



## Partner relationships, functioning, mood and global quality of life in persons with spinal cord injury and traumatic brain injury

M Kreuter<sup>1</sup>, M Sullivan<sup>2</sup>, AG Dahllöf<sup>1</sup> and A Siösteen<sup>1</sup>

<sup>1</sup>Spinal Injuries Unit and <sup>2</sup>Health Care Research Unit, Sahlgrenska University Hospital, S-413 45 Gothenburg, Sweden

The aim of this study was to assess and compare spinal cord injured (SCI) and traumatic brain injured (TBI) persons and people from the general population concerning partner relationships, functioning, mood and global quality of life.

One hundred and sixty seven SCI persons, 92 TBI persons and 264 controls participated in the study. The median age was: SCI persons 33 years (range 19 to 79 years), TBI persons 40 years (range 20 to 70 years), and controls 31 years (range 19 to 79 years). Age at injury ranged among SCI persons from 14 to 76 years (Md 28 years), and among TBI persons from 16 to 56 years (Md 32 years).

Half of the SCI group (51%), 58% of the TBI group and 59% of the controls had a stable partner relationship at the time of the investigation. Many of these SCI and TBI relationships (38% and 55% respectively) were established after injury. Both SCI and TBI persons showed significantly more depressive feelings compared with the controls. Perceived quality of life (global QL rating) was significantly lower in the SCI group compared with the controls, whereas the ratings of TBI persons and controls did not differ significantly.

SCI and TBI persons did not differ significantly in level of education, perceived quality of life or distress. In all three groups, global quality-of-life ratings were significantly lower among single persons compared to those with a partner relationship.

It was concluded that both SCI and TBI appear to affect overall quality of life and mental well-being negatively. The number of partner relationships contracted after injury among both SCI and TBI persons indicates, however, that the injury is not a major barrier to establishing close partner relationships.

Being in good spirits, that is, lack of depressive feelings has a profound impact on the perception of a high quality of life in all three groups. For the SCI and TBI persons, a high level of physical and social independence were further positive determinants of a perceived high quality of life.

**Keywords:** spinal cord injuries; traumatic brain injuries; sexuality; partner relationship; divorce; functioning

### Introduction

Spinal cord injury (SCI) and traumatic brain injury (TBI) occur suddenly, primarily to young people, and result in different degrees of impairment. Both severe SCI and TBI cause drastic changes in the life of the injured person. There is, however, a fundamental difference between these two disabilities. In SCI the implications are mostly physical, whereas in TBI changes in personality and behaviour are common in addition to the physical limitations.<sup>1–5</sup>

Living with a disability, such as an SCI or TBI, is not only a major inconvenience but it may also reduce

the injured person's options. Research on attitudes toward persons with disabilities has shown that persons tend to reject close and intimate relationships with disabled people.<sup>6</sup> Thus, a physical disability may be handicapping not because it imposes actual limitations but because it interferes with social relations or is in conflict with the individual's value system. Psychosocial problems such as impaired body image, lowered self-esteem, and feelings of inadequacy may pose barriers to social relationships. A lack of community access and appropriate opportunities to meet potential partners, along with reduced social skills, may also interfere with the expression of sexuality. The physical losses of mobility and sensation, and society's preference of the 'perfect

Correspondence: M Kreuter, Spinal Injuries Unit Dept. 12, Sahlgrenska University Hospital, S-413 45 Gothenburg, Sweden

body', may limit the injured person's opportunities to meet and attract a new partner.

The trauma may also place a great strain on the non-injured partner in an existing relationship. The results of the studies carried out on the divorce rate among SCI and TBI persons are not consistent.<sup>7-11</sup> El Ghatit and Hanson<sup>8</sup> showed that divorce rates were no higher for their sample of SCI persons than for the general population. DeVivo and Fine<sup>9</sup> examined the influence of SCI on the marital status of 276 injured persons in the United States for a period of 3 years after injury and found that their sample had fewer marriages and more divorces during that period than would be predicted by population base rates. They also found that women with SCI were more likely to be divorced than men. In a later study they showed that the impact of SCI appeared to be almost as great on postinjury marriages as it is on pre-existing marriages.<sup>12</sup> Concerning TBI persons, Walker<sup>11</sup> found that only 11% of a group of heterogeneous brain-damaged persons had divorced. Panting and Merry<sup>10</sup> reported that 40% of the severely brain-damaged persons became divorced after injury. It has been suggested that the change in marital status among TBI persons is related to the continuing changes and challenges of living with the disabilities.<sup>4,13,14</sup> Persons with TBI are exposed to prolonged distress and stress that appear to be related more to the daily coping with the disability than to the severity of the initial injury.<sup>15</sup> In one of the longest follow-up studies, undertaken 10-15 years after the brain injury, the author found that the psychosocial sequelae presented the most serious problem.<sup>16</sup> There were permanent changes in personality and emotion and these were especially frequent among the youngest TBI persons.

One study focusing on the wives' experience compared the two disability types with a control group of non-disabled couples. Compared with the wives of SCI persons, wives of brain-damaged persons experienced drastically disturbing changes in their lives as a result of the TBI. The differences between the two disability types were in the following areas: the wives of TBI persons reported their husbands to be more self-oriented, and display childish dependency as compared with the wives of the spinal cord injured men.<sup>17</sup>

Quality of life (QL) is a composite variable that refers to an individual's subjective overall satisfaction with life. Factors that may influence QL are physical, psychological and emotional functions, ability to work and to perform leisure activities, and relations with other people and society.<sup>18,19</sup> We found in earlier studies<sup>20,21</sup> that the SCI person's mental well-being improved to the extent that it almost corresponded to that of the normal population 4 years after injury. Perceived QL was, however, on average 25% lower compared with a reference group.<sup>20</sup> Quality of life, perceived by the SCI person through a global rating, was closely related to sexual adjustment.<sup>22</sup> Furthermore, young age, a high level of social activity and

gainful employment were closely associated with perceived high QL.<sup>23</sup> Severe pain was the only medical complication that related to lower QL scores.<sup>20</sup> Level or extent of injury was not related to perceived QL, which is consistent with the study of Cushman and Haslett,<sup>24</sup> undertaken 10 and 15 years after the injury. The large British study by Whiteneck and colleagues<sup>25</sup> showed that the level of the lesion did not predict life-satisfaction nor well-being.

A study on long-term quality of life in married and single TBI persons showed that severely injured persons reported more depression, confusion and overall mood disturbance compared to moderately injured TBI persons regardless of marital status. Married TBI persons reported more anxiety, depression, fatigue, confusion and overall mood disturbance than single TBI persons, regardless of age. The study was undertaken an average of 4 years post injury.<sup>26</sup> In another study<sup>27</sup> it was found that QL was severely reduced for those TBI persons who could not occupy their time.

The literature comparing partner relationships, perceived quality of life and mental well-being in persons with disabilities and people from the general population is limited. Better knowledge in these areas will help rehabilitation professionals to understand the nature and extent of barriers that face persons with SCI and TBI and help them to work more effectively with the patients.

The purpose of this study was to assess and compare SCI and TBI persons and people from the general population concerning partner relationships, functioning, mood and perceived quality of life. Persons with spinal cord and traumatic brain injuries were chosen for comparison because the majority of people with these two conditions are young, the injuries are caused by sudden damage to the central nervous system and both severe SCI and TBI cause drastic changes in the life of the injured person. There is, however, a fundamental difference between these disabilities. Individuals with TBI sometimes have the mobility problems seen in SCI persons, but more often have cognitive and behavioural problems.

## Subjects and method

Table 1 provides the sociodemographic characteristics of the SCI, TBI and control persons.

### *SCI persons*

This study included 167 persons with traumatic SCI, who were consecutively admitted to the Gothenburg Spinal Unit during the period November 1982 to July 1991. Further details have been given elsewhere.<sup>28</sup> There were 136 men (81%) and 31 women (19%) and this percentage reflects the sex ratio in the general SCI population. The median age was 33 years, with a range from 19 to 79. Age when injury occurred ranged from 14 to 76 years (Md 28 years), with 53% injured before

**Table 1** Sociodemographic characteristics of the participants

Characteristic	SCI persons (n = 167)	TBI persons (n = 92)	Controls (n = 264)
Sex			
Male	136 (81.4%)	65 (70.7%)	203 (76.9%)
Female	31 (18.6%)	27 (29.3%)	61 (23.1%)
Age			
Median (range)	33 (19–79)	40 (20–70)	31 (19–79)
Mean (SD)	38.9 (15.7)	40.5 (11.1)	36.9 (15.4)
Marital status			
Married/cohabiting	63 (37.7%)	39 (42.4%)	128 (48.5%)
Stable partnership without living together	22 (13.2%)	14 (15.2%)	27 (10.2%)
Single	82 (49.1%)	39 (42.4%)	109 (41.3%)
Partner relationship at the time of the injury	102 (61.1%)	54 (58.7%)	n.a.
Divorced/separated after injury	49 (48%)	30 (55.5%)	n.a.
Education			
Compulsory level	81 (48.5%)	54 (58.7%)	79 (29.9%)
Higher education below university	61 (36.5%)	25 (27.2%)	95 (36%)
University	25 (15%)	13 (14.1%)	90 (34.1%)
Working/studying	99 (66%)	45 (51.1%) <sup>1</sup>	195 (76.6%) <sup>1</sup>
Full-time	25 (16.6%) <sup>1</sup>	19 (20.4%) <sup>1</sup>	172 (69.3%) <sup>1</sup>
Part-time	74 (49.3%) <sup>1</sup>	26 (29.5%) <sup>1</sup>	23 (9.3%) <sup>1</sup>
Unemployed	29 (19.3%) <sup>1</sup>	16 (18.2%) <sup>1</sup>	34 (13.7%) <sup>1</sup>
Sickness benefit 100%	11 (7.3%) <sup>1</sup>	6 (6.8%) <sup>1</sup>	6 (2.4%) <sup>1</sup>
Disability pension 100%	11 (7.3%) <sup>1</sup>	21 (23.9%) <sup>1</sup>	13 (5.2%) <sup>1</sup>
Retired with old age pension	17 (10.2%) <sup>2</sup>	4 (4.3%) <sup>2</sup>	16 (6.1%) <sup>2</sup>

<sup>1</sup>Percentage of those below the age of 65 years. <sup>2</sup>Percentage of all. n.a. = Not applicable

the age of 30. Elapsed time since injury ranged from 1–9 years (Md 5 years).

Out of the 167 SCI persons, 51% were tetraplegic (76% Frankel A, 24% Frankel B, C and D) and 49% were paraplegic (60% Frankel A, 40% Frankel B, C and D). One hundred and twenty-two persons (73%) used wheelchairs; the remainder walked with or without aids. Two persons were ventilator dependent for respiration. Ninety-seven per cent lived in their own homes. Thirty-nine per cent required no assistance from others in performing basic daily activities (ADL), whereas 36% required full assistance. Pain to the extent that it influenced ADL was reported by 40% of the respondents and 21% had spasticity severe enough to interfere with daily function. Seventeen SCI persons (10%) were retired and 66% of the remainder were employed or engaged in studies.

At the time of the investigation, 85 (51%) of the 167 SCI participants were married/cohabitant or had a partner relationship without living together. The single SCI persons and those who had a partner relationship were equivalent in terms of age, age at injury, time since injury, level and completeness of the lesion, level of education and employment. Five older persons in the single group were permanently living in an institution, whereas all of those with a partner were living in their own homes. Furthermore, those who were single needed more help with their personal care

and daily activities, such as assistance with bowel and bladder care, dressing and transfers, compared to those with partners.

The 167 SCI participants were interviewed by phone and subsequently by mail questionnaires to collect the study data. They were assured of the complete confidentiality of their responses. The structured telephone interview covered a variety of topics, including demographic characteristics, living conditions, marital status, and care and services received. All information was controlled by reference inquiries using the medical records. The mailed questionnaire was designed to measure physical and social functioning, perception of loss of independence, perceived quality of life and mood.

#### TBI persons

Ninety-two traumatic brain injured persons treated at the Department of Rehabilitation Medicine at Sahlgrenska Hospital, Gothenburg, during the years 1971–1990 participated in the study. Detailed information on this sample is given elsewhere<sup>29</sup> but 65 were men (70%) and 27 were women, ranging in age from 20–70 years (Md 40 years). Median age at injury was 32 years, ranging from 16–56 years, with 47% injured before the age of 30. Elapsed time since injury ranged from 1–20 years (Md 9 years). At the time of the investigation 11% were classified as

**Table 2** Frequency of symptoms in the TBI population reported by the patient and/or observed at the neurological examination at the time of the investigation ( $n=92$  TBI persons)

Symptoms	n	%
Balance impairments	32	35
Neglect	1	1
Visual impairments	22	24
Vertigo	16	17
Spatial disturbances	7	8
Dysarthria	48	52
Hearing impairments	25	27
Swallowing impairments	6	7
Epilepsy	32	35
Emotional lability	31	34
Personal disorientation	2	2
Spatial disorientation	4	4
Temporal disorientation	12	13
Psychic irritability	45	49
Psychomotor agitation	40	43
Planning disturbances	31	34
Loss of initiative	38	41
Concentration difficulties	56	61
Diminished self-appraisal	40	43

having severe disability and 66% moderate disability, whereas 23% had achieved a level of 'good recovery', on the Glasgow Outcome Scale (GOS).<sup>30,31</sup> The frequency of cognitive and behavioural symptoms is shown in Table 2. Only one person was wheelchair dependent. Eighty-one per cent required no assistance from others in performing basic daily activities (ADL), whereas 4% required full assistance. None of the TBI persons had pain or spasticity that interfered with daily function. Four per cent were retired and 51% of the remainder were employed or engaged in studies.

Fifty-three of the TBI participants (58%) were married/cohabiting or had a partner relationship without living together, and 24 of them (45%) had the same partner as before the injury. The single TBI persons and those who had a partner were similar in terms of age, age at injury, level of education and employment. The TBI persons were examined according to a procedure consisting of a physical and psychoneurological examination, followed by self-assessment of functioning, mood, global quality of life and demographic characteristics, living conditions, marital status, and care and services received. The physical and psychoneurological examination of each patient was performed according to a fixed protocol by two neurologists working independently. Afterwards, each item was checked and, in case of discrepancy, the results were discussed until consensus was reached.

Before giving their informed consent to inclusion in the study, the SCI and TBI persons had received both written and verbal information on the study.

### Control group

The controls, who were age- and sex matched to the SCI group,<sup>28</sup> were selected by the Gothenburg City Registry. The questionnaires were mailed together with a letter that explained the rationale for the study to 334 controls, a two to one match procedure. Seventy-nine per cent (203 men and 61 women) completed the questionnaire covering sociodemographic factors, a visual analogue quality-of-life scale and a mood self-assessment measure. Since only 264 responses were received from the 334 potential controls, the hypothesis that the two groups were no longer age- and sex matched was tested. The analysis showed, however, that there was no significant difference concerning sex and age. Of the 264 respondents, 155 (59%) had a stable partner relationship at the time of the study. No data were available on the non-respondents.

### Measuring instruments

#### Glasgow outcome scale GOS

The Glasgow outcome scale (GOS) is a functional assessment tool for use in brain-injured individuals.<sup>30,31</sup> The assessment technique has been widely adopted as the preferred tool for describing outcome after head injury in large-scale neurosurgical studies. The GOS is a 1–8 point measure with the following categories: 1 = dead, 2 = vegetative state, 3 = dependent with daily living more than half the time, 4 = dependent with daily living less than half the time, 5 = not able to go back to previous work and social activities, 6 = able to go back to previous work or social activities but not with full ability, 7 = able to live a normal life but some symptom after the brain damage, and 8 = no symptom after the brain injury. Score 3 and 4 indicate a severe disability, 5 and 6 a moderate disability, 7 and 8 indicate that the individual has reached a level of good recovery. Two neurologists working independently performed the rating of each patient.

#### Quality of life, physical and social functioning and mood

Perception of global quality of life (QL) was recorded on a visual analogue scale (VAS) and endpoints were labelled 'very low' and 'very high'.<sup>32</sup> For SCI persons and controls, a 0–100 scale was applied while the TBI persons were examined with the aid of an earlier scale version linearly transformed to match the current scale.<sup>20</sup> To further explore the SCI and TBI persons' satisfaction with different areas in life, a brief function and mood self-assessment questionnaire was used. This questionnaire was created in an earlier study of SCI persons where a vast battery of generic questionnaires was applied.<sup>23</sup> This brief version contains ten items from the Sickness impact profile (SIP)<sup>33</sup> covering functional limitations in the SIP categories mobility, body care and movement and social interaction, and six items from the Hospital anxiety and depression (HAD) scale<sup>34</sup> measuring different aspects of depressed

mood. In addition, the SCI persons completed six items from the SCI Problem scale defining the SCI person's perception of loss of independence.<sup>23</sup> The controls completed the six items reflecting Depression from the HAD scale.<sup>34</sup>

#### Statistical methods

Fisher's non-parametric permutation test was used for comparison between groups and Fisher's exact test for comparison of proportions.<sup>35</sup> For overall comparison between the three groups, Kruskal Wallis one-way analysis of variance (ANOVA) of mean ranks was used. The chi-square test was used for overall comparisons of proportions between three 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 evaluated using Pitman's non-parametric permutation test.<sup>35</sup> Pearson's correlation coefficients were only used for descriptive purposes. A step-by-step model of consecutive analyses including bivariate correlation,<sup>35</sup> partial non-parametric correlation<sup>36</sup> 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 from the combination of powerful independent variables. For Pitman's correlation analysis and regression analysis, a *P* value of 0.01 or less was considered significant.

#### Ethical scrutiny

The research protocol was approved by the Ethical Research Committee of Sahlgrenska University Hospital, Gothenburg.

## Results

As shown in Tables 1 and 3, analyses indicated that the three groups were not significantly different in sex and age. No significant differences by sex were found in any study characteristics.

#### Partner relationships

As shown in Table 1, somewhat less of the SCI persons (51%) than TBI persons (58%) and controls (59%) had a partner relationship at the time of the investigation. This difference was, however, non significant (Table 3). More than one-third of the SCI and half of the TBI relationships (38% and 55% respectively) were established after injury. Of those who were single at the time of the investigation, 25% of the SCI persons, 2% of the TBI persons and 9% of the controls mentioned that they had neither the time nor interest in having sexual relationships. Fifteen per cent of the SCI persons reported poor self-esteem in

combination with decreased sexual ability as the main reason for being single. Poor self-esteem was listed by 15% of the TBI persons and by 14% of the controls. Ten per cent of the SCI persons reported that they had difficulties in meeting and attracting a new partner when disabled and in a wheelchair.

Approximately half of the persons with SCI (48%) and TBI (56%) reported that they had divorced or separated after the injury. The most commonly mentioned reasons for the separation among the SCI persons were either difficulties in attaining new physical functioning and maintaining a partner relation at the same time (20%), or the partner's unwillingness to live with a disabled person (25%).

#### Functioning, mood and global quality of life

As shown in Tables 3 and 4, SCI and TBI persons did not differ significantly in level of education, physical and social functioning as measured by the SIP, mood

**Table 3** Test of differences with Fisher's non-parametric permutation test

Variable	SCI <sup>a</sup> - TBI <sup>b</sup>	SCI <sup>a</sup> - Control <sup>c</sup>	TBI <sup>b</sup> - Control <sup>c</sup>
Sex	N.S.	N.S.	N.S.
Age	N.S.	N.S.	N.S.
Marital status	N.S.	N.S.	N.S.
Education	N.S.	<i>P</i> < 0.001	<i>P</i> < 0.001
Work/studies 0–100%	<i>P</i> < 0.001	<i>P</i> < 0.001	<i>P</i> < 0.001
Global quality of life ratings	N.S.	<i>P</i> < 0.001	N.S.
Mood (HAD Depression)	N.S.	<i>P</i> < 0.001	<i>P</i> < 0.001
Physical and social dysfunction (SIP)	N.S.	n.a.	n.a.

<sup>a</sup>Spinal cord injured (SCI) group *n* = 167. <sup>b</sup>Traumatic brain injured (TBI) group *n* = 92. <sup>c</sup>Control group *n* = 264. n.a. = Not applicable. N.S. = not significant

**Table 4** Functioning, mood and global quality of life, mean values and standard deviations (SD) are given

	SCI persons ( <i>n</i> = 167)	TBI persons ( <i>n</i> = 92)	Control ( <i>n</i> = 264)
Physical and Social Dysfunction (SIP) range 0–70 (the lower the better)	30.2 (20.2)	24.6 (24.6)	n.a.
Mood (HAD Depression) range 0–18 (the lower the better)	4.7 (3.8)	4.7 (4.0)	2.7 (2.6)
Global QL (VAS) range 0–100 (the higher the better)	57.2 (28.1)	63.5 (24.3)	69.8 (21.3)

n.a. = not applicable

as measured by the HAD Depression scale and perceived quality of life.

Significantly more of the SCI persons (66%) were employed or studying compared with the TBI persons (51%). Compared with the controls, however, significantly less of both persons with SCI and TBI were employed or engaged in studies.

Both SCI and TBI persons showed significantly more depressive feelings according to the HAD Depression scale compared with the controls. Twenty-two per cent of the SCI persons and 26% of the TBI persons fulfilled HAD criteria for clinical depression, compared with 5% of the controls. Perceived quality of life was significantly lower in the SCI group compared with the controls, whereas the TBI persons' and controls' perception of quality of life did not differ significantly.

In all three groups, perceived QL was significantly lower among persons who were single compared with those in a relationship. Furthermore, physical and social functioning (SIP) was significantly lower in the single SCI and TBI groups compared with those in a relationship. Whereas mood (HAD Depression) was significantly lower among persons who were single in the SCI group, there was no significant difference in mood between those who were single and those in a

relationship in the TBI and control groups. Perceived loss of independence (SCI Problem) showed no significant difference between SCI persons who were single and those that had a partner relationship (Table 5).

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

As shown in Table 6, marital status correlated significantly with the SCI person's perceived QL, whereas no correlation to sex could be found. Young age and young age at injury were associated with high QL scores, whereas elapsed time since injury was not significantly correlated to global quality of life. The level of engagement in employment or studies correlated significantly to the SCI person's global QL, while level of education showed no association with perceived QL. The level and completeness of the lesion showed a slight but non-significant correlation to overall QL. The respondents who reported pain severe enough to interfere with daily function showed lower QL perceptions, whereas spasticity problems showed no significant correlation to perceived overall QL.

Mood (HAD depression), physical and social functioning (SIP) and perceived loss of independence

**Table 5** Functioning, mood and global quality of life ratings

	<i>SCI with partner</i> (n = 85)	<i>Single SCI</i> (n = 82)	<i>p-level</i>	<i>TBI with partner</i> (n = 53)	<i>Single TBI</i> (n = 39)	<i>p-level</i>	<i>Controls with partner</i> (n = 155)	<i>Single Controls</i> (n = 109)	<i>p-level</i>
Physical and social dysfunction (SIP) range 0–70 (the lower the better)									
Mean (SD)	22.4 (19.6)	31.9 (21.7)	***	20.7 (22.9)	30.4 (25.8)	***			
Median	17.4	29.9		12.4	23.7		n.a.	n.a.	
Range	0–70	0–70		0–70	0–70				
Perceived loss of independence (SCI-Problem) range 1–24 (the higher the better)									
Mean (SD)	14.4 (4.3)	14.0 (4.5)	N.S.	n.a.	n.a.		n.a.	n.a.	
Median	14.5	13.0							
Range	6–22	6–24							
Mood (HAD Depression) range 0–18 (the lower the better)									
Mean (SD)	3.9 (3.1)	5.6 (4.3)	***	4.6 (4.1)	5.0 (3.8)	N.S.	2.3 (2.2)	3.1 (3.0)	N.S.
Median	3.0	5.0		4.0	4.0		2.0	2.0	
Range	0–12	0–18		0–17	0–16		0–12	0–13	
Global QL (VAS) range 0–100 (the higher the better)									
Mean (SD)	63.5 (26.0)	50.2 (28.9)	***	66.9 (23.5)	58.8 (24.6)	***	74.2 (19.7)	62.3 (21.3)	***
Median	70.5	51.0		71.0	57.0		79.0	69.0	
Range	1–100	0–100		14–100	0–100		11–100	4–98	

\*\*\* = P < 0.001, N.S. = Non significant (Pitman's non-parametric permutation test) n.a. = Not applicable

(SCI problem) were significantly correlated to the SCI persons' global QL.

The TBI person's sex, age, age at injury, marital status and level of education were not significantly correlated to the TBI person's global QL. Time since injury, the level of engagement in work or studies, mood (HAD depression), physical and social functioning (SIP) and the severity of the disability (GOS) were, however, significantly correlated to the TBI person's global quality of life.

Sex, age and level of education showed no significant correlation with the controls' global QL, whereas marital status, the level of engagement in work or studies and mood (HAD depression) correlated significantly with the control persons' global QL.

*Determinants of quality of life perception*

Partial and multiple correlations were used to determine which of the independent variables were the most powerful predictors of global QL. Concerning SCI persons, 57% of the variance was explained by three variables in combination: the SCI person's mood, physical and social functioning and perceived loss of independence (Table 6).

As shown in Table 6, the most important predictors of the TBI persons' global QL were mood, physical and social functioning, severity of disability and time since injury. Forty-six per cent of the variance was explained by these variables.

Concerning the controls, the most important predictors of global QL were mood, time spent in work or studies and marital status, explaining 50% of the variance (Table 6).

**Discussion**

Some researchers<sup>37</sup> have questioned the ability of TBI persons to give valid and reliable information. However, recent evidence suggests that brain-injured persons' information is valid, in that their information correlates well with measures obtained from relatives.<sup>38</sup> We used the combined questionnaire-interview technique to collect information from the TBI persons. Any difficulty with the questionnaires could then be explained and straightened out in the personal interview. Due to our questionnaire-interview technique, we were able to demonstrate high consistency in response pattern and the information gathered should therefore be regarded as valid.

It may seem surprising that there were no significant sex differences in this study. It has been suggested in the literature<sup>9</sup> that disabled women are disadvantaged in the area of sexuality and partner relationships compared to disabled men. Our results should, however, be interpreted cautiously as the number of SCI and TBI women was small.

Although there were somewhat more of the SCI persons than TBI persons and controls who were single at the time of the study, this difference was non significant. Some of those who remained single had made this choice for the same reasons as single people among the general population, i.e. they had neither the time nor interest in having sexual relationships. The disabled person, as well as the able-bodied individual, has the right to determine whether or not to express himself sexually, as discussed by Comarr and Vigue.<sup>39</sup> Decreased sexual ability contributed to not having a partner relationship among a few injured persons.

**Table 6** Quality of life in relation to sociodemographic, physical and psychosocial variables

Independent Variables	SCI persons (n = 167)		TBI persons (n = 92)		Controls (n = 264)	
	r	p-level	r	p-level	r	p-level
Age	-0.27	***	-0.01	N.S.	-0.01	N.S.
Age at injury	-0.28	***	-0.16	N.S.	n.a.	
Time since injury	0.07	N.S.	<b>0.27</b>	**	n.a.	
Sex	-0.10	N.S.	0.01	N.S.	0.05	N.S.
Marital status <sup>a</sup>	-0.22	**	-0.18	N.S.	-0.27	***
Education	0.19	N.S.	0.13	N.S.	0.14	N.S.
Work/studies 0-100% <sup>a</sup>	0.37	***	0.40	***	0.32	***
Mental State (HAD depression)	<b>-0.69</b>	***	<b>-0.56</b>	***	-0.67	***
Physical and social function (SIP)	<b>-0.57</b>	***	<b>-0.48</b>	***	n.a.	
Perceived loss of independence	<b>-0.59</b>	***	n.a.		n.a.	
Level of lesion	0.21	N.S.	n.a.		n.a.	
Completeness of lesion	0.19	N.S.	n.a.		n.a.	
Pain	-0.23	**	0.01	N.S.	n.a.	
Spasticity	-0.11	N.S.	n.a.		n.a.	
Severity of disability (GOS)	n.a.		0.48	***	n.a.	

r = Pearson's correlation coefficient. \*\* = P < 0.01. \*\*\* = P < 0.001 Pitman's permutation test. N.S. = non significant. n.a. = not applicable. <sup>a</sup> = Marital status analyzed as single against 'married' (ie married/cohabitants/partner relationship without living together) and work/studies analyzed as percentage of work and studies together. Underlined, bold figures denote the strongest independent predictors for perceived high quality of life according to non-parametric partial correlation (Mantel's test)

Some persons with SCI mentioned that they had difficulties in meeting and attracting a new partner when disabled and in a wheelchair. This indicates that individual attitudes toward people with disabilities and the injured person's own prejudices of physical deviance may in some cases make it difficult to develop new relationships or re-establish old ones. The number of partner relationships contracted after injury among both SCI and TBI persons indicates, however, that the injury is not a major barrier to establishing close partner relationships, which is consistent with the study of Berkman *et al.*<sup>40</sup> Crewe and Krause<sup>41</sup> found that only individuals who are especially likeable, active and well adjusted succeed in attracting partners and establishing close relationships after an SCI. The authors found in a later study<sup>42</sup> that SCI persons who get married after injury were more active both socially and vocationally during their single days compared to those who remained single. The authors suggested that the individuals who marry after SCI are a selected group with some special characteristics.

Slightly half (48%) of the SCI persons' and more than half (56%) of the TBI persons' partner relationships existing when injury occurred had terminated. It may be difficult to maintain a partner relationship during the process of attaining better physical functioning and emotional adjustment to the new situation after injury. It is, however, not appropriate to make comparisons of the proportion of divorces or separations between these two groups, since the average time frame differ between the two groups; 5 years for the SCI persons and 9 years for TBI persons.

Being in good spirits, ie lack of depressive symptoms had a profound positive impact on the perception of a high quality of life in all three groups. It appears from the current data that persons who are single – whether disabled or not – tend to experience a poorer overall quality of life compared to those who have a partner relationship. These results may provide support for the assumption that having a close partner relationship can play an important role for a person's satisfaction with life. Other studies<sup>43–46</sup> have identified a positive influence of supportive interpersonal relationships upon adjustment to SCI as well as on life satisfaction and well-being after SCI. The strongest empirically identified contributors to the quality of life for samples of individuals both with and without spinal cord injury, involve emotional support, perceived personal or internal control of situations and events, perceived health status and educational level.<sup>46–48</sup>

The high correlation between the SCI persons' perception of a good quality of life and youth and injury at a young age, respectively, indicates that the person who has a spinal cord injury when young has a greater ability to cope with the disability. Further, older people may be less well provided for in vocational, social and leisure activities. A few studies carried out on SCI persons, suggest that quality of life

may begin to decline in individuals over 45 or 50 years of age<sup>25,49</sup> and among those with disabilities of duration greater than 20 years.<sup>49</sup> The TBI persons' QL perception was significantly and positively correlated to duration of disability, indicating that adaptation to a brain injury occurs over an extended period of time.

The level and completeness of the SCI persons' lesion showed a weak and non-significant relationship with perceived quality of life which is in agreement with our earlier studies<sup>20,21</sup> as well as with other studies.<sup>24,46,49</sup> The TBI person's QL perception was strongly associated with the severity of the disability which may be explained by the prolonged distress to the daily living with both cognitive and physical handicaps. A high level of physical and social activity was positively related to both the SCI and TBI persons' perception of a high quality of life. This is consistent with our findings in an earlier study conducted on SCI persons.<sup>20,21</sup>

We found in our study a strong relationship between perceived quality of life and being employed or engaged in studies, in all three groups. Since this is a cross-sectional study, it is, however, not possible to determine whether being employed or engaged in studies leads to improved QL. It could be that persons with a perceived high QL are more likely to seek, find, and maintain employment. Krause<sup>50</sup> showed in a study carried out on SCI persons that employment is associated with superior adjustment. He suggested that a crucial element in this relationship might be that social relationships are developed and maintained in work and educational environments, which may be as important as the occupation itself. The majority of SCI and TBI persons are able to return to work or studies and this should be strongly promoted by vocational rehabilitation and further formal education. It is important to help SCI and TBI persons overcome feelings of worthlessness and despair by showing them that they still have some control over their lives and that life after injury can be meaningful and rewarding. The rehabilitation programmes should emphasise support on all activities that contribute to a sense of usefulness and life satisfaction, including a person's participation in gainful employment, educational programmes, community services and active leisure. A relatively high unemployment rate in society in general might, however, impair the chances of disabled individuals getting a job.

It can be concluded that both SCI and TBI appear to affect quality of life and mental well-being negatively. The number of partner relationships contracted after injury among both SCI and TBI persons indicates, however, that the injury is not a major barrier to establishing close partner relationships. Being in good spirits, ie lack of depressive feelings had a profound positive impact on the perception of a high quality of life in all three groups. For the SCI and TBI persons, a high level



of physical and social independence were further positive determinants for a perceived high quality of life. Despite the high level of explained variance in global quality of life, the amount of unexplained variance found in this study offers a challenge for further research.

### Acknowledgements

The authors wish to thank Mr G Gudjonsson, MD for performing the neurological examination of the TBI persons, Ms A Andersson OT for collection of data on the TBI persons, and system analyst Nils-Gunnar Pehrson for his invaluable assistance regarding the data processing and statistical analyses. This study was supported by grants from the Association of Cancer and Road Accident Victims (CTRF), National Association of people disabled by Road Accidents and Polio (RTP), the Swedish Council for Planning and Coordination of Research (FRN) and from Greta and Einar Asker Foundation, Sweden.

### References

- 1 Oddy M, Coughlan T, Tyerman A and Jenkins D. Social adjustment after closed head injury: a further follow-up seven years after injury. *J Neurol Neurosurg Psychiatr* 1985; **48**: 564–568.
- 2 Oddy M, Humphrey M and Uttley D. Subjective impairment and social recovery after closed head injury. *J Neurol Neurosurg Psychiatr* 1978; **41**: 611–616.
- 3 Rappaport M, Herrero-Backe C and Winterfield K. Head injury outcome up to ten years later. *Arch Phys Med Rehabil* 1989; **70**: 885–892.
- 4 Thomsen IV. Do young patients have worse outcomes after severe blunt head trauma. *Brain Injury* 1989; **3**: 157–162.
- 5 Thomsen IV. Late psychosocial outcome in severe blunt head trauma. *Brain Injury* 1987; **1**: 131–143.
- 6 Siller J. Psychosocial aspects of physical disability. In: Meislen J (ed). *Rehabilitative medicine and psychiatry*. C.C. Thomas: Springfield, IL 1976.
- 7 Trieschmann RB. Spinal Cord Injuries. Psychological, Social and Vocational Rehabilitation. Demos Publ: New York 1988.
- 8 El Ghatit AZ and Hanson RW. Outcome of marriages existing at the time of a male's spinal cord injury. *J Chronic Diseases* 1975; **28**: 383–388.
- 9 DeVivo MJ and Fine PR. Spinal cord injury: It's short-term impact on marital status. *Arch Phys Med Rehabil* 1985; **66**: 501–504.
- 10 Panting A and Merry P. The long-term rehabilitation of severe head injuries with particular reference to the need for social and medical support for the patient's family. *Rehabilitation* 1972; **28**: 33–37.
- 11 Walker AE. Long-term evaluation of the social and family adjustment of head injuries. *Scand J Rehabil Med* 1972; **4**: 5–8.
- 12 DeVivo MJ, Hawkins LVN, Richards JS and Go BK. Outcomes of post-spinal cord injury marriages. *Arch Phys Med Rehabil* 1995; **76**: 130–138.
- 13 Jacobs HE. The Los Angeles head injury survey: project rationale and design implications. *J Head Trauma Rehabil* 1987; **2**: 37–50.
- 14 Liss M and Willer B. Traumatic brain injury and marital relationships: a literature review. *Int J Rehabil Res* 1990; **13**: 309–320.
- 15 Florian V, Katz S and Lahav V. Impact of traumatic brain damage on family dynamics and functioning: a review. *Brain Injury* 1989; **3**: 219–233.
- 16 Thomsen IV. Late outcome of very severe blunt head trauma: a 10–15 year second follow-up. *J Neurol Neurosurg Psychiatr* 1984; **47**: 260–268.
- 17 Rosenbaum M and Najenson WS. Changes in life patterns and symptoms of low mood as reported by wives of severely brain-injured soldiers. *J Consult Clinl Psychol* 1976; **44**: 881–888.
- 18 Shumaker SA and Berzon R. The International Assessment of Health-Related Quality of Life. Theory, Translation, Measurement & Analysis. Rapid Communication: Oxford 1995.
- 19 Calman KC. Quality of life in cancer patients – an hypothesis. *J Medical Ethics* 1984; **10**: 124–127.
- 20 Lundqvist C et al. Spinal cord injuries. Clinical, functional and emotional status. *Spine* 1991; **16**: 78–83.
- 21 Siösteen A et al. The quality of life of three functional spinal cord injury subgroups in a Swedish community. *Paraplegia* 1990; **28**: 476–488.
- 22 Siösteen A et al. Sexual ability, activity, attitudes and satisfaction as part of adjustment in spinal cord injured subjects. *Paraplegia* 1990; **28**: 285–295.
- 23 Lundqvist C et al. Spinal cord injuries: a shortened measure of function and mood. *Spinal Cord* 1997; **35**: 17–21.
- 24 Cushman LA and Haslett J. Spinal cord injury: Ten and fifteen years after. *Paraplegia* 1992; **30**: 690–696.
- 25 Whiteneck GG et al. Mortality, morbidity, and psychosocial outcomes of persons spinal cord injured more than 20 years ago. *Paraplegia* 1992; **30**: 617–630.
- 26 Moore AD, Stambrock M, Gill DD and Lubusko AA. Differences in long-term quality of life in married and single traumatic brain injured patients. *Canadian J Rehabil* 1992; **6**: 89–98.
- 27 Tennant A, MacDermott H and Neary D. The long-term outcome of head injury: implications for service planning. *Brain Injury* 1995; **9**: 595–605.
- 28 Kreuter M, Sullivan M and Siösteen A. Sexual adjustment and quality of relationships in spinal paraplegia: A controlled study. *Arch Phys Med Rehabil* 1996; **77**: 541–548.
- 29 Kreuter M et al. Sexual adjustment and its predictors after traumatic brain injury. *Brain Injury*, in press.
- 30 Jennett B, Snoek J, Bond MR and Brooks N. Disability after severe head injury: Observations on the use of the Glasgow Outcome scale. *J Neurol Neurosurg Psychiatr* 1981; **44**: 285–293.
- 31 Anderson SI et al. Glasgow Outcome Scale: an inter-rater reliability study. *Brain Injury* 1993; **7**: 309–317.
- 32 Carlsson AM. Assessment of chronic pain. I. Aspects of the reliability and validity of the visual analog scale. *Pain* 1983; **16**: 87–87.
- 33 Bergner M, Bobbitt RA, Carter WB and Gilson BS. The Sickness Impact Profile: Development and final revision of a health status measure. *Medical Care* 1981; **19**: 787–787.
- 34 Zigmond AS and Snaith RP. The Hospital Anxiety and Depression scale. *Acta Psychiatr Scand* 1983; **67**: 361–370.
- 35 Bradley JW. Distribution-free statistical tests. Prentice-Hall: London 1968, pp 68–86.
- 36 Mantel N. Chi-square test with one degree of freedom; extensions of the Mantel Haenszel procedure. *J AM Stat Assoc* 1963; **58**: 690–700.
- 37 McKinlay W and Brooks N. Methodological problems in assessing psychosocial recovery following severe head injury. *J Clin Neuropsychol* 1984; **6**: 87–99.
- 38 Kinsella G, Moran C, Ford B and Ponsford J. Emotional disorder and its assessment within the severe head-injured population. *Psychol Med* 1988; **18**: 57–63.
- 39 Comarr AE and Vigue M. Sexual counselling among male and female patients with spinal cord and/or cauda equina injury. *Am J Phys Med* 1978; **57**: 215–227.
- 40 Berkman AH, Weissman R and Frielich MH. Sexual adjustment of the spinal cord injured veterans living in the community. *Arch Phys Med Rehabil* 1978; **59**: 29–33.
- 41 Crewe NM and Krause JS. Marital relationships and spinal cord injury. *Arch Phys Med Rehabil* 1988; **69**: 435–438.
- 42 Crewe NM and Krause JS. Marital status and adjustment to spinal cord injury. *J Am Paraplegia Soc* 1992; **15**: 14–18.
- 43 Judd FK, Webber JE and Brown DJ. Psychological adjustment following traumatic spinal cord injury: a study using the Psychosocial Adjustment to Illness Scale. *Paraplegia* 1991; **29**: 173–179.



- 44 Elliott T, Herrick S and Witty T. Social support and depression following spinal cord injury. *Rehabil Psychol* 1992; **37**: 37–48.
- 45 Rintala DH, Young ME and Hart KA. Social support and the well-being of persons with spinal cord injury living in the community. *Rehabil Psychol* 1992; **37**: 155–163.
- 46 McColl MA and Rosenthal A. A model of resource needs of aging spinal cord injured men. *Paraplegia* 1994; **32**: 261–270.
- 47 Carpenter C. The experience of spinal cord injury: The individuals perspective – Implications for the rehabilitation practice. *Physical Therapy* 1994; **74**: 614–629.
- 48 Fuhrer MJ *et al*. Relationship of life satisfaction to impairment, disability and handicap among persons with SCI living in the community. *Arch Phys Med Rehabil* 1992; **73**: 552–557.
- 49 Eisenberg MG and Saltz CC. Quality of life among spinal cord injured persons: Long-term rehabilitation outcomes. *Paraplegia* 1991; **29**: 514–520.
- 50 Krause JS. Employment after spinal cord injury: Transition and life adjustment. *Rehabil Couns Bull* 1996; **39**: 244–255.