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Internal consistency and convergent validity of the International Spinal Cord Injury Quality of Life Basic Data Set at discharge from first rehabilitation

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STUDY DESIGN: This study is a cross-sectional analysis using data from the Swiss Spinal Cord Injury Cohort Study.
OBJECTIVES: To examine internal consistency and convergent validity of the International Spinal Cord Injury Quality of Life Basic Data Set (QoL-BDS) at discharge from first inpatient rehabilitation.
SETTING: The study was performed at four rehabilitation centers in Switzerland.
METHODS: Participants were Swiss residents aged over 16 years newly diagnosed with traumatic or non-traumatic spinal cord injury (SCI). Measures included the QoL-BDS, World Health Organization Quality of Life (WHOQOL) items, Hospital Anxiety and Depression Scale (HADS), and Spinal Cord Independence Measure III (SCIM).
RESULTS: A total of 495 participants were included. In all, 57% had a traumatic SCI, 71.1% a motor complete SCI, and 33.3% had tetraplegia. Mean age was 53 (SD = 16.4) years and 68% were male. No floor or ceiling effects were found. Inter-correlations were strong (0.73–0.80) and Cronbach's alpha was good (0.88). QoL-BDS mean scores were 6.4 (SD = 2.2) for life satisfaction, 5.8 (SD = 2.4) for physical health, 6.9 (SD = 2.4) for psychological health, and 6.4 (SD = 2.1) for total QoL. Correlations with reference measures were strongest for QoL-BDS total and WHOQOL general quality of life ($r = 0.67$), QoL-BDS physical health and WHOQOL health and daily activities (r = 0.64 and 0.53), and QoL-BDS psychological health and HADS depression and anxiety ($r = -0.64$ and -0.69). SCIM correlated weakly with all QoL-BDS items.
CONCLUSIONS: The QoL-BDS revealed no floor or ceiling effects and demonstrated good internal consistency and convergent validity in individuals with SCI assessed at discharge from first rehabilitation. This study supports the clinical routine use of the QoL-BDS.

Spinal Cord; https://doi.org/10.1038/s41393-021-00696-4

INTRODUCTION

Quality of life (QoL) is considered to be a key outcome variable of rehabilitation after spinal cord injury (SCI) as reflected in its inclusion in a tool kit of outcome measures validated specifically for SCI populations [1] and the German-speaking Medical Society for Paraplegiology's endorsement of QoL as a standard outcome variable in the setting of first rehabilitation [2]. There is currently no consensus on definition and operationalization of QoL [3, 4] and studies on QoL after SCI have focused on both objective (e.g., health status, functioning) and subjective dimensions of QoL such as subjective well-being [4]. Subjective well-being includes a cognitive component that is captured by QoL and related questions about an individual's satisfaction with life or experience of living circumstance, and an affective component that is captured by self-reported mood, emotions, and general distress [3].

Given increasing interest in using QoL as quality measure for rehabilitation, there is a need to identify measures that are suitable for repeated assessments of QoL over the course of first rehabilitation. Such measures should be psychometrically sound, clinically relevant, and feasible in an inpatient setting. An international working group developed a brief measure of subjective QoL, the International Spinal Cord Injury Quality of Life Basic Data Set (QoL-BDS), which includes three items measuring satisfaction with one's life as a whole and with one's physical and psychological health, respectively [3]. The QoL-BDS was designed to include a minimal number of data elements that can be easily collected in routine clinical practice, minimize measurement error, and ensure international applicability and comparability [3].

A validation study of community-dwelling wheelchair-using individuals with SCI sustained at least 10 years prior to assessment

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Received: 8 January 2021 Revised: 12 August 2021 Accepted: 12 August 2021
Published online: 26 August 2021

demonstrated good internal consistency and construct and convergent validity of the SCI QoL-BDS [5]. Similarly, a psychometric analysis of cross-sectional data from several international studies comparing individuals with traumatic and non-traumatic SCI etiologies to individuals without SCI found acceptable psychometric properties of the SCI QoL-BDS in both community-dwelling and inpatient samples, as indicated by the absence of notable floor or ceiling effects, good internal consistency, and evidence for convergent and divergent validity [6]. A prospective multi-center study using an international sample of adults SCI or disease (SCI/SCD) demonstrated replicability of the SCI QoL-BDS in community and outpatient clinics, including good to substantial test–retest reliability [7]. Most recently, a study of Thai individuals with chronic SCI recruited from outpatient rehabilitation and urodynamic clinics and a rehabilitation ward confirmed good internal consistency and test–retest reliability as well as showing fair to good construct validity [8].

As a short measure, the SCI QoL-BDS may be particularly useful in evaluating QoL as an aspect of rehabilitation success. To our knowledge, no published study has examined the construct validity of the QoL-BDS in patients undergoing first rehabilitation after SCI except for one subgroup from India included in New et al.'s 2019 international study [6]. It is important to establish psychometric characteristics of the SCI QoL-BDS in the inpatient setting because this is where patients are first confronted with the challenge of having to adapt to sudden major changes in physical functioning and independence. Addressing this gap in the literature, this study examined internal consistency and convergent and divergent validity of the QoL-BDS at first rehabilitation discharge.

METHODS

Design

This is a cross-sectional analysis of data collected in the ongoing inception cohort of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) [9]. The SwiSCI is a population-based and longitudinal cohort study performed by Swiss Paraplegic Research in collaboration with the four major specialized rehabilitation centers in Switzerland [10]. A total of four measurement time points are scheduled for the inpatient setting during first rehabilitation (1, 3, and 6 months post injury, and at discharge from clinical rehabilitation), but the present study focuses solely on data from the discharge assessment. The regional Ethics Committees formally approved the SwiSCI study and all participants gave written informed consent.

Participants and procedures

SwiSCI includes Swiss residents aged over 16 years who were newly diagnosed with traumatic or non-traumatic SCI and were admitted for clinical rehabilitation to one of the four collaborating centers. Individuals with congenital conditions leading to SCI (including spina bifida), new SCI in the context of palliative (end-of-life) care, neurodegenerative disorders such as multiple sclerosis, and Guillain–Barré syndrome were excluded. The sample for the present study includes all eligible individuals who consented to participate in the SwiSCI inception cohort, and completed their clinical first rehabilitation by March 2020. Participants who did not take part in the discharge questionnaire ($n = 102$) or did not complete all three items of the QoL-BDS ($n = 6$) were excluded. The final sample included 495 participants out of 1268 eligible (39%; Fig. 1). Non-response analyses have shown that the older, female, and more severely injured individuals are less likely to participate in the SwiSCI inception cohort [9]. Furthermore, the 108 participants excluded from the present study for assessments completion reasons were more likely to present complete lesions than the participants included in the final study sample, but were similar in terms of age, gender, time since injury, etiology and level of lesion, and presence of pain.

Instruments

QOL-BDS. The QOL-BDS measures QoL with three items. The participants are asked to evaluate their (1) "satisfaction with life as a whole," (2) "satisfaction with physical health," and (3) "satisfaction with psychological health, emotions and mood" during the past 4 weeks on an 11-point scale from 0 = "Completely dissatisfied" to 10 = "Completely satisfied" [3, 7].

Convergent and divergent validity measures. Convergent validity of the QOL-BDS' "satisfaction with life as a whole" item was tested using the general QoL item ("How would you rate your quality of life?" from 1 = "Very poor" to 5 = "Very good") of the World Health Organization Quality of Life questionnaire brief version (WHOQOL-BREF) [11, 12].

For the "satisfaction with physical health" item of the QOL-BDS, convergent validity was tested with three other measures: (a) the health item of the WHOQOL-BREF ("How satisfied are you with your health?" from 1 = "Very dissatisfied" to 5 = "Very satisfied"), (b) the daily activities item of the WHOQOL-BREF ("How satisfied are you with your ability to perform your daily living activities?" from 1 = "Very dissatisfied" to 5 = "Very satisfied"), and (c) the Spinal Cord Independence Measure III (SCIM [13], measuring functional independence of individuals with SCI in different daily tasks: mobility, self-care, respiration, and sphincter management). Health care professionals rate participants' performance in each of these tasks based on observation as part of the routine rehabilitation assessments. SCIM total scores range from 0 to 100 with higher scores indicating higher functional independence. The SCIM is a well-validated instrument showing satisfying reliability [14].

Convergent validity of the QOL-BDS' "satisfaction with psychological health" item was tested against the two subscales of the Hospital Anxiety and Depression Scale (HADS [15]). The HADS is a 14-item self-reported measure of symptoms of depression (HADS-D; e.g., "I feel as if I am slowed down") and symptoms of anxiety (HADS-A; e.g., "I feel tense or wound up") experienced in the last week. The items are rated on a 4-point scale (from 0 = "not at all" to 3 = "most of the time") and summed up for each subscale separately into a total sore ranging from 0 to 21. Higher scores indicate higher symptomatology. This measure showed good construct validity and reliability of the Anxiety and Depression scores in Rasch analyses [16].

Sociodemographic and lesion characteristics. Participant's age at onset of SCI, sex, and language of correspondence were included for descriptive purposes. In addition, lesion characteristics included time since SCI, cause of SCI (traumatic vs non-traumatic), level of SCI (tetraplegia, paraplegia, intact, or unable to determine), completeness of SCI (based on the American Spinal Injury Association Impairment Scale; AIS) [17], and presence of pain in the last week (yes vs no).

Analysis

First, we examined the floor and ceiling effects of each item of the QOL-BDS. Floor and ceiling effects were considered as present if more than 15% of the respondents achieved the lowest or highest possible score, respectively [18]. Second, the internal consistency of the instrument was determined. Reliability was considered acceptable if Cronbach's α was at least 0.70 and if the corrected item-total correlations were larger than 0.30 [18]. Third, skewness and kurtosis of the QOL-BDS's items were assessed based on histograms and absolute values of skewness (larger than 2 indicating substantial non-normality) and kurtosis (larger than 7 indicating substantial non-normality) [19].

The convergent validity of the QOL-BDS' items was assessed using Pearson's correlation (or nonparametric Spearman's correlations if the data were not normally distributed). Correlations below 0.30 were interpreted as weak, and correlations of 0.50 or higher were interpreted as strong [20]. To establish convergent validity, positive correlations of 0.60 or higher were expected between the QOL-BDS' general QoL item and the WHOQOL-BREF's general QoL item as well as between the QOL-BDS' physical health item and the physical health and daily activities items of the WHOQOL-BREF, because these items/instruments measure similar constructs [21]. For the psychological health item, negative correlations of –0.60 or below were expected with the HADS-D and HADS-A scores. Based on research demonstrating a moderate relationship between physical components of health-related QoL and functional independence [22], positive correlations around 0.50 were expected between QOL-BDS' physical health item and the SCIM. Correlations between 0.30 and 0.59 were expected for the other associations with the QoL-BDS items because all scores reflect different but related constructs [23].

For descriptive purposes, analysis of the QOL-BDS stratified by sociodemographic and lesion characteristics were conducted and *t*-tests were run to identify significant differences between subgroups. All analyses were conducted using STATA 16 (StataCorp, College Station, TX, USA).

RESULTS

Descriptive statistics of the final sample analyzed in the present study ($n = 495$) are displayed in Table 1. Missing rates varied

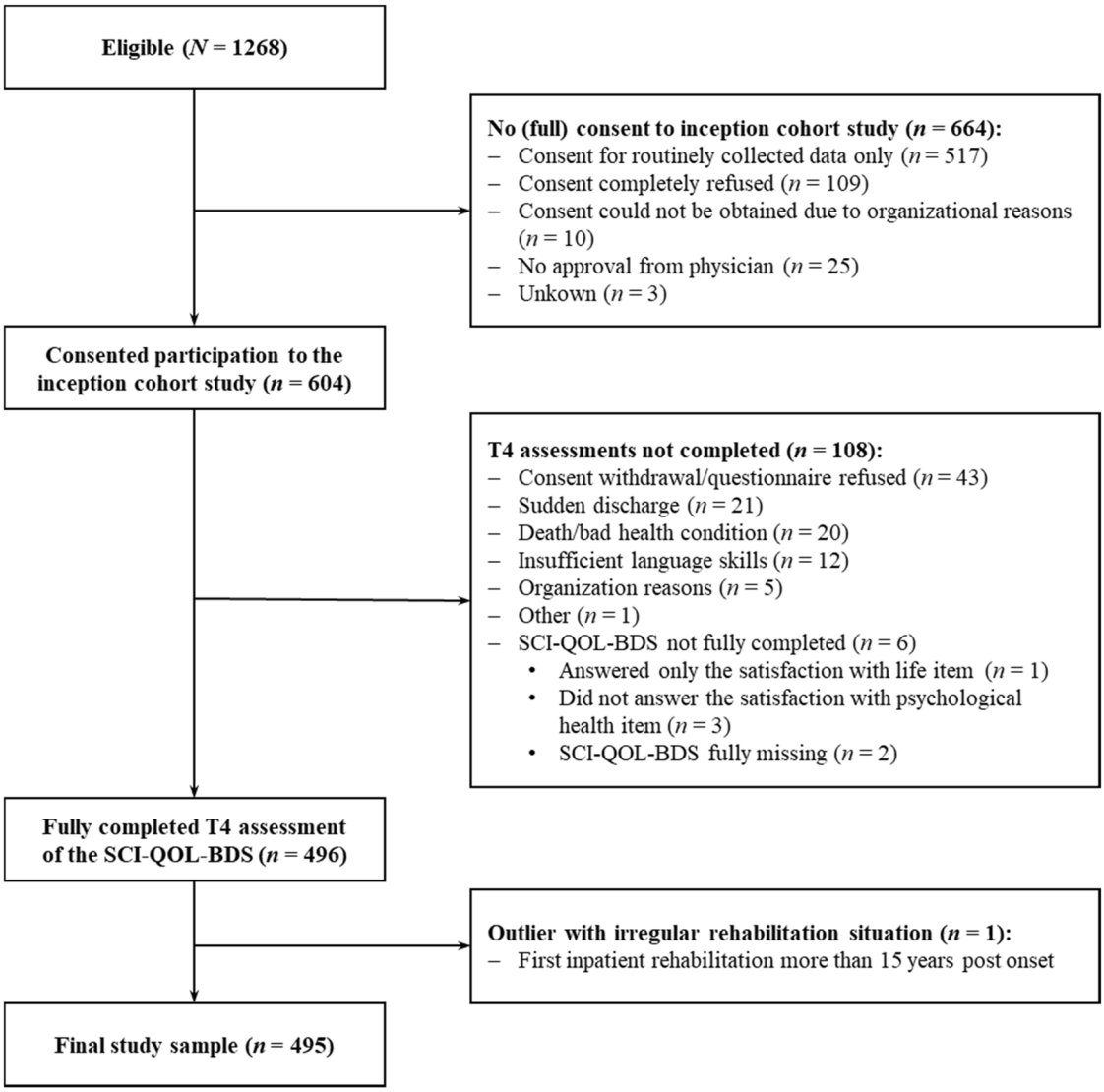

Fig. 1 Flow diagram depicting participation in the current study. T4 discharge time point, QOL-BDS Spinal Cord Injury Quality of Life Basic Data Set.

between 0 and 8.5% with level and completeness of SCI being the only variables with more than 5% of missing values. Given that there is unlikely to be much gain from imputation with missing rates lower than 5% [24], listwise deletion was applied in the correlation and stratified analyses.

Floor and ceiling effects

As displayed in Table 2, the highest rate of minimum or maximum scores across the QOL-BDS items was 13.5% (max score of satisfaction with psychological health). Thus, the QOL-BDS did not present substantial floor or ceiling effects.

Internal consistency

QOL-BDS's Cronbach's alpha was 0.88 with corrected item-total correlations of 0.80, 0.77, and 0.73 for satisfaction with life, physical health, and psychological health, respectively. Thus, the QOL-BDS presented a satisfactory internal consistency.

Skewness and kurtosis

Skewness and kurtosis indices displayed in Table 2 indicate no substantial non-normality. However, the frequency distributions displayed in Fig. 2 indicate some skewness with higher scores being more frequent. Thus, nonparametric Spearman rank-order correlations were used to test convergent validity.

Convergent and divergent validity

The correlations testing convergent and divergent validity of the QOL-BDS are displayed in Table 3. They indicated that, as expected, the satisfaction with life item of the QOL-BDS correlated strongly with the general QoL item of the WHOQOL-BREF. Similarly, the satisfaction with physical health item correlated strongly with the health and the daily activities items of the WHOQOL-BREF. All three items of the QOL-BDS were strongly inversely correlated with the HADS-D and the HADS-A subscales. Regarding divergent validity, health and daily activity items of the WHOQOL-BREF correlated weakly with the satisfaction with psychological health item of the QOL-BDS. Similarly, all three items and the total QOL-BDS score correlated only weakly with the SCIM, indicating divergent validity.

QOL-BDS stratified by sociodemographic and lesion characteristics

The QOL-BDS scores in subgroups defined by age since SCI, sex, time since SCI, cause, level, and completeness of SCI, as well as

presence of pain are displayed in Table 4. Sex and presence of pain were the only characteristics showing significant differences in terms of QoL, albeit with small effect sizes. Male participants scored significantly higher in all QOL-BDS items and the total score (Cohen's *d* between 0.11 and 0.17) compared to their female counterparts. Individuals with SCI reporting the presence of pain in the last week presented significantly lower scores in all QOL-BDS items and the total score (Cohen's *d* between 0.10 and 0.14) compared to the individuals reporting no pain.

Table 1. Descriptive statistics of the SwiSCI inception cohort sample at discharge from first inpatient rehabilitation ($n = 495$).

	n (%) missing	*n* (%)	*M* (SD); range
Age at SCI	0 (0)		53 (16); 16–87
Male	0 (0)	339 (68)	
Language	0 (0)		
German		372 (75)	
French		106 (21)	
Italian		13 (2.6)	
Other		4 (0.81)	
Time since SCI (days)	22 (4.4)		153 (82); 15–455
Traumatic cause of SCI	0 (0)	283 (57)	
Level of SCI	39 (7.9)		
Tetraplegia		164 (33)	
Paraplegia		277 (56)	
Intact		14 (2.8)	
Unable to determine		1 (0.20)	
Completeness of SCI (AIS)	42 (8.5)		
A		66 (13)	
B		25 (5.1)	
C		36 (7.3)	
D		308 (62)	
E		14 (2.8)	
Unable to determine		4 (0.81)	
Presence of pain	5 (1.0)	320 (64)	
WHOQOL-BREF general quality of life	18 (3.6)		3.6 (0.85); 1–5
WHOQOL-BREF health	9 (1.8)		3.3 (1.0); 1–5
WHOQOL-BREF daily activities	7 (1.4)		3.4 (1.1); 1–5
Total score SCIM	9 (1.8)		72 (23); 5–100
Total score HADS-D	12 (2.4)		4.8 (3.8); 0–19
Total score HADS-A	5 (1.0)		4.9 (3.9); 0–19

SCI spinal cord injury, *AIS* American Spinal Injury Association Impairment: Grade A = complete lack of motor and sensory function below the level of injury (including the anal area), Grade B = some sensation below the level of the injury (including anal sensation), Grade C = some muscle movement is spared below the level of injury, but 50% of the muscles below the level of injury cannot move against gravity, Grade D = most (more than 50%) of the muscles that are spared below the level of injury are strong enough to move against gravity, Grade E = all neurologic function has returned, *WHOQOL* World Health Organization Quality of Life measure, *SCIM* Spinal Cord Independence Measure, *HADS* Hospital Anxiety (A) and Depression (D) Scale.

DISCUSSION

This study examined whether the three items and the total score of the QoL-BDS correlate with measures of related constructs at discharge. Despite the fact that the QoL-BDS was presented to participants in a much larger paper–pencil questionnaire, there were very few missing values, indicating good acceptability and feasibility of items in participants with SCI. Internal consistency of the QOL-BDS was good, with Cronbach's alphas comparable to the inpatient subgroup included in New et al.'s international study [6] as well as outpatient and community samples [5–8].

The QOL-BDS showed good convergent validity as indicated by absolute correlations with corresponding items of the WHOQOL-BREF, the HADS-D and HADS-A being larger than 0.60. Taken together with the good internal consistency, these results suggest the BDS-QOL's potential usefulness as a shorter alternative to the usually recommended WHOQOL-BREF, which has 26 items.

Higher scores on all three items and the total score of the QOL-BDS were strongly associated with lower levels of depression and anxiety. The psychological health item had the strongest relationship with mood, which is consistent with previous studies that included mood measures [5, 6]. The strong inverse correlations between QOL-BDS and anxiety and depression suggest that the QOL-BDS may indicate the presence of symptoms of depression and/or anxiety and thus could serve as a quick proxy measure for identifying individuals who could be referred for a psychological evaluation. Given its lack of pathology-focused questions, the QOL-BDS may present a non-stigmatizing starting point for exploring potential mental health problems. In contrast, lesion-related characteristics and etiology were unrelated to QoL, which also converges with findings from other studies showing that level or completeness of SCI did not influence QoL as measured with the QOL-BDS [5, 8] or was limited to satisfaction with physical health [6]. Contrary to our expectation of a moderate correlation between the QoL physical health item and functional status, there was only a weak relationship between the SCIM and all items of the QOL-BDS in the present study. This suggests that both lesion-related characteristics and functional independence may have a relatively small effect on subjective QoL in patients undergoing first rehabilitation. This is consistent with the lack of a significant relationship between QOL-BDS and SCIM that was observed in a cross-sectional study of community-dwelling individuals with chronic SCI [5]. Similarly, a recent prospective cohort study of individuals with SCI found no relationship between mental health-related QoL and the SCIM [22].

The only sociodemographic and clinical characteristics that were significantly associated with QoL in our sample were sex and the presence of pain. Male participants had higher QoL, which is inconsistent with gender effects reported in other studies of QoL

Table 2. Descriptive statistics of the QOL-BDS ($n = 495$).

	M (SD)	% Min score	% Max score	Skewness	Kurtosis
QOL-BDS total score	6.4 (2.1)	1.0	3.0	−0.56	2.9
Satisfaction with life	6.4 (2.3)	1.8	8.1	−0.54	2.9
Satisfaction with physical health	5.8 (2.4)	3.6	4.0	−0.49	2.7
Satisfaction with psychological health	6.9 (2.4)	1.4	13	−0.69	2.8

QOL-BDS Spinal Cord Injury Quality of Life Basic Data Set.

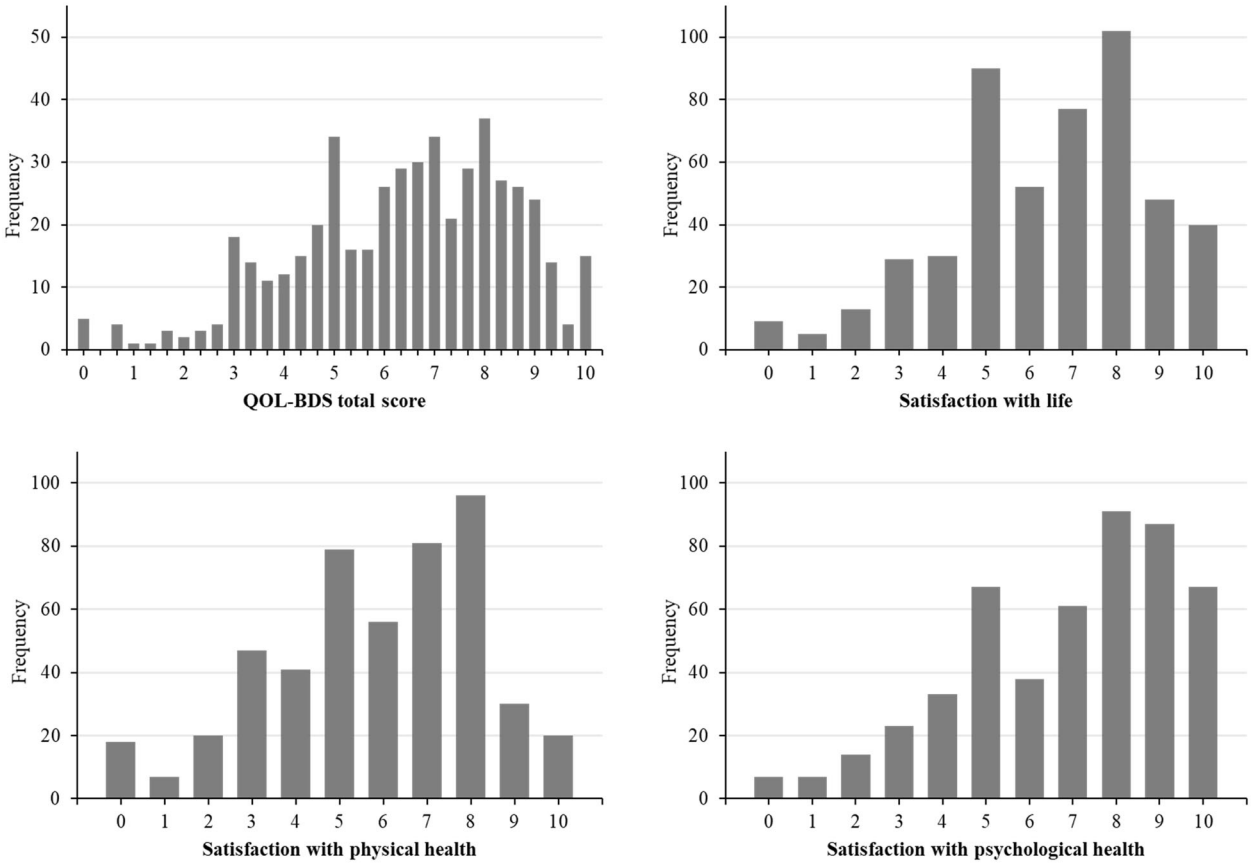

Fig. 2 A–D **Frequency distributions of the QOL-BDS.** Frequencies for the QOL-BDS total score and each QOL-BDS item (satisfaction with life, satisfaction with physical health, and satisfaction with psychological health).

Table 3. Convergent and divergent validity of the QOL-BDS (Spearman correlation coefficients).

	n	QOL-BDS total score	Satisfaction with life	Satisfaction with physical health	Satisfaction with psychological health
WHOQOL-BREF general quality of life	477	0.67	**0.63**	0.57	0.59
WHOQOL-BREF health	486	0.63	0.55	**0.64**	0.49
WHOQOL-BREF daily activities	488	0.54	0.48	**0.53**	0.43
Total score SCIM	486	0.14	0.12	0.14	0.10
Total score HADS-D	483	−0.69	−0.62	−0.58	**−0.64**
Total score HADS-A	490	−0.67	−0.58	−0.50	**−0.69**

QOL-BDS Spinal Cord Injury Quality of Life Basic Data Set, *WHOQOL* World Health Organization Quality of Life, *SCIM* Spinal Cord Independence Measure, *HADS* Hospital Anxiety (A) and Depression (D) Scale.
Bold coefficients indicate associations expected to be strong (≥0.60).

after SCI [6, 25]. Research on depression after SCI found that women are more likely than men to report sadness as well as express sadness through tears and other overt signs of depression [26]. Future research is needed to examine the possibility that the gender effects in QoL as measured with the QOL-BDS are related to a greater likelihood of women reporting negative emotion compared to men [27].

Individuals with pain reported lower QoL than those without pain, consistent with past research linking pain to lower QoL in individuals with SCI [28, 29]. Future studies should use longitudinal designs to examine bidirectional and temporal relationships between pain and QoL after SCI.

Limitations

Limitations of this study include potential sampling bias arising from the exclusion of individuals who refused or withdrew consent. Individuals not participating to the SwiSCI cohort study are on average older, more severely injured, and more often females [9]. The participants further excluded for data completion reasons are also more likely to present complete lesions. Thus, similarly to the majority of cohort studies [30], the most vulnerable individuals with low QoL may be underrepresented in this study.

A second limitation is that our sample did not contain enough Italian- and French-speaking participants to conduct language-specific analyses, which would be the first step to establish the

Table 4. QOL-BDS scores stratified by sociodemographic and lesion characteristics, indicating mean (*M*) and standard deviations (SD).

		QOL-BDS total score		Satisfaction with life		Satisfaction with physical health		Satisfaction with psychological health	
	n	*M*	(SD)	*M*	(SD)	*M*	(SD)	*M*	(SD)
Age at SCI									
Younger than 60	289	6.4	(2.1)	6.4	(2.3)	5.9	(2.4)	6.9	(2.4)
60 or older	206	6.4	(2.2)	6.5	(2.3)	5.7	(2.4)	6.9	(2.5)
Sex									
Male	339	6.6	(2.1)	6.6	(2.3)	6.1	(2.3)	7.1	(2.4)
Female	156	5.9	(2.1)	6.0	(2.2)	5.3	(2.5)	6.3	(2.5)
Time since SCI (days)									
15–89	128	6.5	(2.2)	6.6	(2.4)	6.0	(2.4)	7.1	(2.5)
90–149	119	6.6	(2.2)	6.6	(2.3)	6.1	(2.4)	7.1	(2.4)
150–209	105	6.2	(2.1)	6.2	(2.2)	5.7	(2.4)	6.6	(2.5)
210–455	121	6.4	(1.9)	6.5	(2.0)	5.8	(2.2)	6.9	(2.3)
Cause of SCI									
Traumatic	283	6.4	(2.1)	6.4	(2.3)	5.8	(2.5)	6.9	(2.5)
Non-traumatic	212	6.4	(2.1)	6.4	(2.3)	5.8	(2.3)	6.9	(2.4)
Level of SCI									
Tetraplegia	152	6.3	(2.1)	6.4	(2.4)	5.8	(2.5)	6.8	(2.4)
Paraplegia or intact	303	6.5	(2.1)	6.6	(2.2)	5.9	(2.4)	7.0	(2.4)
Completeness of SCI									
Complete (A of AIS)	14	6.2	(2.1)	6.3	(2.3)	5.7	(2.4)	6.6	(2.4)
Incomplete	435	6.5	(2.1)	6.6	(2.3)	5.9	(2.4)	7.0	(2.4)
Motor completeness of SCI									
Complete (A + B of AIS)	322	6.4	(2.0)	6.5	(2.2)	5.9	(2.4)	6.9	(2.3)
Incomplete	127	6.4	(2.2)	6.5	(2.3)	5.9	(2.4)	6.9	(2.5)
Presence of pain									
Yes	320	6.2	(2.1)	6.2	(2.2)	5.6	(2.4)	6.7	(2.5)
No	170	6.8	(2.2)	6.8	(2.4)	6.3	(2.4)	7.3	(2.4)

QOL-BDS Spinal Cord Injury Quality of Life Basic Data Set, *SCI* spinal cord injury, *AIS* American Spinal Injury Association Impairment Scale.

cross-cultural validity of QoL-BDS items translated from English into German, French, and Italian. Future studies will need to examine whether reliability and validity statistics of questions have equivalent meanings across different languages and cultures. Finally, the focus of the current study was limited to convergent validity and future studies are needed to examine other types of validity (e.g., test–retest reliability and sensitivity to change) that are important for assessing the clinical utility of the QoL-BDS in the inpatient post-acute phase.

CONCLUSION

This study provides evidence for good internal consistency and convergent validity of the QoL-BSD in the inpatient setting. As a short and simple measure, the QOL-BDS could help with decision making and planning during first rehabilitation, and, if administered repeatedly in longitudinal studies, may advance understanding of stability and changes in QoL during rehabilitation and post discharge.

DATA AVAILABILITY

Owing to our commitment to SwiSCI study participants and their privacy, datasets generated during the current study are not made publicly available but can be provided by the SwiSCI Study Center based on reasonable request (contact@swisci.ch).

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ACKNOWLEDGEMENTS

We thank the SwiSCI Steering Committee with its members Xavier Jordan, Fabienne Reynard (Clinique Romande de Réadaptation, Sion); Michael Baumberger, Hans Peter Gmünder (Swiss Paraplegic Center, Nottwil); Armin Curt, Martin Schubert (University Clinic Balgrist, Zürich); Margret Hund-Georgiadis, Kerstin Hug (REHAB Basel, Basel); Laurent Prince (Swiss Paraplegic Association, Nottwil); Heidi Hanselmann (Swiss Paraplegic Foundation, Nottwil); Daniel Joggi (Representative of persons with SCI); Nadja Münzel (Parahelp, Nottwil); Mirjam Brach, Gerold Stucki (Swiss Paraplegic Research, Nottwil); and Armin Gemperli (SwiSCI Coordination Group at Swiss Paraplegic Research, Nottwil).

AUTHOR CONTRIBUTIONS

MW, AS-S, SK, CF, PL, MWMP, and VC conceived the project. All authors contributed to the analysis plan. VC and SK analyzed the data. MW prepared the first draft of the manuscript. All authors contributed to the manuscript revisions and approved the final version.

FUNDING INFORMATION

SwiSCI is hosted and funded by Swiss Paraplegic Research.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICAL APPROVAL

Ethical approval was granted by the Ethics Committee of Northwest- and Central Switzerland (EKNZ, Project-ID: 11042 PB_2016-02608, approved December 2016). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed over the course of this research.

ADDITIONAL INFORMATION

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