Original Article

Health and quality of life of persons with spinal cord lesion in Australia and Sweden

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Study design: Cross-sectional questionnaire study.

Objectives: The aim of the study was to demonstrate the value of common general health-related quality of life (HRQL) instruments, readily available for cross-cultural comparisons, in persons with spinal cord lesion (SCL) treated at spinal units in Melbourne, Australia and in Gothenburg, Sweden. Another aim was to determine as to which of the independent variables were the most powerful predictors of global QL in the two SCL groups.

Settings: Australia and Sweden.

Methods: Two groups consisting of 89 Australian and 71 Swedish SCL persons were surveyed. The two groups were matched according to sex, age, time since injury and level of injury. The 36-item short-form health survey (SF-36) and the Spinal Cord Injuries Quality of Life-23-item questionnaire were used to cover essential generic and specific domains of health and quality of life. Clinical and sociodemographic data were collected using questionnaires. For interpretation purpose, available general population data were used.

Results: The most important predictors of QL perception in the Australian group were the same as for the Swedish group; mood, physical and social functioning and problems regarding injury. In total, 61% (Australian group) and 52% (Swedish group) of the variance was explained by these variables. Despite similarities of health profiles, some areas of the SF-36 differed between the two groups.

Conclusion: The demonstrated HRQL profiles in SCL persons have shown that valid measures can provide new information of clinical value beyond the self-evident physical and practical restrictions due to injury. Illustrative comparisons, such as those presented here between Australia and Sweden, may extend our knowledge about areas where the SCL persons themselves are the logical experts, for example, maintenance of personal roles, social interaction and emotional well-being.

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Introduction

There are few events that affect a person's entire lifestyle as profoundly as a spinal cord lesion (SCL). In most countries and cultures, those who suffer traumatic SCL are mostly young, male and action-oriented.¹ With

rehabilitation and good follow-up, their life expectancy will approach normal.

Therefore, the self-evident goals of rehabilitation and ongoing care of persons with SCL are to limit the complications of their conditions and to assist them in the process of optimising function and quality of life (QL).¹ However, QL is a multidimensional concept that cannot be distinctly defined, because it is a person's own

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sense of well-being that stems from satisfaction or dissatisfaction with the areas of life and living situation that are important to him or her.²⁻⁴ QL is influenced by a variety of factors, including physical, psychological and emotional function, ability to work and to perform leisure activities and relations to other people and society.^{5,6} Measuring these health-related components can assess the broad concept of QL.

The QL of SCL persons has been described in relation to a number of variables. Earlier Swedish studies^{7,8} have shown that the SCL persons' mental well-being did not differ from that of nondisabled persons when 4 years had elapsed after the injury. Perceived QL was, however, on average 25% lower compared with a reference group. The fewer the experienced problems specific to the lesion, the lesser the depressive feelings, and the better the physical and social functioning, the better the overall QL.

Several studies have shown that the level and extent of the lesion are not related to well-being and perceived QL.^{5,7-9} In a meta-analysis study by Evans *et al*,⁶ it was demonstrated that at most 5% of the variance in QL scores is due to the severity or level of the SCL. Studies of the role of chronological age and time since lesion are contradictory. Krause and Crewe¹⁰ concluded that older persons are likely to experience a less active and less rewarding life after SCL than younger persons, while DeVivo *et al*¹¹ found no relation between age and health status. Time since lesion is mostly reported to be positively related to both psychological and functional outcome,^{10,12} while in other studies no such relation has been found.^{11,13} Other factors that have been described to have an impact on adjustment and subjective well being are the amount and quality of social support,¹⁴⁻¹⁷ family relations, sex life^{18,19} and community life.²⁰

A variety of instruments have been used to measure health and QL in SCL persons.²¹ As a result of the poor validity commonly seen in QL measurements, Hallin *et al*²¹ suggest that QL research with SCL persons needs to be better designed and include more uniform and valid criteria. It is recommended that both generic and condition-specific instruments should be used.²¹ Introduction of standardised self-report questionnaires in crosscultural research has opened for new ways of assessments in medicine.²²⁻²⁴ To assess adequately the different health-related components of QL in this study, an established generic measure of health (SF-36)^{24,25} was used together with a condition-specific QL questionnaire (SCI QL-23).²⁶

The aim of the study was to demonstrate the value of common health-related quality of life (HRQL) instruments, readily available for crosscultural comparisons, in persons with SCL treated at spinal units in Melbourne, Australia and Gothenburg, Sweden. The two units are quite similar concerning the philosophy of SCL care and goals of rehabilitation. Another aim was to determine as to which of the independent variables were the most powerful predictors of global QL in the two SCL groups.

The following main questions were addressed:

1. What are the similarities and differences in physical, psychological and social functioning and perceived HRQL in Australian and Swedish people with SCL?
2. What are the most important determinants of perceived HRQL in the Australian and Swedish groups of SCL persons?

Subjects and methods

Study population

The inclusion criteria were that the patients be aged between 15 and 80 years at the time of the lesion, be between 1 and 14 years post-SCL, not have dementia or brain injury and have been treated for at least 3 months at one of the participating spinal units.

Australian group A group of 240 SCL persons were randomly selected from the records at the Austin Health, Melbourne. The questionnaires were mailed together with information on the study and a consent form. When the letters were returned, the written consent was separated from the questionnaires to maintain the participants' anonymity. A total of 64 letters did not reach the receiver due to the correct address not being known. Two patients had died, and an additional three did not fulfil the inclusion criteria. Of the remaining 171 persons who received the questionnaires, 89 (52%) replied.

Swedish group Out of a consecutive group of 122 SCL persons treated at the spinal unit in Gothenburg, 14 did not fulfil the inclusion criteria. Of the remaining 108 persons, 71 (66%) replied. The sample can be considered representative the Swedish SCL population in that it did not differ from an almost total prevalence study of the most populated region of Sweden.²⁷⁻²⁹

As shown in Table 1, the Swedish and the Australian groups can be considered equivalent concerning the distribution of sex, age, age at lesion, time since lesion and level and completeness of lesion. No significant differences between the two groups were found in these aspects.

Measuring instruments

Generic HRQL The Short Form-36 Health Survey (SF-36)²² was used as a generic measure of HRQL. The SF-36 is an extensively used generic measure, where evidence of construct validity and discriminant ability have been found in SCL persons. The SF-36 taps eight health domains representing multiple operational definitions of health, including function and dysfunction, distress and well-being, and favourable and unfavourable self-ratings of one's general health status.²⁵ The physical functioning scale (PF; 10 items) measures the ability to perform activities of daily living and also

Table 1 Demographic and clinical characteristics of the participants

Characteristics	Australian group (n = 89)	Swedish group (n = 71)
Sex		
Male	70 (78.6%)	58 (81.7%)
Female	19 (21.4%)	13 (18.3%)
Age		
Median (range)	42 (17–80)	37 (18–82)
Mean (SD)	43.5 (17.0)	41.4 (15.5)
Age at injury		
Median (range)	34 (16–77)	32 (15–80)
Mean (SD)	38 (17.2)	34.8 (16.2)
Time since injury		
Median (range)	5 (1–14)	7 (1–13)
Median (SD)	5.8 (3.6)	6.5 (4.1)
Level of injury ^a		
Tetraplegia, complete	18 (20.4%)	15 (21.1%)
Tetraplegia, incomplete	25 (28.4%)	18 (25.4%)
Paraplegia, complete	21 (23.9%)	16 (22.5%)
Paraplegia, incomplete	24 (27.3%)	22 (31.0%)

^aMissing data from one of the Australian participants

strenuous activities. Role physical (RP; four items) reflects the extent that physical health has a limiting effect on work or other activities. Bodily pain (BP; two items) concerns the amount of pain felt and whether it interferes with normal activities. General health (GH; five items) measures perceived general health status. Vitality (VT; four items) includes items on energy, tiredness, etc. Social functioning (SF; two items) concerns how social activities are affected by physical health or emotional problems. Role-emotional (RE; three items) reflects the extent that work or other activities are limited by emotional problems. Mental health (MH; five items) measures emotional well being. All scale scores range from 0 to 100 after weighting and linear transformation according to algorithm, where high scores represent optimal physical functioning and psychological well being. Three of the scales (PF, RP and BP) are particularly measures of physical components, whereas MH, RE and SF are predominantly measures of mental health. Vitality and general health are more overarching and represent both physical and mental aspects of health. The SF-36 values are for interpretation purposes compared to an age- and sex-matched reference group ($n=1102$) from the Swedish norm database ($n=13152$).²⁴

SCL-related quality of life The Spinal Cord Injury Quality of Life Questionnaire (SCI QL-23) was used as a specific measure of HRQL.²⁶ Items comprising the SCI QL-23 were derived and adopted from an extensive battery of specific and generic questionnaires applied in a study of persons with SCI.²⁶ The SCI QL-23 consists

of three factors; Physical and social functioning (FUNC; 10 items) was derived from the Swedish version³⁰ of the Sickness Impact Profile (SIP).³¹ FUNC covers functional limitations in mobility, body care, and movement and social interaction. The participants have only to check each item that describes a dysfunction in relation to their health at the time. FUNC-items have predetermined weights in accordance to the weighting system of the SIP that are intended to correspond to severity of dysfunction. Depressive feelings (DEPR; six items) was derived from the Swedish version³² of the Hospital Anxiety and Depression scale (HAD).³³ DEPR reflects distress and depressive symptoms. DEPR has a four-point response scale. Problems regarding injury (PROB; six items), which was derived from a list of items³⁴ describing perceptions of physical dependency, of complications, and of social stigma. PROB thus reflects perceptions of physical independence, of complications and of social stigma due to problems specific to the injury. PROB has a four-point response scale. The SCI QL-23 has been validated for Swedish conditions.²⁶ Perception of global QL was recorded on a 0–100 visual analogue scale (VAS),³⁵ the end points of which were labelled 'very low' and 'very high'.

The reference group completed the six items reflecting Depression from the HAD scale.³³ This reference group was also age- and sex-matched from the Swedish non-SCL population to a representative Swedish and Australian SCL population and was selected by the Swedish person and address register. The questionnaires were mailed together with a letter that explained the rationale for the study. Of 334 initially sent letters, 79% (203 men and 61 women) completed the questionnaire covering sociodemographic factors, the six items from the HAD (DEPR)³² and Global QL (VAS).³⁵ The mean age was 36.9 years with a range from 19 to 79 years (median 31 years).

Clinical and sociodemographic data Sex, age, age when injured, level, completeness and cause of lesion, marital status, level of education, and occupation were recorded using questionnaires.

Statistical methods

For overall comparison between the groups, Kruskal–Wallis one-way analysis of variance was used. Fisher's nonparametric test³⁶ was used for comparisons between two groups. For dichotomous variables the χ^2 test was used for overall comparison between three groups and Fisher's exact test for comparison between two groups. Correlations between the dependent variable, the VAS QL scale, and a number of independent variables, including sociodemographic data, neurological and functional status and psychosocial data, were tested using Pitman's nonparametric permutation test.³⁶ Pearson's correlation coefficients were only used for descriptive purposes. A step-by-step model of consecutive analyses including bivariate correlation,³⁶ partial nonparametric correlation³⁷ and multiple correlation procedures was

applied for the prediction of global QL scores from a selection of potentially important variables. The last step in the model describes the level of explained variance of the dependent variable, VAS QL scale, from the combination of powerful independent variables. For Pitman's correlation analysis and regression analysis, a P value of 0.05 or less was considered significant.

Ethical scrutiny The research protocol was approved by the Human Research Ethics Committee of Austin & Repatriation Medical Centre, Melbourne and the Ethical Research Committee of Göteborg University.

Results

As shown in Table 2, significantly ($P < 0.05$) more persons in the Australian group (55%) were married or cohabiting, compared to the Swedish group (37%). There were also differences between the two groups regarding the levels of education and occupation. Having only compulsory level of education was more common in the Australian group (51%) compared to the Swedish group (28%) ($P < 0.05$). The proportion of persons having a university degree did not differ between the countries. Only 6% of the Swedish participants were unemployed, compared to 23% of the Australian group ($P < 0.05$).

Physical, psychological and social functioning and perceived quality of life

SF-36 ratings As can be seen in Figure 1, the Australian and Swedish groups did not differ concerning BP, GH, VT, and MH. However, the Australian group reported significantly more limitations in physical

functioning (PF; $P < 0.05$), and in role functioning due to physical problems (RP; $P < 0.01$). Limitations in social functioning and interaction with others (SF) and limitations in role functioning due to emotional problems (RE) were significantly more pronounced ($P < 0.05$) among the Australian SCL persons compared to the Swedish group (Figure 1).

The differences between the two SCL groups and a reference group from the Swedish general population are shown in Figure 1. The greatest differences between the SCL groups are seen in PF, and in RP whereas the differences concerning SF, RE and MH were less pronounced. However, differences between each of the SCL groups and the reference group were significant across all the health concepts included in the SF-36 (Figure 1).

Figure 1 SF-36 health profile (mean values) for Australian SCL ($n = 89$), Swedish SCL ($n = 71$) and Swedish reference group ($n = 1102$)

Table 2 Sociodemographic characteristics of the participants

Characteristics	Australian group ($n = 89$)	Swedish group ($n = 71$)	Difference between groups (P -level)
Marital status			$P < 0.05$
Married/cohabiting	49 (55.1%)	26 (36.6%)	
Single	40 (44.9%)	45 (63.4%)	
Occupation ^a			$P < 0.05$
Employed	16 (20%)	25 (39%)	
Student	8 (10%)	5 (8%)	
Old age retired	29 (35%)	19 (30%)	
Unemployed	19 (23%)	4 (6%)	
Early retirement pension, disability pension.	10 (12%)	11 (17%)	
Education ^b			$P < 0.05$
Compulsory school	42 (51%)	19 (28%)	
High school certificate or equivalent	19 (23%)	22 (33%)	
Degree from university or college	11 (13%)	15 (22%)	
Vocational education	11 (13%)	11 (17%)	

Fisher's nonparametric permutation test

^aMissing data from seven of the Australians and 7 of the Swedes

^bMissing data from six of the Australians and 4 of the Swedes

SCI QL-23 rating No difference was found between the two SCL groups concerning physical and social function, as measured by the FUNC scale nor in PROB scale or global QL. As shown in Table 3, significantly higher scores on the DEPR scale were noted in the Australian group, compared to the Swedish group ($P < 0.0001$). One quarter (24%) of the Australians met the criteria for possible clinical depression (> 8 points) *versus* 11% among the Swedes. Ratings on the DEPR scale in the Australian group (mean 5.8, SD 3.8), but not the Swedish group (mean 3.1, SD 3.5), differed significantly ($P < 0.0001$) from those of the reference group from the Swedish general population (mean 2.7, SD 2.6).

Both groups of SCL persons rated their global QL significantly ($P < 0.0001$) lower (Australian group: mean 56.3, SD 28.3; Swedish group: mean 52.4, SD 28.5) compared to the reference group (mean 69.8, SD 21.3).

Quality of life in relation to sociodemographic, physical and psychosocial variables

In the *Australian* SCL group, level of lesion correlated significantly with the persons' perceived QL (the lower

the lesion the better). A higher level of education was associated with higher QL ratings. Depressive feelings (DEPR scale), Physical and Social Dysfunction (FUNC) and problems regarding injury (PROB scale) were significantly correlated to global QL ratings.

No other independent variables, such as age, age at lesion, completeness of lesion, occupation or marital status were significantly correlated with global QL (Table 4). In the *Swedish* group of SCL persons, time since lesion was correlated to QL ratings (the longer the time since lesion the better). Higher QL ratings were associated with lower degrees of depressive feelings (DEPR scale), lower scores of Physical and Social Dysfunction (FUNC scale), and problems regarding injury (PROB scale). The remaining independent variables showed no association with perceived QL (Table 4).

Determinants of QL perceptions

Partial and multiple correlation procedures were used to determine which of the independent variables (listed in Table 4) were the most powerful predictors of global QL in the two SCL groups.

Table 3 Functioning, mood and global quality of life according to QL-23

Variables	Australian group (<i>n</i> = 89)	Swedish group (<i>n</i> = 71)	<i>P</i> -level
Physical and Social Dysfunction (FUNC scale): range 0–70 (the lower the better)	28.8 (21.0)	25.7 (18.9)	NS
Mood (DEPR scale): range 0–18 (the lower the better)	5.8 (3.8)	3.1 (3.5)	$P < 0.0001$
Perceived loss of independence (PROB scale): range 1–24 (the higher the better)	12.8 (4.9)	13.6 (4.6)	NS
Global QL (VAS): range 0–100 (the higher the better)	56.3 (28.3)	52.4 (28.5)	NS

Values listed as mean score (SD). NS = not significant, Fisher's nonparametric permutation test

Table 4 QL in relation to sociodemographic, physical and psychosocial variables

Independent variables	Australian group (<i>n</i> = 89)		Swedish group (<i>n</i> = 71)	
	<i>r</i>	<i>P</i> -level	<i>r</i>	<i>P</i> -level
Age	0.02	NS	−0.06	NS
Age at injury	−0.06	NS	−0.12	NS
Time since injury	0.19	NS	0.24	*
Level of injury	0.21	*	0.03	NS
Completeness of injury	0.17	NS	0.08	NS
Marital status	−0.02	NS	0.20	NS
Level of education	0.27	*	0.14	NS
Occupation	−0.14	NS	−0.13	NS
Mood (DEPR scale)	−0.74	***	−0.52	***
Physical/social function (FUNC scale)	−0.53	***	−0.38	*
Perceived loss of independence (PROB scale)	0.5	***	0.67	***

r = Pearson's correlation coefficient

* $P < 0.05$

** $P < 0.01$

*** $P < 0.001$. Pitman's nonparametric permutation test

NS = not significant

Bold figures denote the strongest independent predictors for perceived high QL according to nonparametric partial correlation, applied from the development procedure of the SCI QL-23²⁶

The most important predictors of QL perception in the Australian group were the same as for the Swedish group; mood, physical and social functioning and problems regarding injury. In total, 61% (Australian group) and 52% (Swedish group) of the variance was explained by these variables.

Discussion

The value of crosscultural comparisons is well demonstrated in this study. In agreement with our results, limitations in generic HRQL as measured by the SF-36 have been reported in Swedish,²⁹ US,³⁸ and Canadian³⁹ samples of persons with SCL. Both the Australian and the Swedish SCL groups in our study differed significantly from the reference group across all the health components measured by the SF-36 instrument. The greatest differences were found in physical functioning, which is not surprising. The differences in mental and social functioning were much less prominent. The functional and emotional state of persons with SCL is strongly dependent on the quality of management and the facilities, options and support available in the physical and social environment to which they return.¹ Individual functional training intended to optimise independent living shall begin very soon after lesion. Newly injured persons must be encouraged to take part as soon as possible in physical and social activities, which will make them active and feeling responsible for the structure of their lives.

Depressive feelings (DEPR scale) were somewhat more common in the Australian group compared to the Swedish group. One explanation may be the higher proportion of persons with only compulsory level of education that was found in the Australian group. A low level of education is typically connected with a physically demanding type of work that might no longer be possible to manage after the SCL. A number of studies have shown that a higher education is associated with higher employment rates among SCL persons.² Unemployment was also significantly more common in the Australian group. However, our results indicate that occupation in itself has no significant impact on perceived QL in either group.

The Spinal Unit at the Austin Health receives patients from a large area also covering the countryside. Living in the countryside with an SCL may imply a larger degree of isolation with less opportunity for activities. SCL persons living in densely populated areas have a greater possibility of independence regarding both physical and social functioning. Trieschmann¹ claims 'accessibility of the environment greatly raises a person's ability to resume a productive life in the community'. Thus, some of the differences between the groups may be due to the fact that the Swedish group was recruited from the city of Gothenburg and its surrounding area.

Being in good spirits, that is, lack of depressive symptoms, a high level of independence in daily activities, mobility and social interaction, and no or minor perceived problems regarding injury had a

profound positive impact on the perception of a high quality of life in both groups. This is consistent with findings in earlier studies carried out on SCL persons.^{7,8,13}

Clinical characteristics have shown mostly little or no linkage to measures of health and QL. Time since lesion was not significantly correlated to QL in some earlier studies,^{5,7,11,13} whereas other studies concluded a positive relation.^{10,12} Our study shows that time since lesion was positively associated with perceived QL in the Swedish SCL group. It is difficult, however, to compare the different studies in this respect due to differences in sociodemographic variables.

The level of lesion was associated with QL (the higher the lesion the lower the QL) in the Australian, but not in the Swedish, group. The completeness of the SCL showed no association with QL in either country. This is in agreement with earlier studies.^{5,7-9,13}

In the two SCL groups included in our study, age was not at all related to QL. This is rather surprising since most studies show a strongly significant correlation between being young and a perceived higher QL.^{7,10,13} A study carried out on SCL persons suggested that QL began to decline in individuals over 45–50 years of age.⁴⁰

An important point concerns the normative data from a Swedish population. There is little reason to assume different norm comparisons in SCL QL ratings in Australia and Sweden.

The consequences of an SCL had a negative impact on perceived quality of life in both the Australian and Swedish group. Although the physical and practical restrictions due to the impairment are evident, personal roles and social activities can often be maintained. This may reflect the determined efforts taken by the spinal units to prepare SCL persons for active and productive lives in the community.

It can be concluded that the demonstrated HRQL profiles in SCL persons have shown that valid measures can provide new information of clinical value beyond the self-evident physical and practical restrictions due to injury. Illustrative comparisons, such as those presented here between Australia and Sweden may extend our knowledge about areas where the SCL persons themselves are the logical experts, for example, maintenance of personal roles, social interaction and emotional well-being.

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