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Responsiveness of the International Spinal Cord Injury Quality of Life Basic Data Set V2.0

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Research Article

Responsiveness of the international spinal cord injury quality of life basic data set V2.0: An international longitudinal study

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Context/Objective: Examine the sensitivity of the International Spinal Cord Injury Quality of Life Basic Data Set V2.0 (QoL-BDS V2.0) to reflect changes in mobility and secondary health conditions (SHCs) between inpatient rehabilitation and one-year follow-up.
Design: International longitudinal study. Questionnaires were administered at baseline (Median 6 weeks, inter-quartile range 4–10 weeks post-onset) and after 12 months.
Setting: Spinal cord rehabilitation institutions in the US, Brazil, Australia and the Netherlands.
Participants: : Individuals with recent onset of spinal cord injury or disease (SCI/SCD) admitted to inpatient rehabilitation.
Outcome measures: The QoL-BDS V2.0, comprises four items on satisfaction with 'life as a whole', 'physical health', 'psychological health', and 'social life'. Mobility level was measured with a single item and SHCs with the SCI Secondary Conditions Scale (SCI-SCS).
Results: Of the 160 participants, 61% had SCI, 48% had tetraplegia and 82% were wheelchair-users. Scores on 'life as a whole', 'physical health' and the total scale were significantly higher at follow-up compared to baseline in the total sample and the SCD subgroup, but not in the SCI subgroup. Increases in 'physical health', 'psychological health', 'social life' and the total score were significantly associated with improvements in the SCI-SCS or mobility scores. Participants with improved SCI-SCS and mobility at follow-up showed significantly more improvement in satisfaction with social life and the total score compared to participants without such favorable changes.
Conclusion: The results of this study provide partial evidence of responsiveness of the QoL-BDS V2.0 total score as a measure of QoL among individuals with SCI/SCD.

Keywords: Spinal cord injuries, Quality of life, Validation studies, Rehabilitation, Adaptation

Introduction
Traumatic spinal cord injury or non-traumatic spinal cord disease (SCI/SCD), is associated with complete or partial loss of body functions below the lesion level and secondary health conditions (SHCs), such as pressure sores, chronic pain, or spasticity that may impact their quality of life (QoL) (1). The World Health Organization (WHO) defines QoL as an individual's perceptions of their position in life in the context of their culture and value system in which they live, and in relation to their goals, expectations,

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standards, and concerns (2). This definition under-scores the subjective nature of QoL as it reflects individuals' overall perception of and satisfaction with their different experiences.

Longitudinal studies of QoL in the first year after the onset of SCI mostly showed increases of QoL, but also diverging trajectories of mental health and life satisfaction during and after rehabilitation, thereby showing individual differences in adjustment to living with SCI (3–6). Functional status and SHCs have been shown to impact QoL among people with a recent SCI/SCD (7). Improvement of functional status and management of SHCs are important rehabilitation goals, but their associations with QoL rarely have been investigated in the inpatient setting. Further, etiology of SCI/SCD might be an important, influencing factor. Compared to individuals with SCI, those with SCD tend to be older, are more likely to be female, have more comorbidities and are more likely to have incomplete lesions (8, 9). Individuals with SCI/SCD may benefit from rehabilitation treatment regardless of diagnosis or etiology, but there are numerous special considerations regarding the rehabilitation of people with SCD that are different from the rehabilitation of people with SCI (10).

Most research on QoL and the impact of etiology, functional status and SHCs on changes in QoL has been done in community samples of people with long-term SCI/SCD (11–13). Administering lengthy and complex QoL measures limit QoL research during inpatient rehabilitation. Therefore, there is a need for QoL measures that are easy to administer, psychometrically sound, clinically relevant, and feasible in an inpatient setting. These measures also should be able to capture clinically meaningful changes, thus providing evidence of their responsiveness (14, 15).

The International Spinal Cord Injury Quality of Life Basic Data Set (QoL-BDS) was developed to standardize the collection and reporting of QoL data in individuals with SCI/SCD, in both clinical and research settings (16). The QoL-BDS showed longitudinal construct validity to assess QoL among individuals with SCI/SCD undergoing first rehabilitation (17). An extended version, the QoL-BDS V2.0, was developed recently, based on earlier findings from our research team (18). Previously published results from this international project showed satisfactory reproducibility and internal construct validity of the QoL-BDS V2.0 (19, 20). However, no publications on the sensitivity of either version of the QoL-BDS to measure meaningful changes in QoL are available.

The aim of the current study is to examine the sensitivity of the QoL-BDS V2.0 to reflect changes in mobility and SHCs between inpatient rehabilitation and after a one-year follow-up. The hypotheses to be tested are:

1. QoL-BDS V2.0 scores will be higher (better) at follow-up than at baseline in the whole sample and in subgroups of participants with SCI and SCD.
2. QoL-BDS V2.0 scores will show significant negative associations with levels of mobility restriction and SHCs, at both baseline and follow-up, in the whole sample and in subgroups of participants with SCI and SCD.
3. Changes in QoL-BDS V2.0 scores from baseline to follow up will be associated with changes in levels of mobility restriction and SHCs between baseline and follow-up, in the whole sample and in subgroups of participants with SCI and SCD.

Methods

Study design

International longitudinal observational study, with measurements at baseline (during first inpatient rehabilitation after onset of SCI) and follow-up 12 months after baseline.

Participants

The study involved QoL data from five sites and four countries: Australia, Brazil, Netherlands, and two sites in the United States (US): Colorado and Michigan. Each of the five study sites aimed to recruit and enroll 48 inpatients for the study. Eligibility criteria for all sites were: (1) documented diagnosis of SCI/SCD without complete functional recovery (ASIA Impairment Scale (AIS) classification A-D); (2) minimum age of 18 at the time of participation; (3) initial inpatient rehabilitation after recent onset of SCI/SCD. Individuals were excluded if they were unable to read and speak the native language of the country in which they lived or were unable to complete a self-report questionnaire due to cognitive limitations. Across the five sites, the study team aimed to recruit similar numbers of participants in terms of neurological classification (all AIS D, Paraplegia AIS A, B or C, and Tetraplegia AIS A, B or C), age (<50 and >50 years), and etiology (SCI and SCD). Participants who were more than 52 weeks post-onset of injury at baseline were excluded from the current analyses.

Procedures

Enrollment took place from October 2017 until October 2019. All participants received oral and

written information about the study and provided informed consent. The study questionnaire was administered by a trained researcher in an oral interview at baseline and in-person or by telephone interview at follow-up. All information used in this study came from the study questionnaire. The study was approved at all sites by their respective Institutional Review Boards and Ethics Committees.

Instruments

The QoL-BDS V2.0 includes four items about the individual's satisfaction with 'life as a whole', their 'physical health', 'psychological health', and 'social life' in the past four weeks. All items are answered on a 0–10 numerical rating scale with higher scores indicating better QoL. The total score is calculated as the mean of the item scores and therefore has the same range from 0 (worst possible QoL) to 10 (best possible QoL). The QoL-BDS was developed in English and this version was used in the US and Australia and was translated into Dutch and Brazilian Portuguese following the recommendations of the International SCI Data Sets project (21–23).

The Spinal Cord Injury Secondary Conditions Scale (SCI-SCS) was used to measure the self-reported impact of SHCs following SCI/SCD (24, 25). This is a reliable and valid scale, with 16 items that cover problems with skin, musculoskeletal system, pain, bowel and bladder, metabolic, respiratory and cardiovascular functioning. The SCI-SCS uses a 4-point ordinal scale that ranges from 0 (not experienced or insignificant problem) to 3 (significant or chronic problem). The total score is calculated as the sum of the item scores and ranges from 0 to 48. Higher scores indicate greater overall problems with secondary conditions.

Restriction in day-to-day mobility was measured with one item on the use of mobility aids in the questionnaire, with 5 response categories: walking without aids, walking with aids, manual wheelchair, power wheelchair and bedridden.

Other variables used in this study included country, age at baseline, sex, years of education, level of SCI/SCD (tetraplegia or paraplegia), and the presence of sensation and voluntary movement below the level of the lesion (none, some, full).

Statistics

Descriptive statistics were used to describe participant characteristics and distributions of the scores on the main measures. For these ordinal measures, non-parametric statistics were used. Wilcoxon Matched Pairs and the McNemar Test were used to analyze changes in mobility, SHCs and QoL between baseline and follow-up. Spearman correlation coefficients were used to analyze associations between these measures. Change scores of the mobility and SHC scores were calculated and changes in mobility restriction and SHCs were dichotomized to identify subgroups of participants who improved in mobility (not able to walk at baseline but able to walk at follow-up), or in SHCs (less impact of SHCs at follow-up than at baseline), respectively. The Mann–Whitney U test was used to compare changes in QoL between participants who showed improvement in mobility or SHCs versus those who did not.

Results

A total of 242 individuals with SCI/SCD were recruited. Sixty-three individuals were lost to follow-up, 12 of whom died, 23 withdrew and 28 could not be contacted. Another 19 were excluded either due to excessive time from onset of injury to initial assessment or having incomplete data on the QoL-BDS V2.0, leaving a total of 160 participants for analysis. Their characteristics are displayed in Table 1. Etiology was traumatic in almost two-thirds of the participants. Non-traumatic etiologies were mainly degenerative (27 participants; 42.9%), vascular (14 participants; 22.2%) and infection (8 participants; 12.7%). Traumatic causes were mainly falls (42 participants; 44.3%), vehicular accidents (27 participants; 27.8%) and sports accidents (20 participants, 20.6%). Significant differences between participants with SCI or SCD were found with respect to study site, sex, age, marital status, employment status, level of lesion and mobility status.

Hypothesis 1, changes in QoL-BDS scores across time

Scores on the Qol-BDS V2.0 and the SCI-SCS at baseline and follow-up are displayed in Table 2. In the whole sample, scores on 'life as a whole', 'physical health' and the total scale were significantly higher at follow-up than at baseline. Satisfaction with 'psychological health' and 'social life' did not change significantly. These results partly confirm hypothesis 1 on the increase of QoL-BDS V2.0 scores between baseline and follow-up, although the corresponding effect sizes were small. Spearman correlation coefficients between the QoL-BDS scores at baseline and follow-up were statistically significant (P < .01) and moderate, in the range of 0.32–0.41.

Baseline QoL-BDS V2.0 scores among participants with SCD were, except for psychological health, all

Table 1 Participant characteristics at baseline (*N* = 160).

	SCD (*n* = 62)	SCI (*n* = 98)	Total *N* = 160
Country			
United States (Ann Arbor)	18 (29.0%)	12 (12.2%)	30 (18.8%)***
United States (Denver)	1 (1.6%)	41 (41.8%)	42 (26.3%)
Australia (Melbourne)	20 (32.3%)	6 (6.1%)	26 (16.3%)
Brazil (Sao Paulo)	5 (8.1%)	23 (23.5%)	28 (17.5%)
Netherlands (Utrecht)	18 (29.0%)	16 (16.3%)	34 (21.3%)
Sex			
Male	39 (62.9%)	79 (80.6%)	118 (73.8%)*
Female	22 (35.5%)	19 (19.4%)	41 (25.6%)
Transsexual	1 (1.6%)	0 (0.0%)	1 (0.6%)
Age (median, IQR)	61.5 (47.5–69.3)	42.0 (28.8–56.5)	51.0 (34.3–64)**
Years of education (median, IQR)	13.5 (12.0–16.0)	13.0 (12.0–16.0)	13.0 (12.0–16.0)
Married/living together	38 (61.3%)	53 (54.1%)	91 (56.9%)**
Employed before onset	34 (54.8%)	75 (76.5%)	109 (68.1%)**
Weeks since onset (median, IQR)	7.0 (4.0–13.3)	6.0 (3.0–9.0)	6.0 (4.0–10.0)
Tetraplegia	23 (37.1%)	54 (55.1%)	77 (48.1%)*
Wheelchair user	46 (74.2%)	85 (86.7%)	131 (81.9%)*
Motor function below lesion			
Full	9 (14.5%)	11 (11.2%)	20 (12.5%)
Some	45 (72.6%)	60 (61.2%)	105 (65.6%)
None	7 (11.3%)	27 (27.6%)	34 (21.3%)
Sensation below lesion			
Full	9 (14.5%)	10 (10.2%)	19 (11.9%)
Some or changed	47 (75.8%)	65 (66.3%)	112 (70.0%)
None	6 (9.7%)	23 (23.5%)	29 (18.1%)

*P < 0.05; **P < 0.01; ***P < 0.001.

significantly lower compared to baseline scores among participants with SCI. At follow-up, no such differences were observed. Changes in QoL-BDS V2.0 scores were more pronounced among participants with SCD, in which all scores except 'psychological health' showed a statistically significant increase, compared to the SCI group, in which none of the QoL-BDS V2.0 scores showed significant change.

The SCI-SCS scores were significantly lower at follow-up compared to baseline for the overall sample, indicating lower impact of secondary conditions. This decrease was significantly stronger among participants with SCI than among those with SCD. The Spearman correlations between the mobility restrictions and SCI-SCS scores at baseline and follow-up were 0.39 and 0.47 (both P < .01), respectively.

Table 2 Median (IQR) quality of life, secondary health conditions and mobility scores at baseline and follow-up (*N* = 160).

	Baseline			Follow-up			Effect Size all
	SCD	SCI	All	SCD	SCI	All	
Life as a whole	5.0 (5.0–7.0)	7.0 (5.0–8.0)	6.0 (5.0–8.0)	7.0 (5.0–7.0)*	7.0 (5.0–8.0)	7.0. (5.0–8.0)*	0.17
Physical health	5.0 (3.0–7.0)	6.0 (4.0–8.0)	6.0 (4.0–8.0)	6.0 (4.8–8.0)*	7.0 (5.0–8.0)	6.0 (5.0–8.0)**	0.21
Psychological health	8.0 (5.0–8.0)	8.0 (6.0–9.0)	8.0 (5.8–9.0)	7.0 (5.8–8.3)	8.0 (6.0–9.0)	8.0 (6.0–9.0)	0.02
Social life	6.0 (3.5–8.0)	8.0 (5.0–9.5)	7.5 (5–9)	7.0 (5.0–8.0)*	8.0 (5.0–9.0)	7.0 (5.0–9.0)	0.10
QoL-BDS total	5.6 (4.5–7.0)	6.8 (5.5–8.3)	6.5 (4.9–7.8)	6.8 (5.4–7.8)**	7.3 (5.5–8.3)	7.0 (5.5–8.0)*	0.19
SCI-SCS total	11.0 (6.5–14.0)	12.0 (7.8–17.0)	11.0 (7.8–16)	10.5 (5.0–16.0)	10.0 (5.0–15)*	10.0 (5.0–15.3)	0.11
Mobility (%)							
No aids/assist	3.2	5.1	4.4	21.0	23.5	22.5**	0.58
Aids/assist	22.6	8.2	13.8	32.3	10.2	18.8	
Man wheelchair	33.9	42.9	39.4	30.6	45.9	40.0	
Power wheelchair	35.5	27.6	30.6	14.5	20.4	18.1	
Bed-ridden	4.8	16.3	11.9	1.6	0	0.6	

Wilcoxon signed-rank test between baseline and follow-up; *P < 0.05; **P < 0.01.

Table 3 Associations between QoL, mobility and secondary health conditions at baseline and follow-up (Spearman correlations, $N = 160$)[#].

QoL-BDS V2.0	SCI-SCS at Baseline			SCI-SCS at Follow-up		
	SCD	SCI	Total	SCD	SCI	Total
Life as a whole	−.34**	−.15	−.21**	−.59**	−.46**	−.53**
Physical health	−.32**	−.23*	−.23**	−.60**	−.47**	−.55**
Psychological health	−.41**	−.15	−.23**	−.35**	−.40**	−.41**
Social life	−.40**	−.22*	−.26**	−.42**	−.47**	−.49**
Total score	−.45**	−.26*	−.28**	−.62**	−.55**	−.60**
	Mobility restriction at baseline			Mobility restriction at follow-up		
Life as a whole	−.07	−.21*	−.14	−.08	−.46**	−.32**
Physical health	−.06	−.14	−.09	−.23	−.24*	−.22**
Psychological health	−.20	−.15	−.15	−.11	−.27**	−.20*
Social life	−.19	−.20	−.13	−.26*	−.38**	−.32**
Total score	−.18	−.27	−.19*	−.20	−.41**	−.32**

[#]Spearman correlation coefficients.
*P < 0.05; **P < 0.01.

Hypothesis 2, associations between mobility restrictions and SHCs and QoL

Spearman correlations between QoL-BDS V2.0, mobility restrictions and SCI-SCS scores are displayed in Table 3. Overall, there were only limited differences in the strength of these correlations across the items of the QoL-BDS V2.0. In the total sample, the QoL-BDS V2.0 total scores showed significant correlations with both SCI-SCS (−.28 at baseline and −.60 at follow-up) and mobility restrictions (−.19 at baseline and −.32 at follow-up), confirming hypothesis 2. However, these associations were substantially stronger at follow-up compared to baseline and were substantially stronger in the SCD group compared to the SCI group at baseline.

Hypothesis 3, associations between change scores

Spearman correlations between changes in scores on the QoL-BDS V2.0 and the mobility and SCI-SCS

Table 4 Associations between changes in QoL and changes in secondary health conditions and mobility ($N = 160$).

	Change in SHCs			Change in mobility		
	SCD	SCI	All	SCD	SCI	All
Change life as a whole	−.14	−.02	−.05	.19	.13	.15
Change physical health	−.17	−.18	−.16*	.28*	−.12	.03
Change psychological heath	−.13	−.08	−.10	.16	.23*	.20*
Change social life	−.08	−.17	−.11	.14	.26*	.21*
Change QoL-BDS total score	−.24	−.15	−.15	.30*	.14	.20*

Spearman correlations, *P < 0.05; **P < 0.01.

scores are displayed in Table 4. Only the increase in 'physical health', was significantly associated with decrease in SCI-SCS scores. In the subgroups of participants with SCD and SCI, no significant associations were found. In the total sample, change in mobility was significantly associated with change in 'psychological health', 'social life' and the total QoL-BDS V2.0 score. Change in mobility was associated with change in 'physical health' and the total score in the subgroup of participants with SCD, and with change in 'psychological health' and 'social life' in the subgroup of participants with SCI.

Finally, comparison of the subgroups that did and did not improve in mobility and SHCs revealed that those who reported less impact from SHCs and greater mobility at follow-up compared to baseline showed significant improvements in 'social life' and the total QoL-BDS score, whereas those who did not show improvement in SHCs or mobility did not show change on any QoL-BDS V2.0 item. However, such differences were not seen with respect to the 'life as a whole', 'physical health' and 'psychological heath' items (Table 5).

Discussion

The results of this study demonstrated responsiveness of the total QoL-BDS V2.0 scale as all but one hypothesis were confirmed for the total score. However, the results were more variable with respect to the individual items comprising this scale. QoL-BDS V2.0 item scores were higher at follow-up compared to baseline for satisfaction with 'life as a whole' and 'physical health', but not for 'mental health' and 'social life'. Moreover, increases in QoL item scores were stronger in the SCD subgroup compared to the SCI subgroup, in

Table 5   Median (IQR) changes in QoL among participants who showed improvements in mobility and SHCs at follow-up compared to baseline and participants who did not show such improvements (*N* = 160).

	SHCs		Mobility		
	Improved	Not improved	Improved	Not improved	All
Change in life as a whole	.5 (−1–2)	0 (−1–2)	1 (0–2)	0 (−1–2)	0 (−1–2)
Change in physical health	1 (−.5–2)	0 (−2–2)	0 (−1–2)	0 (−1–2)	0 (−1–2)
Change in psychological heath	0 (−1–1)	0 (−2–1)	0 (−1–1)	0 (−1–1)	0 (−1–1)
Change in social life	0 (−1–3)*a	0 (−2–1)	1.5 (−.3 - 5)**b	0 (−2–1)	0 (−2–2)
Change in total QoL-BDS score	.8 (−.5–1.8)*c	0 (−1.3–1.3)	1 (0–1.8)*d	.3 (−1–1.5)	.3 (−.8–1.5)

Mann-Whitney U Test, *P < .05; **P < 0.01.
Effect sizes a: 0.18; b: 0.23; c: 0,17; d:0.17.

which no significant changes were found. Hypothesis 2 was largely confirmed with respect to SHCs, but largely rejected for mobility restrictions. Hypothesis 3 was partly confirmed with respect to change in mobility, but largely rejected with respect to change in SHCs.

Levels of QoL

This study is one of the few to measure QoL in an inpatient rehabilitation setting and the first to use the QoL-BDS V2.0. Therefore, QoL results can only be compared to data collected with the three single items of the original QoL-BDS. Median baseline scores found in this study ('life as a whole' 6; 'physical health' 6 and 'psychological health' 8) were somewhat higher compared to mean scores at admission (5.2, 4.3 and 6.3, respectively) at a similar time since onset of 36 days (SD 6.7) in a Swiss study (17). A study performed in India showed very low median baseline QoL-BDS scores (4, 2 and 5, respectively) among rehabilitation inpatients, but this sample consisted of much younger (mean age 27 years) and more severely injured participants (93% complete lesion) (26).

QoL-BDS scores at follow-up (life as a whole 7; physical health 6 and psychological health 8) in our study were similar to scores found in various community samples, with 7, 6 and 7, respectively in an international study (26), and mean scores of 6.5, 5.4 and 6.7 respectively, in a Danish study (27).

Change in levels of QoL (hypothesis 1)

Improvements in QoL between baseline and follow-up were significant for 'life as a whole', 'physical health' and the total QoL-BDS score, but these changes were small. Increase in QoL scores was larger in the SCD group compared to the SCI group, caused by lower baseline scores but similar follow-up scores in the SCD group compared to the SCI group, particularly in the Australian sample. The reason for these lower baseline scores is unclear. It is unlikely that differences in age, sex and severity play a role, since the difference in QoL between the two groups is only present at baseline, not at follow-up. The only other available study to report change in QoL-BDS scores early after onset of SCI showed somewhat lower baseline scores and greater increases in mean scores of all three QoL-BDS items (mean change in 'life as a whole' 1.2, 'physical health' 1.6, 'psychological health' 0.6) between admission and discharge from first inpatient rehabilitation, a period of mean 19.7 weeks (17). Mean time since onset at admission was shorter in that Swiss study, with 36 (SD 6.7) days compared to the mean 8.5 (SD 7.8) weeks at baseline in this study. Further, the baseline questionnaire of this study was administered around the end of the inpatient rehabilitation program in the most sites in this study, limiting the potential to reveal further improvement in mobility, SHCs and consequently QoL.

Associations between mobility restrictions, SHCs and QoL (hypothesis 2)

The analysis of correlations between the QoL-BDS scores and the reference measures revealed several interesting findings. First, the association between the SCI-SCS and the 'physical health' item was strong (−.55) at follow-up, stronger than the associations between the SCI-SCS and 'physical health' in Scandinavian (−.33) and Australian (−.37) and community samples (13, 26). These other studies included individuals with much longer duration (median/mean 15–17 years) of SCI/SCD, suggesting that the duration of SCI/SCD could moderate the association between SHCs and QoL. Psychological adaptation could be the mechanism behind the progressive disconnection between symptoms and physical or mental health found in previous research (11, 28).

Associations between change scores (hypothesis 3)

As far as we know, this is the first study to investigate associations between change in SHCs and change of QoL among people with recent SCI. One previous

study reported significant associations between change in mobility (wheelchair to ambulation or the reverse) with life satisfaction 1 year post-discharge, but did not analyze change of life satisfaction (29). Therefore, the results of this study need confirmation with future research. Although several significant associations between these change scores were found, overall, these associations were weaker than expected. Unreliability of the QoL-BDS is unlikely to be the problem, because other studies showed its reproducibility and longitudinal measurement invariance (17, 19). Several aspects may have contributed to these results. First, associations between the QoL-BDS and the reference scores were substantially weaker at baseline compared to follow-up. At baseline, participants either may have experienced their mobility restrictions and SHCs as temporary inconveniences and thereby less impactful on their QoL, they may not have realized the full impact of their mobility restrictions and SHCs on their future life in the first weeks after onset of SCI, or their stay in the protected inpatient setting (well-adapted, help available) could have played a role. Also, the longitudinal correlations between the baseline and follow-up scores of mobility restrictions and SHCs were somewhat weak. The relatively long time of 12 months between baseline and follow-up, the change of setting, from inpatient to community, and all other changes participants may have experienced in their first year post-onset of SCI might all have contributed to the weakness of the associations between QoL with mobility and SHCs between baseline and follow-up.

QoL-BDS V2.0 items versus total score

The QoL-BDS was developed as a checklist comprising 3 single items (16). The use of a total score was suggested later, supported by strong inter-item correlations and good Cronbach alphas (22, 26). The use of single items is based on the expectation of diverging correlations with reference measures, for example that the 'physical health' item will show stronger correlations with the SCI-SCS compared to the other items. However, this study did not show such differences clearly, and the total score consistently showed the strongest correlations with the SCI-SCS and mobility restrictions. This lack of differences probably is due to the strong inter-correlations between the QoL-BDS items and the higher reproducibility of the total score (19). The previous QoL-BDS study also showed that correlations between the single items with various reference measures were similar to the correlations between the total score and these reference measures (26). This study therefore supports the use of the total QoL-BDS V2.0 score in research and clinical practice.

Limitations

A few limitations of this study should be noted. First, due to dropout and other reasons, only 160 of the intended 240 participants were available for the current analyses, limiting the power of the study. Therefore, we refrained from additional country-specific or site-specific analyses. For the same reason, we did not use advanced statistical models, such as random coefficient models to correct for country or site effects, or latent-variable models to correct for possible response-shift effects, as advised in a previous study (17). That study nevertheless showed a high level of longitudinal measurement invariance of the QoL-BDS.

Second, a baseline measurement earlier after onset could have shown more change in QoL between baseline and follow-up. Feasibility issues however prevented an earlier baseline measurement.

Third, a single item on the use of mobility devices was used to measure mobility restrictions. Using a validated and more comprehensive measure of mobility or functional status, such as the self-report SCIM could have enriched the analyses.

Fourth, only self-report data were used in this study. Future research could replicate this study using clinician-administered versions of mobility and the SCI-SCS.

Fifth, We did not perform regression analyses to correct for possible confounders of the associations between mobility and SHCs and QoL since we primarily aimed to examine the sensitivity of the QoL-BDS to reflect changes in mobility and secondary health conditions (SHCs), not to examine the independent association or unique explained variance between these concepts and scores.

Sixth, inclusion of a well-validated measure of QoL to compare changes in BoL-BDS scores to would have strengthened our study design. Unfortunately, as far as we know there are no QoL measures that have been validated for use in an inpatient SCI rehabilitation setting.

Finally, although data were collected in four countries in different parts of the world, there was no representation of low-income or lower–middle income countries and countries from Africa, the Middle-East or Asia. Research on the psychometric characteristics of the QoL-BDS from such countries is becoming available (30), but further research is necessary to confirm or

reject the generalizability of the results of this study to other parts of the world.

Conclusion

The associations between mobility and the impact of SHCs with QoL found in this study provide partial support for the sensitivity of the QoL-BDS V2.0 as a measure of QoL among individuals with SCI/SCD that is quick and easy to administer in clinical settings and self-report surveys. Future studies on its ability to document changes across time require settings in which substantial change in the reference measures is expected. Inpatient rehabilitation with measurements at admission and discharge could provide such a setting (17), or controlled trials of promising interventions (14).

Disclaimer statements

Contributors None.

Conflicts of interest Authors have no conflict of interests to declare.

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