabilitation practices is required (14).

In 1998, the Health Committee of Helsinki decided to evaluate the present health status and social situation of adults with

traumatic SCL leading to permanent neurological deficits. The aim of this Helsinki Spinal Cord Injury Study (HSCIS) was to determine the prevalence of the population with SCL and to assess their needs. The purpose of the current sub-study was to evaluate HRQoL in this population and to compare it with the population in general. In addition, the effect on HRQoL of gender, age, time since injury, education and the level and completeness of the lesion were assessed.

METHODS

Subjects

The study design was cross-sectional. The cross-section date of the study was 1 January 1999. Subjects to be included in the HSCIS were identified from the registers of the Käpylä Rehabilitation Centre, Helsinki University Central Hospital and the local organization for the disabled people. Local health centres were informed about the study, residential service houses were contacted and announcements were published in patient magazines. Case findings are described in more detail in Dahlberg et al. (15).

Procedure

All identified subjects with SCL were invited to attend a clinical interview. The data were gathered during that visit between September 1999 and February 2001, and at least 1 year after each subject's injury. The data included HRQoL measured by the 15D (16) and clinical investigation based on the manual of the American Spinal Injury Association (ASIA) (17).

The 15D is a generic, comprehensive, 15-dimensional, standardized, self-administered measure of HRQoL that can be used both as a profile and single index score measure. The 15D questionnaire consists of 15 dimensions: mobility, vision, hearing, breathing, sleeping, eating, speech, elimination, usual activities, mental function, discomfort and symptoms, depression, distress, vitality and sexual activity. Each dimension is divided into 5 ordinal levels, by which more or less of the attribute can be distinguished. The person ticks, for each dimension, the level that best describes his or her health status. As an example, the levels of the dimension of elimination are described in Table I.

The valuation system of the 15D is based on an application of the multi-attribute utility theory. The single index (15D score) on a 0–1 scale, representing the overall HRQoL, is calculated from the health state descriptive system by using a set of population-based preference or utility weights. Such a weight for each level of each dimension is obtained by multiplying the level value by the importance weight of the dimension at that level. The level values on a 0–1 scale, reflecting the goodness of the levels relative to no problems on the dimension and to being dead, and the importance weights summing up to unity, have been elicited earlier from representative population samples. A more detailed description of the valuation system is published elsewhere (16, 18). A difference of ≥ 0.03 in the 15D score is clinically important in the sense that people can on average feel the difference (19).

The 15D is well validated and simple to use (16). It has also been used earlier in Finland in HRQoL research amongst persons with SCL (11, 20).

The HRQoL of the study group was compared with that of general population measured by the 15D in the Finnish National Health Survey 1995/96. For the survey random sample of 6018 reference persons was

drawn from the non-institutionalized Finnish population aged 15 years and over. The 15D questionnaire was given to the reference person for self-administration and to be returned by post. The survey reached 5185 reference persons, and, of these, 4774 filled in the 15D questionnaire, 3990 respondents filled it in completely (response rate 3990/5185 = 77%) (21). Of these, 3591 were in the age range of the study group. In order to allow comparison, the population sample was matched with the study group by weights reflecting the age distribution of the study group.

The ASIA classification is widely used in spinal cord injury medicine. The ASIA Impairment Scale (AIS) reflects the completeness of the lesion:

- A = complete lesion, no sensory or motor function is preserved in the lowest sacral segments;
- B = sensory incomplete lesion (including segments S4–S5), but no motor function below the neurological level;
- C = sensory and motor incomplete, but more than half of the 10 pairs of key muscles have strength of less than 3 on a scale of 0–5;
- D = sensory and motor incomplete, at least half of the key muscles have strength of greater or equal to 3;
- E = sensory and motor function normal.

In this study AIS A and B were classified as motor complete injuries and AIS C and D as motor incomplete injuries. The level of the lesion includes only tetraplegia or paraplegia.

Statistical analysis

Variables with normal distribution descriptive values were expressed by mean and standard deviations (SD); statistical comparison between the groups was made using a *t*-test. Variables with ordinal descriptive values were expressed by median and interquartile range (IQR); statistical comparison between groups was made using the Mann-Whitney test. Measures with a discrete distribution are expressed as counts (%) and analysed by chi-square test. We used Bonferroni's adjustments to correct significance levels for multiple testing. Median regression analysis was used to model the relationship between 15D score and of predictor variables.

RESULTS

At the cross-section date of the study (January 1, 1999) there were 546 000 inhabitants in Helsinki. A total of 152 cases of SCL were found. This is a prevalence of 28 per 100 000 inhabitants. Altogether 125 subjects made the clinical visit.

The final study group, with completed 15D questionnaires, consisted of 117/152 subjects (77%). A total of 25 (21%) subjects of the final study group were women and 92 (79%) were men. The mean age during the follow-up was 49 (SD 13) years and the mean time since the injury was 18 (SD 11) years. Altogether 108 (92%) of the subjects were community-residents, 8 (7%) subjects, most of them elderly, were living in a nursing home or in a residential service house and 1 (1%) in a hospital.

Of the 35 dropouts, 11 (31%) were women and 24 (69%) were men. The mean age during the follow-up was 47 (SD 12) years and the mean time since the injury was 18 (SD 13) years. There

Table I. Descriptions for the levels of elimination dimension of the 15D questionnaire (16)

	Description
1	My bladder and bowel work normally and without any problems.
2	I have slight problems with my bladder/bowel function, e.g. difficulties with urination, or loose or hard bowels.
3	I have marked problems with my bladder/bowel function, e.g. occasional "accidents", or severe constipation or diarrhoea.
4	I have serious problems with my bladder/bowel function, e.g. routine "accidents", or need of catheterization or enemas.
5	I have no control over my bladder and/or bowel function.

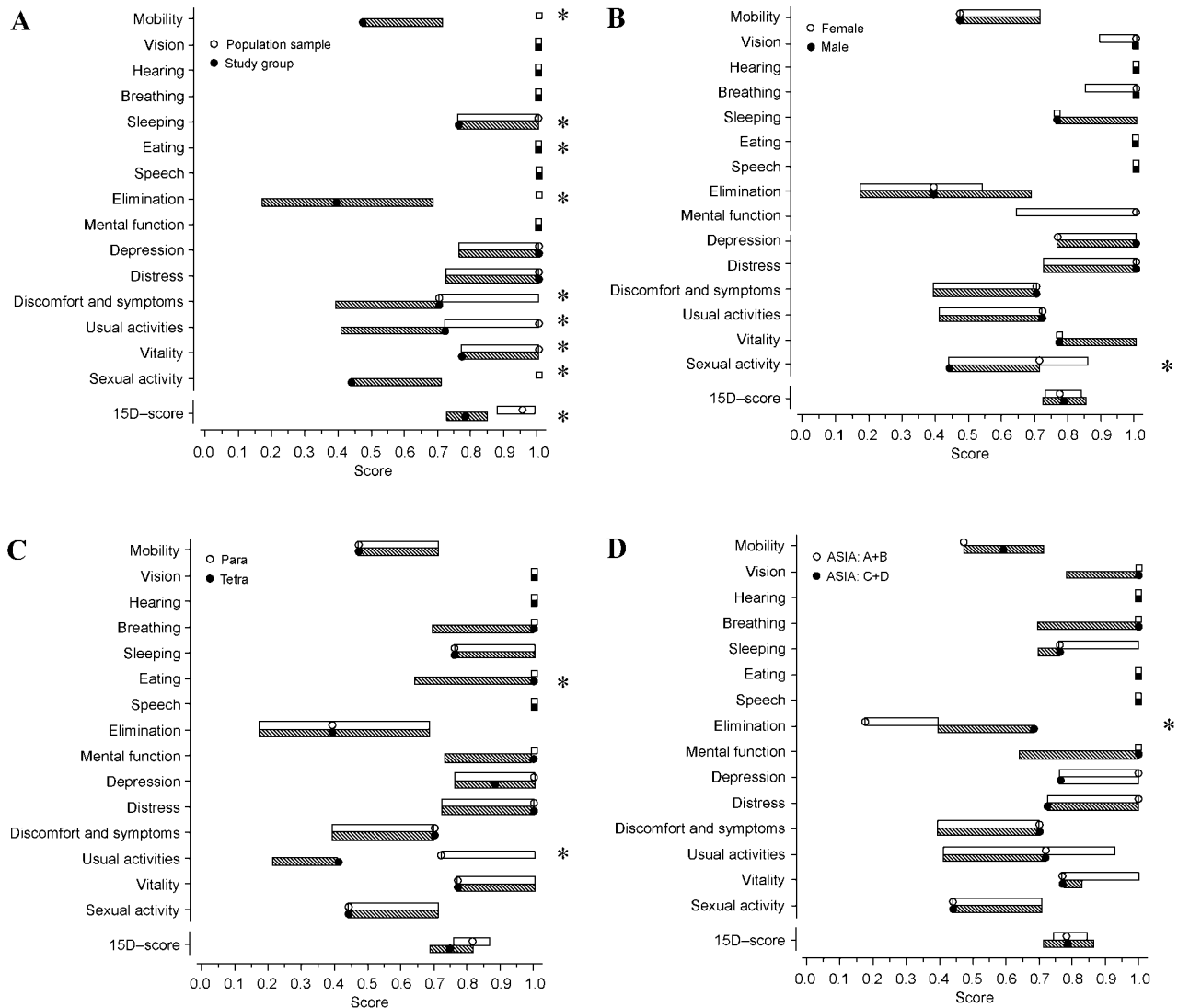


Fig. 1. (A) Medians of 15D profiles in the study group and a population sample. Open circle shows the population sample ($n = 3571$) and solid circle the study group ($n = 117$); In the dimension of eating the population sample scored significantly higher because of the lowest quartile, which is not visualized in the figure; (B) Medians of 15D profiles in women and men. Open circle shows subjects with women ($n = 25$) and solid circle subjects with men ($n = 92$); (C) Medians of 15D profiles in subjects with paraplegia and with tetraplegia. Open circle shows subjects with paraplegia ($n = 62$) and solid circle subjects with tetraplegia ($n = 52$); (D) Medians of 15D profiles in subjects with motor complete lesion and with motor incomplete lesion. Open circle shows subjects with motor complete lesion ($n = 68$) and solid circle subjects with motor incomplete lesion ($n = 46$). Boxes indicate interquartile ranges. *Statistically significant difference in comparison between each sub-group in A, B, C and D figures.

were no statistically significant differences between the dropouts and the study group in gender ($p = 0.22$), age at the follow-up ($p = 0.40$) or the time since injury ($p = 0.81$).

The data on completeness and level of the lesion were available from 114 subjects of those 117 who had completed the 15D questionnaire. Altogether 50 (44%) subjects had a complete lesion and 64 (56%) had an incomplete lesion. A total of 52 (46%) subjects had tetraplegia and 62 (54%) had paraplegia.

The median (IQR) 15D score of the study group (0.78 [0.73, 0.85]) was significantly lower ($p < 0.001$) than that measured in the age-matched population sample (0.95 [0.88, 0.99]). The difference is also clinically important. The 15D profiles of the study

group and population sample are shown in Fig. 1A. The population sample scored significantly higher on the dimensions of mobility ($p < 0.001$), sleeping ($p < 0.001$), eating ($p < 0.001$), elimination ($p < 0.001$), discomfort and symptoms ($p < 0.001$), usual activities ($p < 0.001$), vitality ($p = 0.015$) and sexual activity ($p < 0.001$). There were no significant differences on the other dimensions.

The 15D profiles of women and men are shown in Fig. 1B. There was no significant difference in the average 15D score. There was a significant difference in the 15D profile only on the dimension of sexual activity where women scored significantly higher ($p = 0.028$) than men.

Table II. Median regression analysis for relationship between 15D and characteristic variables

Variables	Coefficient (95% CI)*	p-value
Gender (male)	2.23 (-4.47-8.93)	0.51
Age (years)	-0.15 (-0.40-0.11)	0.26
Years since injury	0.16 (-0.12-0.43)	0.27
Completeness of the lesion (AIS A + B)	-2.17 (-8.18-3.84)	0.47
Level of the lesion (paraplegia)	6.87 (1.09-12.64)	0.02
Years of education	0.07 (-0.67-0.81)	0.85
Constant	78.51	

* Regression coefficients multiplying by 100.
AIS = ASIA Impairment Scale.

The median (IQR) 15D score of subjects with tetraplegia (0.75 [0.69, 0.82]) was significantly lower ($p < 0.001$) than in subjects with paraplegia (0.82 [0.76, 0.87]). The difference is also clinically important. The 15D profiles of the subjects with tetraplegia and paraplegia are shown in Fig. 1C. There was a significant difference in the 15D profile only on the dimension of eating ($p < 0.001$) and usual activities ($p < 0.001$) where subjects with paraplegia scored significantly higher than those with tetraplegia.

The 15D profiles of subjects with motor complete lesions (AIS A + B, $n = 68/114$) and motor incomplete lesions (AIS C + D, $n = 46/114$) are seen in Fig. 1D. There was no significant difference in the average 15D score. The persons with motor incomplete lesions scored significantly higher on the dimension of elimination ($p < 0.001$). There was no significant difference on the other dimensions. There was, however, a tendency for more depression and distress amongst the subjects with motor incomplete lesion than those with motor complete lesion.

Median regression model was used to determine which sociodemographic and clinical characteristics influenced the average 15D score (Table II). The explanatory variables were gender, age, time since injury, completeness of the lesion, level of neurological the lesion and years of education. Only the level of the neurological lesion of the regression coefficients was significant.

DISCUSSION

A reasonable effort was made to find all subjects with SCL in the Helsinki area. In the Stockholm Spinal Cord Injury Study (22) (using similar methods) the prevalence rate was 22.3/100 000 inhabitants. The rate in Helsinki (28/100 000) is even higher. The final study group comprised 77% of the whole population with traumatic SCL. The study group can be estimated to represent rather well the population of persons with traumatic SCL in Finland. This report is one of the few that measures HRQoL of persons with SCL on prevalence basis.

HRQoL was measured by the 15D. It was chosen, because it is one of the few generic utility instruments and it compares favourably in most important properties among the instruments of its kind (23, 24). Also, its set of dimensions was considered particularly suitable for persons with traumatic spinal cord lesion.

The age-matched population sample scored higher on several dimensions than the study group. This may be explained partly by the neurological lesion. On the other hand, the study population scored lower on dimensions such as sleeping and discomfort and symptoms, which can be defined as indirect consequences of the lesion caused, for example, by spasticity, pain and bladder problems. This is consistent with findings that the prevalence of pain is high among persons with SCL (25, 26) and that chronic pain induces problems in sleeping (27). Also the prevalence of sleeping disorders has been reported to be high (28, 29).

The study group also scored significantly lower on the dimension of vitality which naturally may be due to problems with sleeping and low scoring on the dimension of discomfort and symptoms. Also the activities of daily living may be more of a burden to persons with SCL than to the population sample, and this affects vitality.

Women scored significantly higher on the dimension of sexual activity, which reflects the more vulnerable function of male sexual organs in men. Sexual counselling should be encouraged and recent methods, such as oral drug treatment for erectile dysfunction, may have already been changing the situation (30).

Persons with motor complete lesions scored lower on the dimension of elimination, which is a very important aspect on HRQoL. On the other hand, there was a tendency for more depression and distress in persons with motor incomplete lesions than those with motor complete lesion. This might indicate poorer adjustment to the disability of those with a motor incomplete lesion. In the light of the results of this study the finding that those who are marginally disabled are those who are most at risk of suicide should also be taken into account (31).

Subjects with paraplegia scored significantly higher than those with tetraplegia only on the dimensions related to physical function (eating and usual activities), which can be explained by the level of the lesion in the spinal cord. A similar finding has also been reported by Westgren & Levi (8). On the other hand, in regression analysis only the level of the neurological lesion explained statistically significantly the variance in the average 15D score. Subjects with paraplegia had a higher average score compared with subjects with tetraplegia. In this study age or time since injury had no significant effect on HRQoL.

In conclusion, the 15D reflects well most of the obvious impairments caused by SCL in the study group. The average 15D score was significantly lower in the study group than that measured in the age-matched population sample. This could be explained mainly by the neurological lesion. It should, however, be pointed out that subjects with SCL may have problems in the areas of sleeping, discomfort and symptoms or vitality, in particular. Subjects with paraplegia scored significantly higher than those with tetraplegia, but gender or the completeness of the lesion had no effect on the average 15D score. On the other hand, the results indicate that more attention should be paid to finding ways of improving the situation of persons with motor incomplete lesions, especially in terms of psychological function.

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