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Psychosocial aspects of health-related quality of life and the association with patient-reported bladder symptoms and satisfaction after spinal cord injury

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Abstract

Study design Prospective, multi-centered, observational.

Objectives To characterize the relationship between psychosocial aspects of health-related quality of life (HRQoL) and patient-reported bladder outcomes.

Setting Multi-institutional sites in the United States, cohort drawn from North America.

Methods We performed a cross-sectional analysis of data collected as part of the multicenter, prospective Neurogenic Bladder Research Group Spinal Cord Injury (SCI) Registry. Outcomes were: *Neurogenic Bladder Symptom Score* (*NBSS*), *Neurogenic Bladder Symptom Score Satisfaction* (*NBSS-Satisfaction*), and *SCI-QoL Bladder Management Difficulties* (*SCI-QoL Difficulties*). Adjusted multiple linear regression models were used with variables including demographic, injury characteristics, and the following psychosocial HRQoL measures; *SCI-QoL Pain Interference (Pain), SCI-QoL Independence*, and *SCI-QoL Positive Affect and Well-being (Positive Affect)*. Psychosocial variables were sub-divided by tertiles for the analysis.

Results There were 1479 participants, 57% had paraplegia, 60% were men, and 51% managed their bladder with clean intermittent catheterization. On multivariate analysis, higher tertiles of *SCI-QoL Pain* were associated with worse bladder symptoms, satisfaction, and bladder management difficulties; upper tertile *SCI-QoL Pain* (*NBSS* 3.8, $p < 0.001$; *NBSS-satisfaction* 0.6, $p < 0.001$; *SCI-QoL Difficulties* 2.4, $p < 0.001$). In contrast, upper tertiles of *SCI-QoL Independence* and *SCI-QoL Positive Affect* were associated with improved bladder-related outcomes; upper tertile *SCI-QoL Independence* (*NBSS* −2.3, $p = 0.03$; *NBSS-satisfaction* −0.4, $p < 0.001$) and upper tertile *SCI-QoL Positive Affect* (*NBSS* −2.8, $p < 0.001$; *NBSS-satisfaction* −0.7, $p < 0.001$; *SCI-QoL Difficulties* −0.7, $p < 0.001$).

Conclusions In individuals with SCI, there is an association between psychosocial HRQoL and bladder-related QoL outcomes. Clinician awareness of this relationship can provide insight into optimizing long-term management after SCI.

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Introduction

In the general U.S. population, ~282,000 people are living with spinal cord injury (SCI) [1]. The estimated annual incidence of SCI is about 17,000 cases, with trauma being the most common cause amongst all age groups [1]. The resulting neurological injury presents a wide range of challenges, with considerable long-term disability. Some studies on individuals with SCI have identified loss of normal bladder and bowel function as a significant source of both physical morbidities, as well as psychologic stress [2–4]. Furthermore, several studies have shown an association between psychosocial aspects of health-related quality of life (HRQoL) (such as pain interference, positive affect and well-being, independence) and overall quality of life (QoL) following SCI [5–9].

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In our previous work, we have established relationships between demographic factors, bladder management method, injury characteristics, SCI complications and bladder-related symptoms and satisfaction [10–13]; however, very little is known about how psychosocial aspects of HRQoL influence bladder-related QoL. Studies have established relationships between psychosocial aspects of HRQoL factors and general QoL outcomes following SCI and how psychosocial factors such as depression, chronic pain, and independence all can influence the way people perceive biologic function [5, 7, 9]. A good example of this is the association between post-traumatic stress disorder (PTSD) and lower urinary tract symptoms in veterans [14].

In this study, our objective was to examine the relationship between psychosocial aspects of HRQoL and bladder-related QoL using validated neurogenic bladder patient-reported outcome measures and measures of pain, independence, and well-being. Understanding how psychosocial aspects of HRQoL are associated with bladder symptoms and satisfaction is important and may need to be considered in future studies of how to improve bladder function and satisfaction. We hypothesized that psychosocial aspects of HRQoL factors would demonstrate significant associations with bladder symptoms and satisfaction in individuals with SCI.

Methods

We used the Neurogenic Bladder Research Group (NBRG) SCI Registry to conduct a cross-sectional study of participants. The NBRG SCI Registry (https://www.NBRG.org) was a multicenter, prospective, observational study conducted through the Universities of Michigan, Minnesota and Utah, which measured neurogenic bladder-related QoL after SCI. The study was conducted in multiple settings within each of these sites, including but not limited to rehabilitation hospitals, nursing facilities, physical medicine and rehabilitation clinics and urology clinics. Participants were recruited throughout the United States and Canada. Detailed information regarding study protocol, recruitment methods, duration, and study aims have previously been published [15]. Eligibility requirements included: age ≥ 18 years, English speaking, and a diagnosis of acquired SCI (i.e., traumatic injury, spinal cord bleed/abscess or stroke, spinal cord tumor without active malignancy, iatrogenic causes, transverse myelitis and miscellaneous disorders such as cauda equina syndrome). Participants with congenital conditions (e.g., cerebral palsy, myelomeningocele) or progressive SCI (e.g., multiple sclerosis, neurologic disorders) were excluded from the study. Participants were enrolled in the study over a span of 1.5 years, ending on June 30th, 2017. Enrollment interview, with study coordinators, included questions that assessed participant's baseline demographics, medical and surgical history, injury characteristics, bladder management over time, and complications. Participants then answered a panel of questionnaires that included information about bladder symptoms, satisfaction, bowel dysfunction, chronic pain, mobility, independence, depression, and satisfaction with aspects of social participation.

Primary outcome measures

i. *Neurogenic Bladder Symptom Score (NBSS)*: the *NBSS* is a tool developed for people with neurogenic bladder and SCI. Its 22 questions assess urinary symptoms including voiding, incontinence and storage as well as urinary complications. The scores range from 0 to 74 with lower scores indicating less symptoms [11, 16, 17].

ii. *Neurogenic Bladder Symptom Score – Satisfaction (NBSS-satisfaction)*: this is the separately scored final question of the *NBSS* (range 0–4) which assess satisfaction with urinary function. It is phrased - *"If you had to live the rest of your life with the way your bladder (or urinary reservoir) currently works, how would you feel?"* (0-pleased, 1-mostly satisfied, 2-equally satisfied and unsatisfied/mixed, 3-mostly unsatisfied, 4-unhappy) [11, 16, 17].

iii. *Spinal Cord Injury Quality of Life Bladder Management Difficulties (SCI-QoL Difficulties)*: this is one item bank from SCI-QoL measurement system. It specifically assesses the ability to carry out a bladder program, as well as concerns about incontinence and impact on daily life. The *SCI-QoL Difficulties* uses computer adaptive testing and is scored from 0 to 100 with a median of 50. Similar to the *NBSS*, lower scores indicate less bladder difficulties [18].

Analysis variables

Participant variables that were analyzed included: (1) demographic variables: age, gender, obesity (body mass index (BMI) ≥ 30 kg/m^2), education level (bachelor's degree or higher), (2) injury characteristics: level of injury (tetraplegia i.e., cervical level 1–8 vs. paraplegia i.e., thoracic level 1 and below, including sacral levels and cauda equina), years since injury, primary bladder management (clean intermittent catheterization [CIC], chronic indwelling catheter [IDC, Foley catheter or suprapubic cystotomy], surgery [conduit urinary diversions, continent catheterizable pouch, augmentation cystoplasty with or without catheterizable channel], or spontaneous voiding [credé voiding, condom catheter, volitional voiding into a toilet, leaking into diapers]), number of self-reported urinary tract

infections (UTI) in the last year (categorical: 0, 1–3, 4 or more), severe bowel dysfunction (*Neurogenic Bowel Dysfunction (NBD) Score* > 14) [15], and (3) measures of psychosocial aspects of HRQoL: *SCI-QoL Pain Interference (Pain)*, *SCI-QoL Independence*, and *SCI-QoL Positive Affect and Well-being (Positive Affect)*.

Measure of psychosocial aspects of HRQoL

For measures of psychosocial aspects of HRQoL, we considered nine validated measures of psychosocial and physical experience after SCI. Many of these measurement tools are from the SCI-QoL measurement system and have similar methodology to the *SCI-QoL Difficulties* (one of the primary outcome measures). They use computer adaptive testing and are calibrated to a mean of 50. The nine measurement tools were: *SCI-QoL Fine Motor*, *SCI-QoL Independence*, *SCI-QoL Basic Mobility*, *SCI-QoL Pain*, *SCI-QoL Positive Affect*, *SCI-QoL Self-Care*, and SCI-*QoL Satisfaction with Social Roles and Activities*, *Short Form Survey (SF-12) Mental*, and the *SF-12 Physical*. The SF-12 is an instrument made up of 12 questions selected from the Medical Outcomes Study (MOS) 36-item Short-Form Survey (SF-36) [19]. The 12 questions were combined, scored and weighted to create two scales that assess mental and physical functioning and overall health-related QoL [20]. Since some of these psychosocial aspects of HRQoL measure similar concepts and there was a recognized likelihood of correlations between some of these factors, to minimize correlations when selecting measures for the study, a Pearson correlation matrix was created between each of these factors. We considered pairs of factors with a significant correlation with a magnitude >0.5 to have a relevant correlation. After review of the correlation matrix, we selected those factors with the least correlation that had face value to investigators in measuring concepts we felt were important within the psychosocial domain of experience. Complete data for the correlation matrix can be found in Table 1.

The three measurement tools of the psychosocial aspects of HRQoL with the least correlation with one another were *SCI-QoL Pain interference*, which assesses self-reported consequences of pain on everyday life [21, 22], *SCI-QoL Independence*, which assesses perceptions of personal independence, ability to communicate needs with others and a sense of control over one's life [22–24], and *SCI-QoL Positive Affect*, which assesses aspects that relate to a sense of well-being, life satisfaction and sense of purpose [22, 25, 26].

Statistical analysis

Some participants had incomplete data and were not included in the analysis. There were 1358 participants with non-missing values for all our adjustment variables for NBSS-total and NBSS-satisfaction and 1355 participants for SCI-QoL Difficulties. All statistical analysis was performed using SAS Software, Version 9.4 (SAS Institute, Cary, NC. The associations between psychosocial aspects of HRQoL (*SCI-QoL Pain*, *SCI-QoL Independence* and *SCI-QoL Positive Affect*) and primary outcomes (*NBSS-total*, *NBSS-satisfaction* and *SCI-QoL Difficulties*) were assessed using multiple linear regression models. Measures of the psychosocial aspects of HRQoL were separated into tertiles to better illustrate associated changes with bladder-related outcome measures. For continuous variables such as age and years since injury, the values were scaled by a factor of 10, thus changes in outcome measures represent changes associated with 10 years of change rather than 1 year of change for those variables. Continuous variables were presented as mean ± standard deviation (s.d.), and categorical variables presented as frequency (percent). Using the central limit theorem, we assumed that the sample means were approximately normally distributed.

Collinearity between all variables and psychosocial aspects of HRQoL factors were assessed using the variance inflation factor (VIF) to determine whether there was any significant collinearity between the variables selected for inclusion in the multivariate regression model. A VIF value <2.5 was used as a threshold to indicate no significant collinearity between the variables in the model. Separate multiple linear regression models were used for all three measures of psychosocial aspects of HRQoL to observe how each measure was associated with bladder-related outcome measures, when controlling for additional participant characteristics (primary bladder management, level of injury, age, sex, years since injury, BMI, number of UTIs, severe bowel dysfunction and education level). In each model, the continuous scores for the measures of psychosocial aspects of HRQoL were replaced by tertiles (lower, middle and upper) and the Bonferroni correction was applied to the p values to adjust for multiple testing. Statistical significance was set at $p < 0.05$, representing 95% confidence level.

Results

Participant demographic and clinical characteristics

A total of 1479 participants were enrolled in the study; most were male (60.4%) and had paraplegia (57.0%). The mean age of participants was 44.8 ± 13.1 years and the mean time since injury was 14.6 ± 11.8 years. The most common primary bladder management method used was CIC (51.0%), followed by IDC (18.3%). Detailed baseline demographic and clinical characteristics are shown in Table 2.

Table 1 Correlation matrix of participants' psychosocial aspects of health-related quality of life.

	SCI-QoL fine motor	SCI-QoL independence	SCI-QoL basic mobility	SCI-QoL pain interference	SCI-QoL positive affect and well-being	SCI-QoL SF-12 mental	SCI-QoL SF-12 physical	SCI-QoL self-care	SCI-QoL satisfaction with social roles and activities
SCI-QoL fine motor	1	0.65	0.77	-0.01	0.14	0.01	0.14	0.90	0.36
SCI-QoL independence	0.65	1	0.70	-0.20	0.34	0.20	0.36	0.72	0.58
SCI-QoL basic mobility	0.77	0.70	1	-0.03	0.16	0.02	0.15	0.84	0.36
SCI-QoL pain interference	-0.01	-0.20	-0.03	1	-0.33	-0.36	-0.57	-0.04	-0.40
SCI-QoL positive affect and well-being	0.14	0.34	0.16	-0.33	1	0.58	0.28	0.17	0.65
SF-12 mental	0.01	0.20	0.02	-0.36	0.58	1	0.01	0.03	0.46
SF-12 physical	0.14	0.36	0.15	-0.57	0.28	0.01	1	0.17	0.47
SCI-QoL self-care	0.90	0.72	0.84	-0.04	0.17	0.03	0.17	1	0.39
SCI-QoL satisfaction with social roles and activities	0.36	0.58	0.36	-0.40	0.65	0.46	0.47	0.39	1

SCI-QoL spinal cord injury measurement system, *SF* short form.

Table 2 Baseline demographic and clinical characteristics.

Demographic	
Age in years	
Mean (s.d.)	44.8 (13.1)
Gender	
Male, *n* (%)	894 (60.4)
Education level	
≥Bachelor's degree, *n* (%)	605 (40.9)
Clinical characteristics	
Injury level	
Paraplegia, *n* (%)	843 (57.0)
Years since injury	
Mean (s.d.)	14.6 (11.8)
Primary bladder management	
Intermittent catheterization (CIC), *n* (%)	754 (51.0)
Chronic Indwelling catheter (IDC), *n* (%)	271 (18.3)
Surgery, *n* (%)	195 (13.2)
Spontaneous voiding, *n* (%)	259 (17.5)
BMI	
≥ 30 kg/m2, *n* (%)	356 (24.1)
Number of UTIs	
0, *n* (%)	388 (26.2)
1–3, *n* (%)	677 (45.8)
≥4, *n* (%)	413 (27.9)
Severe bowel dysfunction i.e., NBD > 14, *n* (%)	570 (38.5)
Psychosocial factors	
SCI-QoL independence	
Lower tertile (24.7–46.2), *n* (%)	491 (33.2)
Middle tertile (46.3–55.7), *n* (%)	486 (32.9)
Upper tertile (55.8–68.9), *n* (%)	493 (33.3)
SCI-QoL pain	
Lower tertile (38.7–53.0), *n* (%)	500 (33.8)
Middle tertile (53.1–59.6), *n* (%)	484 (32.7)
Upper tertile (59.8–82.5), *n* (%)	491 (33.2)
SCI-QoL positive affect	
Lower tertile (29.8–48.6), *n* (%)	481 (32.5)
Middle tertile (48.7–55.2), *n* (%)	498 (33.7)
Upper tertile (55.3–73.1), *n* (%)	489 (33.1)
Primary outcomes	
NBSS	
Mean (s.d.)	24.2 (10.8)
Median (IQR)	23.0 (16.0, 32.0)
NBSS-satisfaction	
Mean (s.d.)	2.1 (1.2)
Median (IQR)	2.0 (1.0, 3.0)
SCI-QoL difficulties	
Mean (s.d.)	58.1 (7.7)
Median (IQR)	58.8 (54.2, 62.9)

Missing values: BMI = 11; Number of UTIs = 1; Severe bowel dysfunction = 106; Education = 1; SCI-QoL Independence = 9; SCI-QoL Pain Interference = 4; SCI-QoL Positive Affect and Well-being = 11.

IQR interquartile range, *NBSS* neurogenic bladder symptoms score.

Psychosocial aspects of HRQoL and bladder-related QoL

In the unadjusted analysis, there was no defined relationship between *SCI-QoL Independence* and bladder-related outcomes. However, both *SCI-QoL Pain and SCI-QoL Positive*

Table 3 Unadjusted comparison of SCI-QoL independence, SCI-QoL pain interference and SCI-QoL positive affect and well-being tertiles.

	NBSS total (N = 1358)		NBSS-satisfaction (N = 1358)		SCI-QoL bladder management (N = 1355)	
	Coefficients (95% CI)	p value	Coefficients (95% CI)	p value	Coefficients (95% CI)	p value
Intercept (lower tertile)	**23.6 (22.7, 24.5)**	**<0.001**	**2.2 (2.1, 2.3)**	**<0.001**	**57.8 (57.2, 58.5)**	**<0.001**
SCI-QoL independence						
Middle tertile (46.3–55.7)	2.1 (0.7, 3.4)	0.002	−0.1 (−0.3, 0.0)	0.097	1.1 (0.1, 2.1)	0.025
Upper tertile (55.8–68.9)	−0.4 (−1.7, 1.0)	0.595	−0.3 (−0.5, −0.2)	<0.001	−0.4 (−1.3, 0.6)	0.43
Intercept (lower tertile)	**21.5 (20.6, 22.4)**	**<0.001**	**1.8 (1.7, 1.9)**	**<0.001**	**56.3 (55.6, 57.0)**	**<0.001**
SCI-QoL pain						
Middle tertile (53.1–59.6)	2.2 (0.8, 3.5)	0.001	0.3 (0.2, 0.4)	<0.001	1.8 (0.9, 2.8)	<0.001
Upper tertile (59.8–82.5)	5.9 (4.6, 7.2)	<0.001	0.7 (0.6, 0.9)	<0.001	3.5 (2.6, 4.5)	<0.001
Intercept (lower tertile)	**26.1 (25.2, 27.1)**	**<0.001**	**2.4 (2.3, 2.5)**	**<0.001**	**59.4 (58.7, 60.1)**	**<0.001**
SCI-QoL positive affect and well-being						
Middle tertile (48.7–55.2)	−2.0 (−3.4, −0.7)	0.003	−0.3 (−0.4, −0.1)	<0.001	−1.3 (−2.2, −0.3)	0.009
Upper tertile (55.3–73.1)	−3.8 (−5.2, −2.5)	<0.001	−0.7 (−0.9, −0.6)	<0.001	−2.8 (−3.7, −1.8)	<0.001
Intercept (tetraplegia)	**21.7 (20.9, 22.5)**	**<0.001**	**2.0 (1.9, 2.1)**	**<0.001**	**56.5 (55.9, 57.1)**	**<0.001**
Diagnosis						
Paraplegia	4.3 (3.2, 5.4)	<0.001	0.2 (0.1, 0.3)	0.002	2.8 (2.0, 3.6)	<0.001

The bold entries indicate the values that represent the intercept for the analysis.

Affect had significant association with all bladder-related outcome measures. As tertiles of *SCI-QoL Pain* increased, *NBSS*, *NBSS-satisfaction*, and *SCI-QoL Difficulties* worsened (increased, $p < 0.001$), indicating worse bladder-related symptoms and QoL. The reverse was observed with tertiles of *SCI-QoL Positive Affect*, where an increase in tertile was associated with better bladder-related symptoms and QoL i.e., lower *NBSS* score, *NBSS-satisfaction* score and *SCI-QoL Difficulties* score ($p < 0.001$). Results are shown in Table 3.

In the multivariable analysis, after adjusting for the analysis variables, *SCI-QoL Pain* and *SCI-QoL Positive Affect* maintained the same effect as seen in the unadjusted analysis on all three bladder-related outcome measures. The upper tertile of *SCI-QoL Pain* was associated with higher *NBSS* score (Beta 3.8 95% CI 2.5, 5.0, $p < 0.001$), *NBSS-satisfaction* score (Beta 0.6 95% CI 0.4, 0.7, $p < 0.001$) and *SCI-QoL Difficulties* score (Beta 2.4 95% CI 1.5, 3.4, $p < 0.001$), while the upper tertile of *SCI-QoL Positive Affect* was associated with lower *NBSS* score (Beta −2.8 95% CI −4.1, −1.6, $p < 0.001$), *NBSS-satisfaction* score (−0.7, 95% CI −0.8, −0.5, $p < 0.001$) and *SCI-QoL Difficulties* score (Beta −0.7, 95% CI −0.8, −0.5, $p < 0.001$). The upper tertile of *SCI-QoL Independence* was associated with lower *NBSS* score (Beta −2.3, 95% CI −3.7, −0.8, $p = 0.03$) and *NBSS-satisfaction* (Beta −0.4, 95% CI −0.6, −0.2, $p < 0.001$). The VIF measures were <2.5 indicating low collinearity in these analyses. These results are detailed in Table 4. Complete multivariable analysis for all *SCI-QoL independence* and *SCI-QoL positive affect and well-being* are shown in Tables 5 and 6.

Discussion

In this study, we assessed the impact of pain, independence, and well-being on patient-reported bladder symptoms and satisfaction. We adjusted for demographic, and injury specific factors that we know are associated with differences in patient-reported bladder outcomes [11] and still found strong associations with these psychosocial aspects of HRQoL and how individuals with SCI perceive their bladder symptoms and satisfaction. Pain was associated with worse bladder symptoms and satisfaction, while greater independence and a better positive affect and well-being were associated with less bladder symptoms and greater satisfaction with bladder function. This is an important observation given that objective symptoms may be perceived very differently by two individuals depending upon their overall mental and physical state.

Our study findings reveal that the presence or absence of pain is associated with bladder symptoms (*NBSS*) and patient satisfaction (*NBSS-Satisfaction* and *SCI-QoL*

Table 4 Multivariable comparisons reflecting the associations of SCI-QoL pain with outcomes.

	NBSS (N = 1358)		NBSS-satisfaction (N = 1358)		SCI QoL bladder management difficulties (N = 1355)	
	Coefficient (95% CI)	p value[a]	Coefficient (95% CI)	p value[a]	Coefficient (95% CI)	p value[a]
Intercept	**25.0 (22.6, 27.4)**	**<0.001**	**2.2 (1.9, 2.5)**	**<0.001**	**58.6 (56.8, 60.5)**	**<0.001**
SCI-QoL pain						
Middle tertile (53.1–59.6)	1.5 (0.3, 2.7)	0.190	0.2 (0.1, 0.4)	0.020	1.4 (0.5, 2.3)	0.040
Upper tertile (59.8–82.5)	3.8 (2.5, 5.0)	<0.001	0.6 (0.4, 0.7)	<0.001	2.4 (1.5, 3.4)	<0.001
Primary bladder management						
Chronic indwelling catheter	−7.1 (−8.5, −5.6)	<0.001	−0.1 (−0.3, 0.0)	1.000	−2.7 (−3.8, −1.6)	<0.001
Surgery	−3.9 (−5.5, −2.2)	<0.001	−0.7 (−0.9, −0.5)	<0.001	−3.3 (−4.5, −2.0)	<0.001
Spontaneous voiding	4.2 (2.8, 5.6)	<0.001	0.07 (−0.10, 0.23)	1.000	1.4 (0.4, 2.5)	0.131
Diagnosis						
Paraplegia	2.2 (1.2, 3.3)	<0.001	0.08 (−0.04, 0.21)	1.000	1.8 (1.0, 2.6)	<0.001
Age 10 years[b]	−0.8 (−1.2, −0.4)	0.003	−0.06 (−0.11, 0.01)	0.297	−0.5 (−0.8, −0.2)	0.028
Gender						
Male	−4.1 (−5.1, −3.0)	<0.001	−0.2 (−0.3, −0.1)	0.030	−2.3 (−3.1, −1.5)	<0.001
Years since SCI[b]	−0.3 (−0.8, 0.2)	1.000	−0.2 (−0.3, −0.1)	<0.001	−0.5 (−0.8, −0.1)	0.226
BMI						
≥ 30 kg/m^2	1.9 (0.7, 3.0)	0.030	0.02 (−0.12, 0.16)	1.000	1.3 (0.4, 2.2)	0.096
Number of UTIs						
1–3	2.9 (1.7, 4.1)	<0.001	0.2 (0.1, 0.3)	0.098	1.2 (0.3, 2.1)	0.169
4 or more	6.5 (5.1, 7.9)	<0.001	0.6 (0.4, 0.7)	<0.001	2.8 (1.7, 3.8)	<0.001
Severe bowel dysfunction						
NBD > 14	1.1 (0.1, 2.1)	0.500	0.2 (0.0, 0.3)	0.107	1.1 (0.4, 1.9)	0.063
Education						
Bachelor's degree or higher	−0.9 (−1.9, 0.1)	1.000	0.1 (0.0, 0.2)	0.731	0.1 (−0.7, 0.9)	1.000

The bold entries indicate the values that represent the intercept for the analysis.

SCI spinal cord injury, *BMI* body mass index, *UTI* urinary tract infection.

[a]p values adjusted for multiple testing using the Bonferroni correction.

[b]Age, years since injury were scaled by dividing by 10, thus 10 years becomes 1 year of change.

Difficulties). Individuals with lower pain interference had fewer bladder symptoms and felt more satisfied with their bladder function and management, even after controlling for patient and injury-related variables such as age, gender, time since injury and level of injury. In individuals with SCI, chronic pain can interfere with day-to-day life, which can affect overall satisfaction. This is consistent with previously published data that showed a negative relationship between pain and QoL amongst individuals with SCI [27, 28]. In addition, increased pain interference has been shown to be associated with having a greater number of other health conditions such as PTSD and depression in individuals with SCI [6, 29], which could also influence a person's perception of their bladder symptoms. It is unclear how or why pain would have significant impact on bladder symptoms, as intuitively one would expect bladder symptoms to be related directly to actual bladder function and be a more objective measure. The results could be from a confounding factor we have not accounted for or that pain actually worsens participant's bladder function.

We also found that having better positive affect and well-being is associated with fewer bladder symptoms and improved overall satisfaction with bladder function. Although this has not been measured in relation to bladder-related QoL, others have shown key associations between these themes and general QoL in individuals with SCI [7]. In the systemic review conducted by van Leeuwen, Kraaijeveld, Lindeman and Post, a person's total perceived degree of control in life and positive feelings of purpose and self-worth were the most consistent determinants of QoL after SCI [30]. In addition, evidence from other studies on individuals with SCI have also revealed that, self-efficacy is a significant determinant of resilience [31, 32]. The explanation for the observed association between positive affect and well-being and bladder-related outcomes is not clear; however, perhaps those individuals with a very positive outlook are not bothered by their bladder symptoms and minimize their actual objective symptoms and the perception of their bladder's impact on their life.

Interestingly, our data indicates that higher independence scores are significantly associated with better bladder satisfaction but have no effect on bladder symptoms and management difficulties. This outcome was unexpected; however, it may reflect the complex interaction between

Table 5 Multivariable comparisons reflecting the associations of SCI-QoL Independence with outcomes.

	NBSS (N = 1358)		NBSS-satisfaction (N = 1358)		SCI QoL bladder management difficulties (N = 1355)	
	Coefficient (95% CI)	p value[a]	Coefficients (95% CI)	p value[a]	Coefficients (95% CI)	p value[a]
Intercept	**27.0 (24.5, 29.6)**	**<0.001**	**2.6 (2.3, 2.9)**	**<0.001**	**60.0 (58.1, 61.9)**	**<0.001**
SCI-QoL independence						
Middle tertile (46.3–55.7)	0.6 (−0.7, 1.9)	1.000	−0.1 (−0.3, 0.0)	1.000)	0.4 (−0.5, 1.4)	1.000
Upper tertile (55.8–68.9)	−2.3 (−3.7, −0.8)	0.030	−0.4 (−0.6, −0.2)	<0.001	−1.4 (−2.5, −0.3)	0.164
Primary bladder management						
Chronic indwelling catheter	−7.3 (−8.8, −5.8)	<0.001	−0.2 (−0.4, −0.0)	0.663	−2.8 (−3.9, −1.7)	<0.001
Surgery	−4.0 (−5.6, −2.3)	<0.001	−0.7 (−0.9, −0.5)	<0.001	−3.3 (−4.6, −2.1)	<0.001
Spontaneous voiding	4.5 (3.1, 5.9)	<0.001	0.1 (−0.0, 0.3)	1.000	1.6 (0.6, 2.7)	0.043
Diagnosis						
Paraplegia	3.2 (2.0, 4.3)	<0.001	0.2 (0.1, 0.4)	0.009	2.4 (1.5, 3.2)	<0.001
Age, 10 years[b]	−0.8 (−1.2, −0.4)	0.003	−0.06 (−0.11, −0.01)	0.389	−0.5 (−0.8, −0.2)	0.035
Gender						
Male	−4.1 (−5.2, −3.0)	<0.001	−0.2 (−0.3, −0.1)	0.021	−2.3 (−3.1, −1.5)	<0.001
Years since SCI[b]	−0.3 (−0.8, 0.2)	1.000	−0.2 (−0.3, −0.1)	<0.001	−0.5 (−0.8, −0.1)	0.264
BMI						
≥ 30 kg/m^2	1.7 (0.5, 2.9)	0.070	0.00 (−0.14, 0.14)	1.000	1.2 (0.3, 2.1)	0.158
Number of UTIs						
1–3	2.7 (1.5, 4.0)	<0.001	0.2 (0.0, 0.3)	0.284	1.1 (0.1, 2.0)	0.383
4 or more	6.5 (5.1, 7.9)	<0.001	0.6 (0.4, 0.7)	<0.001	2.8 (1.7, 3.8)	<0.001
Severe bowel dysfunction						
NBS ≥ 14	1.1 (0.1, 2.2)	0.543	0.2 (0.0, 0.3)	0.096	1.1 (0.4, 1.9)	0.070
Education						
Bachelor's degree or higher	−1.1 (−2.2, −0.1)	0.480	0.09 (−0.04, 0.21)	1.000	−0.03 (−0.81, 0.76)	1.000

The bold entries indicate the values that represent the intercept for the analysis.

SCI spinal cord injury, *BMI* body mass index, *UTI* urinary tract infection.

[a]*p* values adjusted for multiple testing using the Bonferroni correction.

[b]Age, years since injury were scaled by dividing by 10, thus 10 years becomes 1 year of change.

independence and QoL that is influenced by both adaptation to physical disabilities and mental functioning [30]. Although physical disability is an important factor of overall health, studies into its effect on QoL have had varying outcomes [9, 33], with only a weak relationship between physical disability and QoL demonstrated on a recent meta-analysis [34].

This study has methodological limitations that should be acknowledged. We used self-reported survey data, which makes it subject to inclusion and/or recall bias. For instance, those participants that had bladder problems may have been more likely to enroll in the study, to obtain additional information or in hopes of improving their bladder function. Inclusions bias may be especially relevant in a study of psychosocial aspects of HRQOL, as most study participants were sophisticated and entered the study via enrollment from Facebook. Recall of complex medical history is hard for even the most sophisticated person. In addition, we are unable to ascertain the nature of chronic pain, where it was located, whether it was directly related to the bladder or arose from more typical neuropathic pain after SCI. Another limitation of the study result lies in the clinical significance of differences in QoL measures due to the scale that was applied; for example, on the *SCI-QoL Difficulties* scale, a 1-point change may be statistically significant but may not have any clinical relevance. Changes in the *NBSS* and *NBSS-satisfaction* were often close to or >10% (compared to the referent) meeting the generally agreed upon axiom for clinically significant change for a patient-reported outcome measure; however, formal testing to determine the minimum clinical difference has not been done for these measurement tools. Finally, we measured association, so it is not possible to determine if there was a causative relationship

Table 6 Multivariable comparisons reflecting the associations of SCI-QoL positive affect and well-being with outcomes.

	NBSS (N = 1358)		NBSS-satisfaction (N = 1358)		SCI QoL Bladder Management Difficulties (N = 1355)	
	Coefficient (95% CI)	p value[a]	Coefficients (95% CI)	p value[a]	Coefficients (95% CI)	p value[a]
Intercept (lower tertile)	**28.1 (25.6, 30.7)**	**<0.001**	**2.8 (2.5, 3.1)**	**<0.001**	**2.8 (2.5, 3.1)**	**<0.001**
SCI-QoL positive affect and well-being						
Middle tertile (48.7–55.2)	−1.7 (−2.9, −0.5)	0.091	−0.3 (−0.4, −0.1)	0.008	−0.3 (−0.4, −0.1)	0.008
Upper tertile (55.3–73.1)	−2.8 (−4.1, −1.6)	<0.001	−0.7 (−0.8, −0.5)	<0.001	−0.7 (−0.8, −0.5)	<0.001
Primary bladder management						
Chronic indwelling catheter	−7.1 (−8.5, −5.6)	<0.001	−0.1 (−0.3, 0.1)	1.000	−0.1 (−0.3, 0.1)	1.000
Surgery	−3.7 (−5.4, −2.1)	<0.001	−0.7 (−0.8, −0.5)	<0.001	−0.7 (−0.8, −0.5)	<0.001
Spontaneous voiding	4.6 (3.2, 6.0)	<0.001	0.1 (−0.0, 0.3)	1.000	0.1 (−0.0, 0.3)	1.000
Diagnosis						
Paraplegia	2.5 (1.4, 3.6)	<0.001	0.1 (0.0, 0.3)	0.517	0.1 (0.0, 0.3)	0.517
Age, 10 years[b]	0.8 (−1.2, −0.4)	0.004	−0.07 (−0.11, −0.02)	0.136	−0.07 (−0.11, −0.02)	0.136
Gender						
Male	−4.2 (−5.2, −3.1)	<0.001	−0.2 (−0.3, −0.1)	0.013	−0.2 (−0.3, −0.1)	0.013
Years since SCI[b]	−0.3 (−0.8, 0.2)	1.000	−0.2 (−0.2, −0.1)	<0.001	−0.2 (−0.2, −0.1)	<0.001
BMI						
≥30 kg/m^2	1.9 (0.7, 3.1)	0.030	0.03 (−0.11, 0.16)	1.000	0.03 (−0.11, 0.16)	1.000
Number of UTIs						
1–3	2.7 (1.5, 4.0)	<0.001	0.2 (0.0, 0.3)	0.429	0.2 (0.0, 0.3)	0.429
4 or more	6.6 (5.2, 8.0)	<0.001	0.6 (0.4, 0.7)	<0.001	0.6 (0.4, 0.7)	<0.001
Severe bowel dysfunction						
NBS ≥ 14	1.2 (0.1, 2.2)	0.389	0.2 (0.0, 0.3)	0.108	0.2 (0.0, 0.3)	0.108
Education						
Bachelor's degree or higher	−1.1 (−2.2, −0.1)	0.447	0.10 (−0.02, 0.22)	1.000	0.10 (−0.02, 0.22)	1.000

The bold entries indicate the values that represent the intercept for the analysis.

SCI spinal cord injury, *BMI* body mass index, *UTI* urinary tract infection.

[a]p values adjusted for multiple testing using the Bonferroni correction.

[b]Age, years since injury were scaled by dividing by 10, thus 10 years becomes 1 year of change.

between the psychosocial aspects of HRQoL and urinary symptom or satisfaction and the associations noted may indeed be due to unaccounted for confounders.

Conclusion

Our results show that independent of demographic and injury-related factors such as, level of injury, duration of injury, and bladder management method—pain, independence, and positive affect are all associated with better or worse bladder symptoms, satisfaction or both. Treatment efforts geared toward identifying and implementing rehabilitation services that decrease pain interference while improving independence and positive affect and well-being may help in optimizing bladder-related QoL after SCI.

Data availability

The datasets generated and/or analyzed during the current study are available from the corresponding author on reasonable request.

Author contributions OM was responsible for interpretation of results and paper writing. JH and AP were responsible for data analysis, result interpretation and paper revision. JTS, SE, BW, SL and JBM aided in study design, acquired data, and revised the paper. All authors approved the final version of the paper.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval I/we certify that all applicable institutional and government regulations concerning the ethical use of human volunteers/animals were followed during the course of this research.

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