

ORIGINAL ARTICLE

Health-related quality of life in patients with traumatic spinal cord injury in Estonia

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Objectives: To describe health-related quality of life (HRQoL) in persons with traumatic spinal cord injury (TSCI) and to assess factors that affect HRQoL.

Study design: Cross-sectional.

Methods: Eighty Estonian-speaking TSCI patients from the Estonian TSCI database were included in the study. The RAND-36 questionnaire, the Life Orientation Test, the Emotional State Questionnaire and the Brief Social Support Questionnaire were used.

Results: There were 66 men and 14 women; the mean age was 38.9 ± 14.8 years. The mean time that had elapsed since injury was 4.2 years. According to the RAND-36 scales, the lowest scores were given for physical health-related domains, followed by the energy/fatigue and the general health domains. The regression analysis adjusted to age and gender revealed that age, employment and category of the American Spinal Injury Association (ASIA) Impairment Scale during the acute phase of injury were significant factors in predicting physical functioning ($P < 0.001$). Age, depression and general anxiety were significant predictors of emotional well-being ($P < 0.001$). Age and depression were independently associated with general health ($P < 0.001$).

Conclusion: As expected, physical functioning and physical role limitation were the most pronounced deficits in HRQoL. Compared with data from other countries, all scores for the RAND-36 scales are lower in Estonian TSCI patients. The HRQoL following TSCI is affected by severity of injury, depression, age and employment status.

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INTRODUCTION

The annual incidence rate of traumatic spinal cord injury (TSCI) in Estonia is 39.7 per 1 000 000 population,¹ being the highest among other European countries where the mean incidence rate is about 15 per 1 000 000 population.² One possible explanation for this difference in incidence rates is the variance in surveillance methods.

Similarly to the other studies, the most frequent cause of TSCI was falls followed by traffic accidents, and the majority of patients were young.^{1,2}

The TSCI can result in devastating effects not only on physical functioning and independence but also on the psychological and social functioning of the injured person.³ The outcomes of TSCI can be assessed in several ways, such as physiological functioning as well as social and psychological adjustment. Recently, there has also been growing interest in evaluation of the individual's well-being after diseases or disabilities, because improvement in daily functioning and well-being are important goals in treatment of people with TSCI. The impact of TSCI on quality of life (QOL) is important information, especially for monitoring and organising health-care services.⁴ There are no comparable studies from Eastern Europe dealing with how individuals with SCI have scored on HRQoL measures.^{5,6} The Medical Outcomes Study 36-item short-form health status survey (MOS SF-36) has proved to be useful in estimating the relative burden of different diseases in general and specific populations. It is one of the most widely used validated QOL instrument used in many patient populations including patients with TSCI. However,

only a few studies have investigated the use of the SF-36 in individuals with TSCI.^{6,7}

The aim of this study was to assess the HRQoL of persons with TSCI; to identify the relative contributions of different factors, such as demographics, physical impairment, life orientation, depressive symptoms, social support and pain to HRQoL in persons with TSCI.

MATERIALS AND METHODS

Patients

A total of 166 Estonian-speaking patients from the Estonian TSCI database were identified to participate in the study. The Estonian TSCI database consists of 595 patients with TSCI from 1997–2007.¹ To collect data, all medical records of the patients with the possible diagnosis from all Estonian regional, rehabilitation, central and general hospitals were retrospectively reviewed. Demographic data, level of injury, extent of injury according to the American Spinal Injury Association (ASIA) Impairment Scale (AIS), cause of injury and presence of spinal fracture were recorded. This study included only patients who were injured between 2003 and 2007 and whose data was found from the medical records of the regional and rehabilitation hospitals.

At first, whenever possible, patients were invited to attend the study via telephone. All persons were contacted between October 2009 and May 2010 by a letter to request their participation. Meanwhile, the contacts were checked and questionnaires were sent for the second time to those who had not responded.

Retrospective information such as demographic and injury-related data at the time of injury were obtained from medical records. ASIA assessment was used to determine the level and completeness of injury⁸ and the AIS category was documented. In this study the AIS categories A and B were

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classified as motor complete injuries and the AIS categories C and D were classified as motor incomplete injuries.

This study was approved by the Ethics Review Committee on Human Research of the University of Tartu, and informed consent was obtained from all study participants.

Measurements

The HRQoL after TSCI was estimated using the Estonian version of the Medical Outcome Study 36-item short-form health status survey (RAND-36-item health survey 1.0).^{9,10} The presented 36 items are identical with the 36 items of the short-form health survey (MOS SF-36),⁹ which allows users of the MOS SF-36 and the RAND-36 to compare their findings.

This multi-dimensional instrument of choice consists of eight subscales designed to measure the following health aspects: physical functioning (PF)—ten items; role limitations owing to problems of physical health (R-P)—four items; role limitations owing to personal or emotional problems (R_E)—three items; emotional well-being (MH)—five items; social functioning—two items (SF); energy/fatigue (V)—four items; bodily pain (BP)—two items and general health (GH)—five items. In addition, a single unscaled item expressed changes in the respondent's health over the past year. The initial scores were standardized to range from 0 (the poorest possible health state measured with the use of the questionnaire) to 100 (the best possible health state).

The Emotional State Questionnaire (EST-Q) is a self-rating scale developed in Estonia for the screening of depression (8 items, cutoff score (CS) > 11), general anxiety (8 items, CS > 11), agoraphobia-panic (5 items, CS > 6), social anxiety (2 items CS > 3), fatigue (4 items, CS > 6) and insomnia (3 items, CS > 5) for previous 4 weeks. The EST-Q comprises 28 questions rated on a 0- to 4-point scale. It has been found to be a reliable and valid instrument for assessing the above psychiatric dimensions and for discriminating between patients with mood or anxiety disorders and the population group. Good differentiating properties suggest its usefulness as a screening instrument.¹¹ The respondents were divided into the symptomatic and the nonsymptomatic group with a cutoff score.

To characterize the patients' life orientation, that is, optimistic or pessimistic, the adapted Estonian version¹² of the Life Orientation Scale¹³ with 12 statements was used. The response choices varied from 0 ('I do not agree with this') to 4 ('I wholly agree with this'). The summary score of all items was calculated; the range of possible values was 0–48; the higher the score, the more optimistic life orientation characterized of the patient.

Social support was assessed using the adapted Estonian version¹⁴ of the Brief Social Support Questionnaire (SSQ).¹⁵ It was based on a 7-item self-report measure. The SSQ scores are differentiated into two types: (a) the perceived number of social supports (SSQ-N) and (b) satisfaction with available social supports (SSQ-S). The participants identified the individuals who provided them with support, help, emotional uplift, care and trust. The mean ratings across the relationship categories yielded the summary scores for the relatives and the nonrelatives. The size of the social network was calculated as the total number of all listed social support contacts. The participants were also inquired about satisfaction with social supports, the response choices varying from 1 ('not satisfied') to 6 ('highly satisfied').

Statistical analysis

The data were analysed using the statistical analysis package SPSS Professional Statistics (SPSS 18, SPSS Finland Oy, Espoo, Finland). *P*-values ≤ 0.05 were considered statistically significant. Descriptive data were presented as percentage or mean and standard deviation. Spearman's correlations were used to investigate correlations. Different groups were compared with the Kruskal-Wallis and the Mann-Whitney *U*-tests.

We estimated regression models adjusted to age and gender to examine the association between individual characteristics and HRQoL. The factors influencing HRQoL were identified using backward stepwise multiple linear regression with three subscale scores of the RAND-36 (PF, MH and GH) as the dependent variables.

RESULTS

Eighty patients (response rate 48%) constituted the study population. Seventy-eight patients did not respond to the questionnaire and eight

questionnaires were returned because the persons had moved elsewhere. No significant functional or demographic differences were found between the responders and the nonresponders (Table 1).

The data were gathered between October 2009 and December 2010. The time that had elapsed since trauma was 2–8 years, mean 4.2 ± 1.78 years. As in similar studies, the most important demographic data for each subject were collected.

The mean scores of the RAND-36, life orientation and social support scales are presented in Table 2.

HRQoL

The lowest scores were given for the physical health-related domains followed by the V and GH domains. The highest scores were given for the MH-related domains.

According to the EST-Q data, 22.5% of the subjects were considered to have substantial depressive symptoms; 21.3% tended to have general anxiety; 10%, panic; 12.5%, social anxiety; 47.5%, fatigue; and 50%, insomnia.

HRQoL and sociodemographic factors

Spearman's correlation analysis revealed that age correlated negatively with GH ($r = -0.4$; $P < 0.001$) and weakly with pain ($r = -0.28$; $P < 0.01$). Comparison of HRQoL for the two education based groups by the Mann-Whitney *U*-test revealed that the GH score ($P < 0.01$) was higher for patients who had graduated from secondary school or who had higher education compared with patients with primary education. We found that level of education was associated with the

Table 1 Characteristics of the participants and nonrespondents with traumatic spinal cord injury in Estonia from 2003–2007

Category	Participants (N = 80)	Nonrespondents (N = 86)
<i>Gender</i>		
Male, N (%)	66 (82.5)	73 (84.7)
Female, N (%)	14 (17.5)	13 (13.3)
Mean age at injury (s.d.)	38.9 (14.8)	35.2 (15.1)
<i>Impairment group (%)</i>		
AIS A and B	39 (48.8)	30 (35.3)
AIS C and D	29 (36.3)	41 (47.0)
NA (only sensory symptoms)	12 (15.0)	15 (17.7)
<i>Employment status before the TSCI (%)</i>		
Employed	53 (66.3)	28 (32.9)
Student	10 (12.5)	8 (9.4)
Unemployed or retired	15 (18.8)	10 (11.8)
Unknown	2 (2.6)	40 (45.9)
<i>Employment status after TSCI (%)</i>		
Occupation is the same as before TSCI	19 (23.8)	
Occupation has changed after TSCI	11 (13.8)	
Unemployed or retired	50 (62.5)	
<i>Education status (%)</i>		
Basic education (9 years or less)	34 (42.5)	
Secondary school (11–12 years)	40 (50)	
Higher education	6 (7.5)	

Abbreviations: AIS, American Spinal Injury Association Impairment Scale; NA, not applicable; TSCI, traumatic spinal cord injury.

possibility to get a job after injury. People who were employed after TSCI gave higher scores for GH ($P < 0.001$), SF ($P < 0.03$) and PF ($P < 0.001$). The other sociodemographic factors were nonsignificant.

HRQoL, time from trauma and completeness of injury

The Mann–Whitney U -test revealed that in patients with complete TSCI the score for PF was significantly lower ($P < 0.001$) than in patients with incomplete injury and the score for SF showed a trend to be lower ($P < 0.1$). The time that had elapsed from trauma had a weak negative correlation with PF ($r = -0.25$; $P < 0.03$).

All correlations of HRQoL with subscales of EST-Q, life Orientation Scale and SSQ are presented in Table 3.

HRQoL and emotional state (EST-Q)

General health correlated negatively with symptoms of depression ($P < 0.001$) and fatigue ($P < 0.01$). Depressive symptoms and fatigue were also negatively correlated with Health Change (both $P < 0.002$). Patients with symptoms of depression, anxiety, panic, social anxiety,

fatigue and insomnia gave lower scores for all subscales of the RAND-36.

Spearman's correlation analysis revealed relationships between life Orientation Scale and MH ($r = 0.43$, $P < 0.0001$), as well as weak correlations with SF ($r = 0.25$, $P = 0.04$) and GH ($r = 0.25$, $P = 0.04$).

HRQoL and social support

Satisfaction with available social supports had a weak positive correlation with GH ($r = 0.26$, $P = 0.04$).

Models describing HRQoL

Multiple regression analysis with GH, PF and MH as dependent variables are presented in Table 4. The determination coefficients (adjusted R^2) were the highest for MH (71%), followed by GH (65%) and PF (39%). Regression analysis showed that increasing age, unemployment and a greater degree of disability by the AIS were related to lower scores of PF. Age, symptoms of depression and anxiety were significant predictors for lower scores of MH. GH scores decreased with age and prevalence of depressive symptoms.

Table 2 Mean scores of the RAND-36 health domains, the Social Support Questionnaires and Life Orientation Scale in patients with TSCI

ASIA impairment scale	A and B			C and D			NA			Total		
	Mean	N	s.d.	Mean	N	s.d.	Mean	N	s.d.	Mean	N	s.d.
Domains of RAND-36												
Physical functioning	13.5	39	15.7	55	28	28.8	70	11	27.7	36.3	78	32.6
Role-physical	29.4	34	38.2	44.4	27	41.2	45.5	11	41.6	37.5	72	40.0
Role-emotional	60.8	34	44.5	69.1	28	42.4	51.5	11	43.1	62.6	73	43.3
Energy/fatigue	46.9	35	19.3	49.5	29	18.1	41.8	11	16.0	47.1	75	18.3
Emotional well-being	67.2	36	21.9	72.6	29	15.2	62.9	11	21.0	68.6	76	19.5
Social functioning	56.3	36	27.8	67.3	29	29.2	68.2	11	33.7	62.2	76	29.4
Bodily pain	47.3	37	33.3	57.5	29	24.6	51.8	11	27.4	51.8	77	29.5
General health	46.5	36	18.6	51.6	28	19.4	50.9	11	21.1	49.1	75	19.2
Health changes	63.2	38	23.1	58.6	29	19.2	38.6	11	13.1	58.0	78	21.9
SSQ-N												
relatives	3.5	34	2.0	3.8	25	2.0	5.1	11	3.2	3.8	70	2.2
nonrelatives	1.5	34	1.4	1.5	25	1.4	1.7	11	1.2	1.6	70	1.3
SSQ-S	33.1	33	6.3	33.1	23	5.2	35.0	10	4.9	33.4	66	5.7
LOS	29.1	33	5.9	29.4	27	4.8	29.1	10	5.8	29.2	70	5.4

Abbreviations: LOS, Life Orientation Scale; SSQ-N, number of social supports; SSQ-S, satisfaction with available social supports; TSCI, traumatic spinal cord injury.

Table 3 Correlations of HRQoL with subscales of EST-Q, LOS and SSQ in patients with traumatic spinal cord injury in Estonia from 2003–2007

EST-Q subscales	Domains of RAND-36								
	Physical functioning	Role physical	Role emotional	Energy/fatigue	Emotional well-being	Social functioning	Bodily pain	General health	Health change
Depression	-0.15	-0.37*	-0.36*	-0.57*	-0.71*	-0.48*	-0.51*	-0.39*	-0.35*
Anxiety	0.04	-0.38*	-0.42*	-0.44*	-0.72*	-0.25*	-0.49*	-0.25	-0.19
Panic	-0.18	-0.44*	-0.15	-0.33*	-0.40*	-0.34*	-0.31*	-0.16	-0.11
Social anxiety	-0.18	-0.32*	-0.12	-0.33*	-0.33*	-0.30*	-0.24*	-0.18	-0.25
Fatigue	-0.07	-0.55*	-0.49*	-0.71*	-0.66*	-0.44*	-0.64*	-0.40*	-0.36*
Insomnia	-0.06	-0.35*	-0.42*	-0.39*	-0.48*	-0.30*	-0.47*	-0.23	-0.11
SSQ-S	0.04	0.16	0.14	-0.02	0.22	0.11	0.14	0.26*	0.14
LOS	0.01	0.00	0.05	0.21	0.43**	0.25*	0.31**	0.25*	0.17

Abbreviations: EST-Q, Emotional State Questionnaire; HRQoL, health-related quality of life; LOS, Life Orientation Scale; SSQ-S, satisfaction with available social supports. Correlations Spearman's ρ (two tailed).

*Correlation is significant at the 0.05 level (two tailed).

**Correlation is significant at the 0.01 level (two tailed).

Table 4 Multiple regression models of predictors of physical functioning, general health and emotional well-being

	Physical functioning (PF)		General health (GH)		Emotional well-being (MH)	
	r/mean (s.d.)	β (p)	r/mean (s.d.)	β (p)	r/mean (s.d.)	β (p)
<i>Gender</i>		-0.09 (0.220)		-0.10 (0.282)		-0.11 (0.121)
Male	37.6 (32.6)		50.6 (19.7)		71.1 (18.8)	
Female	35.7 (36.9)		45.0 (18.6)		59.7 (21.8)	
Age at the time of injury	-0.10	-0.15 (0.050)	-0.40*	-0.42 (0.000)	-0.17	-0.17 (0.013)
Time from injury	-0.25*		0.01		-0.01	
<i>Impairment group</i>						
AIS A and B	13.5 (15.6)*		46.5 (18.6)		67.2 (21.9)	
AIS C and D	55.0 (28.7)*	0.48 (0.000)	51.6 (19.4)		72.5 (15.2)	
NA (only sensory symptoms)	70.0 (27.7)	0.45 (0.000)	50.9 (21.1)		62.9 (21.0)	
<i>Employment status before TSCI</i>						
Employed	38.8 (32.9)		51.2 (16.4)		71.3 (15.4)	
Student	46.7 (36.2)		58.5 (21.1)		72.0 (22.9)	
Unemployed or retired	24.3 (28.2)		38.6 (25.1)		61.5 (28.9)	
Unknown	47.5 (67.2)		40.0 (14.1)		44.0 (17.0)	
<i>Employment status after TSCI</i>						
Occupation is the same as before TSCI	70.8 (25.2)		51.9 (18.3)		71.4 (13.7)	
Occupation has changed after TSCI	52.3 (38.8)	-0.17 (0.060)	68.2 (21.1)		79.6 (18.5)	
Unemployed or retired	20.7 (21.5)	-0.41 (0.000)	44.3 (16.8)		65.6 (21.3)	
<i>Education status</i>						
Basic education (9 years or less)	39.1 (28.7)		44.7 (19.7)		66.0 (19.8)	
Secondary school (11–12 years)	31.8 (34.9)		51.7 (17.1)		71.4 (19.2)	
Higher education	62.5 (37.3)		61.7 (27.9)		70.0 (24.0)	
<i>EST–Q</i>						
Depression	-0.15		-0.39*	-0.42 (0.000)	-0.71*	-0.44 (0.000)
Anxiety	0.04		-0.25		-0.72*	-0.40 (0.001)
Panic	-0.18		-0.16		-0.40*	
Social anxiety	-0.18		-0.18		-0.33*	
Fatigue	-0.07		-0.40*		-0.66*	
Insomnia	-0.06		-0.23		-0.48*	
SSQ-S	0.04		0.26*		0.22	
LOS	0.01		0.25*		0.43**	
<i>R</i> ²		0.65		0.39		0.71

Abbreviations: β, standardized regression coefficient (beta weight); AIS, American Spinal Injury Association Impairment Scale; EST-Q, Emotional State Questionnaire; HRQoL, health-related quality of life; LOS, Life Orientation Scale; NA, not applicable; r, Correlations Spearman's ρ (two tailed); SSQ-S, satisfaction with available social supports; TSCI, traumatic spinal cord injury.

*Correlation is significant at the 0.05 level (two tailed).

**Correlation is significant at the 0.01 level (two tailed).

DISCUSSION

The present study is the first in Estonia addressing the HRQoL of persons with TSCI. In the earlier studies where the PF level of TSCI patients was similar to that for our study group (Figure 1), Estonian TSCI patients showed lower results in all domains of RAND-36 scores compared with persons with spinal cord injury in Norway,¹⁶ Sweden¹⁷ and Australia,¹⁸ as well as with the general Estonian population.¹⁹ As in other studies, the lowest RAND-36 scores were given for the physical health -related domains.²⁰ The trends of changes are similar in all domains. It is possible that differences among different countries are caused by health care and other support services provided to individuals with SCI. This may indicate that more marked decrease in QOL after TSCI is not caused by the injury per se but by social disadvantages, social isolation and withdrawal, and difficulties in returning to previous professional work. In

Figure 1, the greatest differences compared with other studies/countries are seen in RP and SF scores. However, differences are not so evident when compared with the Australian study.¹⁸ Both domains are known to be potentially manageable by adequate support systems. At the same time, differences are not so obvious for the BP, V and MH domains. It should be noted that the Figure 1 is only illustrative to show differences in the HRQoL of TSCI patients, between Estonia and other countries.

The HRQoL following TSCI is affected by severity of injury, age, depression and employment status. This finding may have important implications as the latter two factors are potentially modifiable.

Sociodemographic factors

Our study demonstrated that 79% of the patients were working or studying before injury but only 37% of the patients had gained

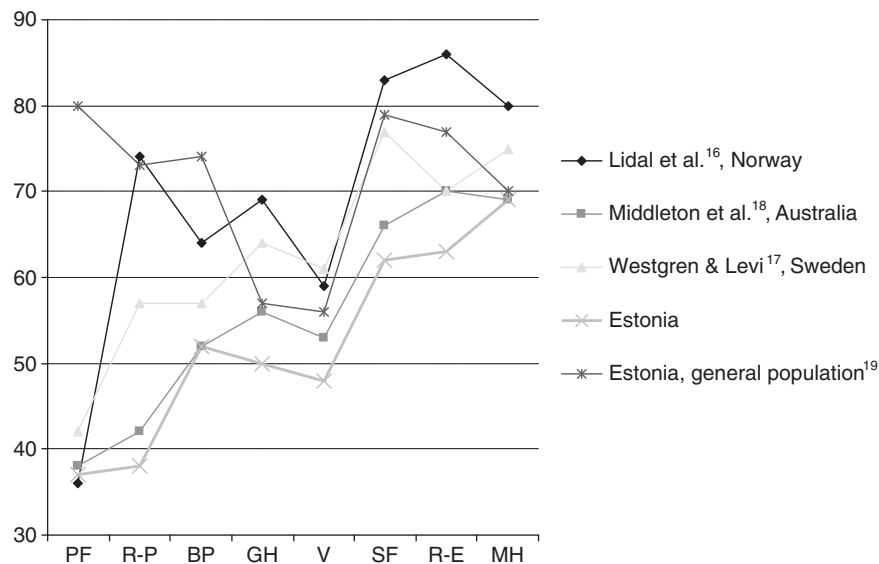


Figure 1 Mean scores of the RAND-36 scale for Estonian TSCI patients compared with the earlier studies and general Estonian population. Values interpolated from the table in Boakye *et al.*,⁵ and from a healthy cohort of 1989 Estonian individuals (Lai *et al.*¹⁹). The figure is illustrative, statistical significance has not been calculated. BP, bodily pain; GH, general health; MH, mental health; PF, physical functioning; R-E, role-emotional, R-P, role physical; SF, social functioning; V, Vitality (energy and fatigue).

employment following injury. The patients who were working after injury perceived their QoL higher than the patients who were not working. Significant correlations were found between GH, SF and PF. The importance of post-traumatic employment also became evident in the model describing PF. Conroy *et al.*²¹ have emphasized that employment is considered an important indicator for good HRQoL, although this variable is strongly influenced by economic and social opportunities, as well as by age and educational level. Because a big part of the patients had only basic education, most of them would probably need requalification and encouragement to re-enter the job market. Even though post-traumatic employment is a factor that can be changed, it depends to a large degree on health-care policy and economic possibilities but also on the readiness of the society to employ people with physical disability. However, not all persons with TSCI are able to return to work because of their serious physical condition.

According to the present study, age was an important factor predicting HRQoL. It is consistent with the finding that older patients assess their GH as worse. Yet some previous studies have shown that age is not a statistically important factor for HRQoL in these patients.²²

Our study also showed that satisfaction with social support does not depend on the number of supporters. The number of supporters was generally small but the patients perceived that the quality of social support was high. The number of supporters did not correlate significantly with different HRQoL domains. The very small number of nonrelative supporters can indicate the social isolation of patients. According to a systematic literature review, social support is associated with better health and functioning in individuals with TSCI.²³ However, the subjective perception of social support has yielded the strongest positive correlation with health outcomes.²⁴

Disability related factors

Considering the domains of HRQoL in combination with severity of injury, we found statistical associations with PF and Change in health over the past year. The AIS category was a significant predicting factor

for PF in the regression model. This aspect has already been pointed out before.¹⁷

It is well-known that patients with chronic pain have higher rates of depression and vice versa.²¹ According to our study, patients with depressive symptoms gave a significantly lower score for Bodily pain. The concept of pain used in this study was based on RAND-36 where the lowest score means very severe and extremely limiting pain. In the future, more systematic assessment of pain with determination of its types, location and duration would be necessary.

Psychosocial variables

Symptoms of depression proved important in the models describing MH and GH. This finding is not surprising and has been previously described in the medical literature in recent decades. One quarter of the participants exhibited signs of depression, which correlated negatively with GH and Health change. In our study, depressive patients had significantly lower scores for almost all RAND-36 domains.

Future directions and limitations

It would be valuable to examine the same group of patients longitudinally and to study the effects of secondary medical complications on QoL. A qualitative component should also be added to the study in the future. In the present study the number of participants was small, which may reflect the social isolation and depressiveness of TSCI patients in Estonia. Economic limitations for QoL were beyond the scope of the study.

CONCLUSION

The Estonian patients with TSCI showed lower results in all domains of QoL compared with patients from other countries or the general population of Estonia. It can be supposed that the possibilities of Estonian rehabilitation and social support system are insufficient to ensure as high QoL for patients with SCI as reported from other countries. Emotional disorders are frequent after TSCI in Estonia and are significantly associated with impaired HRQoL. For patients with

TSCI, more attention should be paid to recognising the symptoms of depression, as well as to diagnosing and treating them. The pain suffered by patients with TSCI should be systematically assessed and treated accordingly. There are several factors which affect the HRQoL of patients with TSCI: clinical consequences of traumatic injury; psychological, emotional and social factors; patients' outlook on life; and demographic factors. It is important to expand the results of the present study with the aim to promote physical, psychological and social well-being after SCI. This is possible through improvement of rehabilitative care and development of corresponding supportive psychological and social systems. The results of this study highlight the need for further research into the HRQoL of patients with TSCI in Estonia.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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