REVIEW

Quality of life instruments and definitions in individuals with spinal cord injury: a systematic review

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Study design: A systematic review.

Objective: To critically review quality of life (QOL) instruments used with spinal cord injury (SCI) populations.

Setting: Vancouver, Canada.

Methods: A systematic literature review was conducted for publications assessing the measurement properties of QOL outcome measures. Pre-established criteria were used to evaluate the measurement properties.

Results: Fourteen articles reporting on 13 QOL instruments met the inclusion criteria, including the Patient Reported Impact of Spasticity Measure (PRISM), Quality of Well-being Scale, Qualiveen, Sickness Impact Profile (SIP68), Short Form (SF)-36, SF-36V, SF-12, SF-6D, Quality of Life Index, Quality of Life Profile for Adults with Physical Disabilities (QOLP-PD), Satisfaction with Life Scale, Sense of Well-being Index (SWBI), and the World Health Organization Quality of Life–BREF scale (WHOQOL-BREF). The SF-36 and WHOQOL-BREF have been widely used and validated. The SIP68, QOLP-PD, SF-36V, and SWBI are promising with limited investigation. The Qualiveen and PRISM performed well and are specific to SCI complications.

Conclusion: The WHOQOL-BREF is presently the most acceptable and established instrument to assess QOL after SCI. The SIP68, QOLP-PD, SF-36V, and SWBI are promising; however, require further evaluation of their measurement properties.

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Keywords: quality of life; spinal cord injuries; outcome assessment; validity; reliability

Introduction

Attaining an acceptable quality of life (QOL) is considered by many to be the ultimate goal of rehabilitation after spinal cord injury (SCI).[1,2] During the past few decades, advances in medical care are enabling persons with SCI to survive the initial injury and to prolong their life expectancy post-SCI.[3] The need for outcome measures assessing health and QOL after rehabilitation is, therefore, becoming increasingly important.[4–9] It is clear that simple outcomes-assessing function are insufficient in measuring rehabilitation after SCI[7,9] and in capturing the adaptation of perceptions and values in patients after SCI.[7,9] In fact, it has been suggested that high levels of QOL is synonymous with positive rehabilitation outcomes, and many agree that QOL should be measured in tandem with traditional outcomes assessing functional rehabilitation.[9,10] Such measurements provide different yet complimentary information that aid clinicians in their efforts to help those with SCI. Although an altered life is an inevitable outcome of SCI, literature shows that QOL after SCI is not uniformly worse, but rather a spectrum of recovery outcomes exist that range from QOL well below the general population to QOL that surpasses healthy population averages.[9]

QOL is a difficult construct to capture. Description of what constitutes the quality of someone's life is an important factor in our ability to assess, measure, and improve treatment outcomes and post-injury lifestyles. A clear definition of QOL has yet to emerge, which is due in part to a lack of consensus on a general definition of QOL.[11]

As such, our ability to accurately measure QOL among populations is limited. This is especially true with SCI populations.

Dijkers[12] proposed a scheme for classifying QOL instruments whereby they are conceptualized from the perspective of an outsider, an 'objective' view, or an insider, a 'subjective' view. All QOL instruments include reactions to or evaluations of the characteristics of a person's life (achievements) in the context of their expectations about those achievements, either implicitly or explicitly.[12] Therefore, the distinction whether the instrument is based on an 'objective' or 'subjective' view is determined by (1) whose expectations and evaluations are used and (2) which of the three (reactions/evaluations, achievements, expectations) are made explicit.

The objective approach to assessing QOL evaluates characteristics that can be impartially measured by an external appraiser.[12] These types of instruments assume (1) that all individuals have the same domains that are important in their lives or same goals and (2) happiness or satisfaction in life is directly proportional to the degree to which an individual achieves these standards or goals.[12] Most instruments assessing health status (also known as health-related QOL, HRQOL), are considered to be objective approaches.[12] These types of instruments, however, are limited as they tend to overestimate the impact of health and underestimate the other non-medical aspects such as the individual's values and preferences.[13,14]

The subjective approach to measuring QOL assumes that QOL can only be determined by the individual.[12] Instruments developed using this approach consider an individual's emotions or feelings (happiness/affect) or evaluation (life satisfaction) in the context of their expectations and achievements.[12] Life satisfaction can be further differentiated into satisfaction with overall QOL and satisfaction in specific domains (for example job relationships, health, etc.) comprising QOL.[15]

As improved QOL, be it subjective or objective, is indicative of the success of treatment programs or progress in the life of an SCI patient,[9,16] it should be routinely measured among SCI patients. Our purpose in this review, therefore, is to classify QOL instruments in use among SCI population as either objective or subjective, present evidence from the literature on the measurement properties of various QOL measures, and evaluate the properties against pre-established criteria. Such classification and evaluation will assist both clinicians and researchers select QOL measures appropriate to the context of their rehabilitation programs or research studies.

Materials and methods

Search strategy
A review of the QOL literature from 1986 to April 2009 was conducted. Primary data sources included the Pubmed, CINAHL, Embase, Medline, HaPI, Psycinfo, and Sportdiscus electronic databases.

The key word SCI and its related terms, paraplegia, quadriplegia, or tetraplegia, were used in conjunction with the terms validity, reliability, or responsiveness. To complete the search, these terms were then combined with the names and abbreviations of instruments used to assess the QOL in individuals, including the names of all measures, which met the criteria. After deleting non-relevant and duplicate papers, titles, key words, and objectives were examined by two investigators, and papers that did not specifically assess measurement properties of the outcome measures listed above with an intent to validate their usage, and papers with populations not entirely with SCI were eliminated. Eligibility and the measurement properties of the instruments were evaluated by three team members.

Inclusion criteria
To be included in this review, the instruments had to satisfy several requirements, which included (1) the primary purpose of the paper was to evaluate the measurement properties of a QOL instrument, that is Level one papers based on the classification of Kalpakjian et al.;[17] (2) the sample included an SCI population, 18 years of age and older; (3) the data specific to SCI were reported; (4) the paper was published in a peer-reviewed journal; and (5) the paper was written in English.

Classifying the instruments
Instruments were classified as either primarily objective or subjective QOL measures as per Dijkers[12] guidelines. Most authors clearly distinguish their instrument or definition of QOL as objective[5,16,18–20] or subjective.[1,6,9,20,21] Where no distinction was specified, instruments were classified according to the authors' definition of QOL[7] and/or the item content and scoring model.[22,23] For example, instruments addressing HRQOL or the presence, severity, and impact of specific health factors relating to QOL were considered objective, and instruments measuring life satisfaction or using scoring relationships between satisfaction and importance were classified as subjective.

Evaluation criteria
Criteria for assessing the instruments' measurement properties are based on the Outcome Measures chapter in the Spinal Cord Injury Rehabilitation Evidence (SCIRE)[24] systematic review, which are adapted from the Desirable Characteristics of Outcomes Research Measures for People with Disabilities defined by Andresen et al.[25] Table 1 provides a description of the evaluation criteria.

In addition to the SCIRE and Andresen's criteria and definitions, we have included hypothesis testing to support instruments validity.[26] We investigated factorial structure in more detail. When domains were not expected to cover similar constructs, we reversed the Andresen criteria, considering poor correlation scores ($r \leqslant 0.30$) excellent, moderate correlation scores (0.29–0.59) moderately discriminant, and high correlation scores ($r \geqslant 0.60$) poor discriminant evidence. In known-groups validity tests, little is known of these relationships in QOL, so known-group tests could not be

Table 1 Criteria for instrument evaluation

Criteria	Description	Evaluation
Reliability	Degree to which an instrument is consistent or free from random error	Test–retest repeatability (ICC and kappa) $A = \geqslant 0.75$; $B = > 0.40$, < 0.75; $C = \leqslant 0.40$ Internal consistency (coefficient α) $A = \geqslant 0.80$; $B = < 0.80$, > 0.70; $C = \leqslant 0.70$
Validity	Degree to which an instrument measures what it intends to measure	Factorial structure (exploratory or confirmatory factor analysis, Rasch analysis) $A =$ confirmed, Rasch analysis is good $B =$ factorial analysis is good or Rasch has some problems $C =$ inadequate statistical analysis
	Types include factorial structure (assess dimensionality); convergent correlations (comparisons with other measures); discriminant (differentiate based on known groups); hypothesis testing (outcomes support authors' hypothesis)	Convergent validity $A = \geqslant 0.60$; $B = > 0.30$, < 0.60; $C = \leqslant 0.30$
		Discriminant validity $A =$ strong, in expected direction $B =$ moderate or conflicting evidence $C =$ weak Hypothesis testing $A =$ clear hypothesis, evidence supportive $B =$ clear hypothesis, evidence contradictory or unclear hypothesis with good supportive evidence of study purpose $C =$ evidence does not support hypothesis or purpose
Item/instrument bias	Assess in practical terms if individual questions or summary scores are biased for individuals with SCI	$A =$ persons with SCI reviewed the instrument and acceptability is published $B =$ there is adequate face validity to support low bias $C =$ bias is evident or tested
Measurement model	Examines whether there are problems with floor effects (lowest level of ability) or ceiling effects (highest level of ability)	The instrument has scales or measures in which 20% of persons with SCI are grouped at scoring extremes. In addition, can consider the score distribution: $A =$ no problems $B =$ few or marginal problems $C =$ substantial skewing of scales/measures

assigned A, B, or C based on Andresen's criteria. Groups are defined differently and different statistical methods are used by each study's author. We simply report groups showing statistical differences in mean or total QOL scores.

When more than one paper provided validity or reliability values, a range of scores was assigned. Where more than one measurement was provided for reliability or validity within one domain (for example multiple item scores), a range was provided, and scores were assigned conservatively based on the lowest measured item.

Results

Fourteen Level one studies reporting on 13 QOL instruments have been investigated with SCI populations: eight objective instruments, including the Patient Reported Impact of Spasticity Measure (PRISM),[22] the Quality of Well-being Scale (QWB),[6] the Qualiveen,[23] the Sickness Impact Profile (SIP68),[27] the Short Form (SF)-36,[28] SF-36V,[19] SF-12,[29] SF-6D,[30] and five subjective instruments, including the Quality of Life Index (QLI),[2,21] the Quality of Life Profile for Adults with Physical Disabilities (QOLP-PD),[7] the Satisfaction with Life Scale (SWLS),[6,31] the Sense of Well-being Index (SWBI),[9,32] and the World Health Organization Quality of LIfe–BREF scale (WHOQOL-BREF).[1,33]

Table 2 presents instrument information, and Table 3 provides information on the studies included in this review. Reliability is presented in Table 4. Validity data is presented in Tables 5 and 6. Table 7 presents a summary of measurement property scores, including results of the factor analyses and hypotheses testing.

Objective QOL instruments
The PRISM measures QOL relative to spasticity,[22] with six domains addressing negative consequences of spasticity, and one, the positive impact. Negative PRISM QOL scores worsened in a significant manner with increasing severity of negative spasticity symptoms, as expected by the authors, and persons reporting that benefits of spasticity outweigh problems scored higher on the positive impact scale ($P < 0.001$). However, greater negative interference did not correlate to higher negative impact scores. The PRISM domains correlated moderately to one another ($r = 0.45$–0.73), covering related topics such as need for assistance/positioning and social embarrassment, with the exception of the positive impact scale ($r = 0.07$–0.29). Factor analysis confirmed that the domains are addressing distinct facets of spasticity-related QOL.[22]

The QWB measures health status and well-being;[34] it provides quality adjusted life years for health economic analyses. In persons with SCI, this generic measure did not

Table 2 QOL Instruments

Name	Description	Items	Domains (No. of questions)	Scoring and response	Measurement model	Time taken (min)	Alternate languages	Item bias	Interview (I) or self-Administration (SA)
Objective tools									
Patient reported impact of spasticity measure (PRISM)	Addresses negative and positive impact of spasticity on QOL in SCI population	41	Societal avoidance/anxiety (11); psychological agitation (5); daily activities (6); need for assistance/positioning (5); impact on activities:+/– (4); need for intervention (5); social embarrassment (5)	• 5-point Likert scale • Sub-scale scores are obtained by averaging item scores and dividing by number of items • Higher is unhealthier	'Relative to the range of the scale, more persons scored in lower ranges (indicating less impact)'	Not available	None	Developed in SCI population	SA
Quality of well-being questionnaire-SA (QWB-SA)	Point-in-time preference measure designed to measure HRQOL	71	Symptoms and problems (58); mobility, physical activity, social activity (13)	• 0.0—death to 1.0—optimum health • Higher is healthier	No floor and ceiling effects	<20	Various	Face validity supports low bias	SA
Qualiveen	Disease-specific perspective on QOL in SCI for urinary disorders	30	Limitations (9); constraints (8); fears (8); feelings (5)	• 5-point Likert scales (0–4); total range 0–100 • Tabulate total • Higher is unhealthier	Minimal	Not available	Various	Developed in SCI population	I or SA
Sickness impact profile (SIP68)	Generic health status measure, measures health-related changes in behavior associated with the carrying out of daily activities	68	Somatic autonomy (17); mobility control (12); mobility range (10); social behavior (12); emotional stability (6); psychological autonomy and communication (11)	• No=0, yes=1; total range 0–68 • Yes responses are tabulated; can divide into SIPSOM, SIPPSY, SIPSOC sub-scales • Higher is unhealthier	Ceiling effects MR (31.3%), ES (54%) & PAC (53.8%) domains	~15–20	Dutch	Scoring on one question adjusted for SCI	I or SA
Short form 36 (SF-36)	Addresses basic human values relevant to QOL and well-being through individual domains and two global components	36	Physical functioning (10); role limitations because of physical health problems (4); bodily pain (2); general health (2); vitality (4); social functioning (2); role limitations because of emotional problems (3); mental health (5)	• Total range 0–100 • Norm-based score is S0, with standard deviation 10. Can be divided into two summary scores: physical and mental, calculated by a system of + and – weights on domain scores • Higher is healthier	Floor and ceiling effect PF (12.2–24.2%; free—29.7%), RLP (28.1–36.3%; 22.5–54.4%); ceiling effect SF (free—33.5%), RLE (63.8–75.3%)	<15	Available in most major languages	Face validity supports low bias	I or SA
Short form 36 veterans/SCI (SF-36V)	Version of SF-36 designed for use in the disabled population. Physical functioning section has been modified to accommodate SCI population	36	Physical functioning (8)	• each domain converted to range of 0–100 • Divided into two summary scores: physical and mental components, are norm based; general population score 50 and standard deviation of 10 • Higher is healthier	'Descriptive responses to the items showed a floor effect on many of the items'	Not available	None	PF domain altered in SCI population	I or SA
Short form 12 (SF-12)	A shortened version of the SF-36, used in population studies	12	Physical functioning (2); role limitations because of physical health problems (2); bodily pain (1); general health (1); vitality (1); social functioning (1); role limitations because of emotional problems (2); general mental health (2)	• Total range 0–100 • Divided into two summary scores: physical and mental components, are norm based; general population score 50 and standard deviation of 10 • Higher is healthier	Summary scores free of floor and ceiling effects	~2–4	Available in most major languages	Face validity supports low bias	I or SA

Table 2 Continued

Name	Description	Items	Domains (No. of questions)	Scoring and response	Measurement model	Time taken (min)	Alternate languages	Item bias	Interview (I) or self-Administration (SA)
Short form 6-disability (SF-6D)	A six-dimensional health state classification based on the SF-36	11	Physical functioning (3); role limitation physical (1); role limitations emotional (1); social functioning (1); pain (2); mental health (2); vitality (1)	• 0.29 (the worst health state)—1.00 (perfect or full health) • Preference-based weights were assigned to each response; negative responses detract from perfect health score • Higher is healthier	Floor effect PF (37%); ceiling effect RLP and E (55%), SF (50%), P (36%), MH (35%)	Not available	Available in most major languages	Face validity supports low bias	I or SA
Subjective tools									
Quality of life index (QLI)	Measures subjective QOL in terms of satisfaction	32–37	Health and functioning (8); social and economic (8); psychological and spiritual (8); family (8)	• 6-point Likert scales for both importance and satisfaction sub-sections • Weigh satisfaction (S) scores with corresponding importance (I) scores; 3.5 subtracted from S scores, raw I score used. Total and sub-scale scores tabulated • Higher is healthier	None	~10	None for SCI version	SCI version evaluated by SCI patients	I or SA
Quality of life profile for adults with physical disabilities (QOLP-PD)	A holistic approach to QOL that empowers individuals in which elements of QOL are the same for people with and without disabilities, but each may address issues differently; questions address aspects of daily life	102	Being (32): physical, psychological, spiritual; belonging (37): physical, social, community; becoming (33): practical, leisure, growth	• 5-point Likert item scales 1—not at all satisfied to 5—extremely satisfied and 1—not important to 5—very important • Weigh satisfaction and importance scores for each item; three points are subtracted from S scores, raw I scores used • Higher is healthier	None reported	Not available	None	Developed in disabled and SCI population	I or SA
Satisfaction with life survey (SWLS)	Addresses life satisfaction as a whole, reflecting a global perspective of individual's values	5	In most ways my life is close to ideal; the conditions of my life are excellent; I am satisfied with my life; so far I am getting the important things I want in life; if I could live my life over, I would change almost nothing	• 7-point Likert scale • Global score is computed • Higher is healthier	Floor effects seen on some items	<5	Various	Face validity supports low bias; some questions may be inappropriate for SCI	I or SA
Sense of well-being index (SWBI)	Measures subjective QOL for people with disabilities in work rehabilitation	26	Physical well-being and associated feelings about self (6); psychological well-being (7); family and social well-being (6); financial well-being (8)	• 4-point Likert scale • Tabulate total and domain scores • Higher is healthier	None reported	'Brief'	None	Altered for and evaluated in SCI population	I or SA
World Health Organization quality of life (WHOQOL-BREF)	Instrument that conceptually fits with the WHO definition of QOL	26	Physical health/capacity (7); psychological health/well-being (6); social relationships (3); environment (8); overall QOL (1); general health (1)	• 5-point Likert scale • Domain scores calculated by multiplying mean of facet scores by four, and transformed onto a scale of 0-100 • Higher is healthier	None; floor effect in one item: mobility (29.7%)	Not available	Available in most major languages	Face validity supports low bias	SA

Abbreviations: HRQOL, health-related quality of life; PF, physical functioning; QOL, quality of life; SCI, spinal cord injury. SIPSOM, physical dimension of functional status; SIPPSY, psychologic dimension of functional status; SIPSOC, social dimension of functional status.

Table 3 Summary of included papers

Author	Measures	n	Sample characteristics (mean+/−s.d.)	Purpose	Study Design and Analysis
Cook et al.[22]	PRISM	32 (development) 180 (validity and reliability study)	15+/−11 years of injury; 52+/−12 years of age; USA veterans	To develop and validate the PRISM	Factor analyses and content validity was carried out to develop the PRISM. One week test-retest and internal consistency were calculated for reliability and discriminative ability among known groups was carried out to validate the scale.
Andresen et al.[4]	QWB-SA, SF-36, SF-12	183	17.9+/−11.36 years of injury; 50.52+/−12.73 years of age; USA veterans	To evaluate the performance of health-related quality of life instruments	Cross-sectional study to assess the instruments' respondent burden and acceptability, pattern of correlations, floor and ceiling effects, and discriminative ability among known groups
Costa et al.[23]	Qualiveen	281	11 years of injury; 41 years of age; France	To develop and validate the Qualiveen for SCI patients with urinary difficulties	The Qualiveen was psychometrically assessed through multi-trait and principal component analysis. Test-retest reliability was also evaluated
Post et al.[28]	SIP68	315	3.6+/−1.9 years of injury; 39.4+/−12.5 years of age; Netherlands	To validate the SIP68	Cattell's similarity index was used to assess the expected theoretical factor structure. Criterion validity was assessed, as was reliability through internal consistency
Forchheimer et al.[16]	SF-36	215	1–13 years of injury; 34.5 years of age; USA	To evaluate the applicability of the SF-36 for assessing health-related quality of life	To test the hypotheses that: (1) the SF-36's physical and mental component scores are two distinct constructs; and (2) that the relationship between the component scores and neurologic impairment would support both convergent and divergent validity. Internal consistency was also calculated
Lin et al.[38]	WHOOQOL-BREF, SF-36	187	7.4 years of injury; 42.9 years of age; Taiwan	To compare the psychometric performance of the WHOQOL-BREF and the SF-36	Internal consistency, intrainterviewer and interinterviewer test–retest reliabilities, convergent and known-groups validities, and the responsiveness between the WHOQOL-BREF and the SF-36 were compared
Luther et al.[19]	SF-36V	359	Post-discharge; all ages; USA veterans	To develop a SCI-specific physical functioning scale on the SF-36V	Exploratory factor analysis was conducted to identify factors. Item Response Theory (IRT) analyses were further conducted on each item. Internal consistency, convergent, divergent validity were also assessed
Lee et al.[18]	SF-6D	305	1 month–61 years of injury; 43.5+/−13.5 years of age; Australia	To evaluate the SF-6D's discriminative ability and determine its responsiveness to clinically important change	Discriminative ability was assessed through known groups. Responsiveness was determined by minimal important differences (MID)
Jang et al.[1]	WHOQOL-BREF	280 (including 111 SCI respondents)	6+/−6 years injury; 40+/−13 years of age; Taiwan	To validate the WHOQOL-BREF	Multi-trait analysis was used to confirm the domain structure of the WHOQOL-BREF. The measure's discriminative ability was evaluated in its ability to distinguish between known groups. Internal consistency was also calculated
Chapin et al.[9]	SWBI	132	15.21+/−11.63 months of injury; 45.82+/−15.67 years of age; USA	To assess the validity of the SWBI	Factor analyses were carried out to validate the original SWBI factors among SCI. Concurrent validity was also assessed
Dijkers[5]	SWLS	2183	Various points post-injury; all ages; USA	To validate the SWLS	Follow-up of subjects studied prospectively since onset of injury (1–20 years). Predictors of subjective well-being were correlated with the SWLS
May and Warren[21]	QLI	11	10.5 years of injury; 33.1 years of age; Canada	To modify and validate the QLI	The meaningfulness of the QLI items was evaluated among the SCI sample through 'think out loud' interviews. The structure of the QLI was assessed by a 'free sort' exercise
May and Warren[2]	QLI	98	15.5 years of injury; 45.3 years of age; Canada	To validate the QLI	To test the hypotheses that there would be no significant relationship between QOL and five other variables; and that the factor structure would be similar to the original four factor structure
Renwick et al.[6]	QOLP-PD	40	2–30 years of injury; 35.85+/19.29 years of age; Canada	To validate the QOLP-PD	Internal consistency and correlations between sub-scale scores and the total score

Abbreviations: PRISM, Patient Reported Impact of Spasticity Measure; QLI, Quality of Life Index; QOLP-PD, Quality of Life Profile for Adults with Physical Disabilities; QWB-SA, Quality of Well-being Scale; SF, Short Form; SCI, spinal cord injury; SIP68, Sickness Impact Profile; SWBI, Sense of Well-being Index; SWLS, Satisfaction with Life Scale; WHOQOL-BREF, World Health Organization Quality of Life–BREF scale.

Table 4 Reliability

Instrument	Alpha Internal consistency	ICC or kappa		
		Test–retest	Intrainterviewer	Interinterviewer
Objective tools				
PRISM	0.74–0.96[22]	0.82–0.91[22]		
Qualiveen	0.8–0.85[23]	0.85–0.92[23]		
SIP68	0.92[28]			
	0.68–0.91[28]			
SF-36	0.76–0.9[16]			
	0.72–0.98[38]		0.71–0.99[38]	0.41–0.98[38]
SF-36V	0.9[19]			
Subjective tools				
QOLP-PD	0.84–0.98[7]			
SWLS		0.39–0.65[6]		
SWBI	0.79–0.88[9]			
WHOQOL-BREF	0.75–0.87[38]		0.84–0.98[38]	0.56–0.95[38]
	0.54–0.78[1]			

Abbreviations: PRISM, patient reported impact of spasticity measure; QOLP-PD, quality of life profile for adults with physical disabilities; SF, short form; SIP68, sickness impact profile; SWBI, sense of well-being index; SWLS, satisfaction with life scale; WHOQOL-BREF, World Health Organization quality of life–BREF scale.

correlate well with other QOL measures such as the SF-36 ($r = 0.044$–0.29),[5] and reliability has not been established in an SCI population.

The Qualiveen measures the impact of urinary disorders on QOL as well as overall ratings of QOL in persons with SCI.[23] Qualiveen QOL scores decreased as urinary problems increased. ($P < 0.0001$–0.01) The Qualiveen was originally developed in French for the SCI community. The instrument showed excellent reliability in the SCI population ($\alpha = 0.80$–0.85)[23] (Table 4).

The SIP68 is derived from the original 136-question version SIP136.[20,35] The SIP68 showed high correlation with physical measurements such as the Barthel ADL index ($r = -0.91$--0.41).[27,36] However, Post *et al*.[27] argued that, because SIP68 correlates highly with a measure of life satisfaction, it must be measuring a broader concept than health state and self-care ability. Internal consistency was high for the SIP68 ($\alpha = 0.8$–0.92), but the emotional stability domain showed consistently low reliability in the SCI population ($\alpha = 0.68$).[27]

The SF-36 is a widely used HRQOL instrument. It has been translated and widely promoted by the International Quality Of Life Assessment project;[37] translations have been developed for >60 countries. The SF-36 has been validated in multiple SCI studies.[5,16,38,39] Data strongly supports authors' hypotheses that the mental and physical components would correlate to similar domains on other QOL instruments,[5,38] but not to one another.[16] Factor analysis has been conducted extensively in other populations; see http://www.sf-36.org. Reliability was moderate to high for the SF-36 ($\alpha = 0.72$–0.98),[16,38] except the general health item (interinterviewer ICC = 0.41).The SF-36 was shortened to contain just 12 questions (SF-12) and only provide mental and physical subscores. The SF-12 has not been widely used and validated in the SCI population, but has shown expectedly high correlation with the SF-36 ($r = 0.78$–0.99).[5,38] Reliability was not examined in the SF-12.

The Veterans Health Administration version of SF-36 (SF-36V) modified the physical functioning domain for SCI populations. The modifications generally involved substituting activities more appropriate to SCI clients, such as 'climbing… wheel chair ramps' rather than stairs, or 'getting up and down from a curb.'[19] The SF-36V supported the authors' hypothesis that it more accurately reflects SCI QOL, showing internal validity with the physical, but not the mental component score. It was necessary to alter the wording of the questions based on SCI consumer input more than anticipated, and mobility was rated as if respondents were using their assistive devices. Internal consistency was high ($\alpha = 0.90$).[19]

A preference-based health measure, the SF-6D, has also been derived from the SF-36 and SF-12.[40] Its usefulness was evaluated by assessing its responsiveness to urinary tract infection. It could discriminate between SCI and non-SCI respondents; however, floor effects were seen in the physical domain (37%), and reliability was not examined.[18]

Subjective QOL instruments
Ferrans' and Powers' QLI attempts to cover all facets of QOL.[41,42] The revised SCI version is comprised of 37 items making up two sub-sections: one measuring satisfaction with various life aspects and the other measuring the importance of those aspects. Although the language of the SCI version of the instrument was well received by SCI clients,[21] the domain structure did not fit with subject interpretations.[21] Further, the correlations between the QLI total scores and each of the satisfaction ($r = 0.99$)[2] and importance ($r = 0.43$)[2] sub-section scores were contrary to the authors' hypothesis that significant relationships of equal magnitude between the total score and section scores would exist. Rather, the scoring relationships suggest that the satisfaction and importance ratings contribute to the overall score, but in unequal amounts.

Table 5 Construct validity—factor analyses, item or subscale correlations

		Subscales or items	Correlations
Objective tools			
PRISM[22]	Exploratory factor analysis resulted in 12 factors. The first seven factors were made into subscales. Moderate subscale correlations indicate that the domains are distinct.	Social avoidance/anxiety	NA
		Psychological agitation	0.12–0.70
		Daily activities	0.29–0.64
		Need for assistance/positioning	0.27–0.64
		Positive impact	0.12–0.28
		Need for intervention	0.15–0.63
		Social embarrassment	0.26–0.70
Qualiveen[23]	Principal components analysis resulted in one item in the Fears subscale being excluded (items were excluded if correlations were ⩽0.40).	Limitations	0.52–0.65
		Constraints	0.43–0.66
		Fears	0.39–0.60
		Feelings	0.50–0.77
SIP-68[28]	Subscale correlations indicate little redundancy (with the exception of mobility range and social behavior $r = 0.67$).	Somatic autonomy	0.12–0.54
		Mobility control	0.08–0.54
		Mobility range	0.27–0.67
		Social behavior	0.41–0.67
		Emotional stability	0.08–0.48
		Psychic autonomy and communication	0.21–0.47
SF-36[16]	Subscale correlations indicate, as hypothesized, that the two scales are not related to each other and thus are measuring two distinct constructs among SCI.	PCS and MCS	−0.075
SF-36V[19]	Exploratory factor analysis resulted in a one-factor, nine-item physical functioning solution. After item response modeling, one item was removed.	Items: vigorous activities; getting up and down from the curb; bending or stooping; opening a heavy outside door; making a bed; reaching overhead; lifting or carrying groceries; shopping for groceries	NA
Subjective tools			
QLI[2]	Participants allocated QLI items to the conceptual subscales. There was poor structural agreement between the participants and the developer.	Health and functioning	0.21
		Social and economic	0.23
		Psychological and spiritual	0.34
		Family	0.42
QOLP-PD[7]	Subscale to total correlations revealed moderate-to-high correlations.	Subscales: Physical being; psychological being; spiritual being; physical being; social belonging; community belonging; practical becoming; leisure becoming; growth becoming	0.58–0.88[a]
SWBI[9]	Factor analysis resulted in a 26-item, four-factor solution for SCI, similar to the original SWBI. Moderate correlations exist between subscales.	Psychological	0.53–0.58
		Financial	0.37–0.57
		Social	0.37–0.53
		Physical	0.47–0.58
WHOQOL-BREF[1]	Item to subscale correlations revealed that all items had the highest correlations with the subscale they were originally assigned.	Physical health	0.55–0.73
		Psychological health	0.59–0.73
		Social relationships	0.65–0.77
		Environment	0.52–0.75

Abbreviations: PRISM, Patient Reported Impact of Spasticity Measure; QLI, Quality of Life Index; QOL, Quality of Life; QOLP-PD, Quality of Life Profile for Adults with Physical Disabilities; SF, Short Form; SIP68, Sickness Impact Profile; SWBI, Sense of Well-being Index; WHOQOL-BREF, World Health Organization Quality of Life–BREF scale.
[a]After removal of the $r = 0.28$ Physical Belonging outlier.

As expected, the QLI scores correlated to both community integration (participation) ($r = -0.65$) and self-esteem ($r = 0.61$), but not to body functions and structure or the level of activity. The instrument was unexpectedly not correlated to locus of control ($r = -0.02$), and reliability was not examined.[2]

The QOLP-PD takes an extremely subjective approach to QOL assessment. It holds that QOL elements are common to most human beings, with and without disabilities, but that adults with physical disabilities may address life issues somewhat differently. Reliability ($\alpha = 0.84$–0.98) and construct validity ($r = 0.63$–0.88) are both excellent.[7]

The SWLS contains five statements about life satisfaction: three set in the present, one in the past, and one in future. It is 'one of the few existing instruments that measure life satisfaction as a global entity, rather than requiring subjects to rate their satisfaction with each of a number of domains of life.'[5] In accordance with the authors' hypotheses, impair-

Table 6 Validity: multi-trait multi-method

Instrument		Validity		Discriminant validity	
		Excellent or moderate correlation	Poor or no correlation		
Objective tools					
QWB	Total score	IADL ($r=-0.454$);[5] SF-36 physical summary ($r=0.417$);[5] SF-12 physical summary ($r=0.34$)[5]	SF-36 domains ($r=0.044-0.29$);[5] SF-12 mental summary ($r=0.164$);[5] BRFSS items ($r=-0.25-0.182$)[5]	Total	Para/tetra, upper body difficulty[5]
Qualiveen				Domains	SQLP how well patients urinate, patient satisfaction with urination, time taken to urinate[23]
SIP68	All domains, overall	BI ($r=-0.91$ to -0.41),[28] LSQ ($r=-0.53$ to -0.32)[28]	LSQ versus SIP mobility control ($r=-0.22$);[28] BI versus SIP 68 emotional stability ($r=-0.11$); psychic autonomy and communication ($r=-0.21$);[28]	Domains	Vocationally active, level of lesion[28]
SF-36	All domains	WHOQOL-BREF domains ($r_s = 0.33-0.78$),[38] RS ($r_s = 0.32-0.72$);[38] RFSS items ($r_s = -0.795-0.3083$; $0.389-0.789$);[5] F-36 physical functioning, social functioning, mental health versus IADL ($r=-0.454$ to -0.308)[5]	QWB ($r=0.044-0.261$);[5] IADL ($r=-0.3-0.201$);[28] SF-36 Role limitations: emotional versus WHOQOL-BREF Overall QOL & General Health (0.3), Social Relationships ($r=0.24$)[38] SF-36 physical functioning versus BRFSS items ($r=-0.226-0.088$); SF-36 role limitations: physical ($r=-0.219$), general health (-0.295), social functioning ($r=-0.293$), role limitations: emotional ($r=-0.29$) versus BRFSS days without enough sleep;[5] BRFSS other items ($r=-0.354-0.217$),[5]	Domains	Age, ASIA impairment severity, employment status, level of injury, marital status, self-care ability[38], severe work disability, upper body difficulty[5]
	Physical component score	SF-12 physical health summary ($r=0.799$);[5] WB ($r=0.417$);[5] ADL ($r=-0.357$);[5] RFSS items good days ($r=0.443$), days full of energy ($r=0.489$), poor physical health days ($r=-0.458$);[5]	QWB ($r=0.116$);[5] IADL ($r=-0.262$);[5]		
	Mental component score	BRFSS items ($r=-0.761-0.427$),[5] F-12 mental health summary score ($r=0.922$)[5]			
SF-36V	Physical functioning	SCDRQ ADL ($r=0.63$);[19] CDRQ IADL ($r=0.7$);[19]			
SF-12	Physical health summary	SF-36 physical component score ($r=0.779$);[5] WB ($r=0.34$);[5] RFSS items good days ($r=0.306$), days full of energy ($r=0.333$), poor physical health days ($r=-0.324$);[5]	IADL ($r=-0.272$);[5] RFSS other items ($r=-0.2-0.064$);[5]	Physical health summary, mental health summary	Upper body difficulty, severe work disability[5]
	Mental health summary	BRFSS items ($r=-0.799$ to -0.37, 0.639 to 0.665)[5] F-36 mental component score ($r=0.922$);[5] ADL ($r=-0.37$)[5]	QWB ($r=0.164$)[5]		
SF-6D	Total score			Total	Employment status, tetra/para, time since injury[18]
Subjective tools					
QLI	Total score	Reintegration to normal living index ($r=-0.654$);[3] osenberg's self-esteem scale ($r=0.609$)[2]	Rotter's internal–external scale of locus control ($r=-0.024$)[2]		
SWLS				Total	CHART scores, employment status, FIM motor score, FIM socio-cognitive score, level of education, level of injury, marital status, number of hospitalizations in the last year, number of pressure ulcers, race/ethnic group, sex, years since injury[6]
SWBI	Psychological well-being	WHOQOL-BREF psychologic ($r=0.75$)[9]		Domains	Education, employment status, family income, marital status, perceived socio-economic status, years since disability onset[9]
	Financial well-being	WHOQOL-BREF environment ($r=0.59$)[9]			
	Family and social well-being	WHOQOL-BREF social relationship ($r=0.45$)[9]			
	Physical well-being	WHOQOL-BREF physical health ($r=0.63$)[9]			
WHOQOL-BREF	All domains	RS ($r_s = 0.54-0.73$);[38] F-36 domains ($r_s = 0.33-.78$)[38]	WHOQOL-BREF overall QOL and general health ($r_s = 0.3$), social relationship domains ($r_s = 0.24$) versus SF-36 role emotional[38]	Domains	Age, employment status, level of injury, marital status, self-care ability,[38] SCI to non-SCI[1]

Abbreviations: BI, Barthel index; BRFSS, centers for disease control and prevention behavioral risk factor surveillance survey; IADL, instrumental activities of daily living; LSQ, Life Satisfaction Questionnaire; QOL, quality of life; QLI, Quality of Life Index; QWB, Quality of Well-being Scale; SCI, spinal cord injury; SF, Short Form; SIP68, Sickness Impact Profile; SWBI, Sense of Well-being Index; SWLS, Satisfaction with Life Scale; WHOQOL-BREF, World Health Organization Quality of Life–BREF scale.

Table 7 Summary[a]

Instrument	Number of studies	Measurement model	Item bias	Reliability		Hypothesis testing	Validity		
				Internal consistency	Test–retest		Factor analysis	Convergent	Discriminant
Objective tools									
PRISM	1	B	A	B	A	B	A	B	A
QWB	1	A	B	—	—	C	—	—	—
Qualiveen	1	A	A	A	A	A	B	B	B
SIP68	1	B	A	A-C	—	A		B	A-C
SF-36	3	B (domains); A (subscores)	B	B	B	A-B	—	—	A
SF-12	1	A	B	—	—	C	—	—	—
SF-36V	1	C	A	A	—	B	A	A-C	A-B
SF-6D	1	C	B	—	—	A	—	—	—
Subjective tools									
QLI	2	A	A	—	—	C		A-C	—
QOLP-PD	1	—	A	A	—	C	—	A	—
SWLS	1	B	B	—	C	C	A	—	—
SWBI	1	—	A	B		A		—	B
WHOQOL-BREF	2	A	B	B-C	B	A-C	-	B	B-C

Abbreviations: PRISM, Patient Reported Impact of Spasticity Measure; QLI, Quality of Life Index; QOLP-PD, Quality of Life Profile for Adults with Physical Disabilities; QWB, Quality of Well-being Scale; SF, Short Form; SIP68, Sickness Impact Profile; SWBI, Sense of Well-being Index; SWLS, Satisfaction with Life Scale; WHOQOL-BREF, World Health Organization Quality of Life–BREF scale.
[a]Ranges are presented in which information from more than one study was available.

ment (level of injury), number of hospitalizations, and the number of pressure ulcers related to life satisfaction ($P < 0.05$), but completeness of injury did not. Two weeks test–retest was moderate to low (ICC $= 0.39$–0.65).[5] The SWLS reflects general life satisfaction, but is not detailed as to specific aspects of QOL.

The SWBI was developed to assess QOL in disabled populations in vocational rehabilitation programs. The authors argue that to achieve maximum potential in the rehabilitated worker, rehabilitation programs must assess overall QOL, both subjective and objective, as 'research indicates that there is a dynamic interaction between quality of work life and QOL in general.'[9] The authors correctly hypothesized that the revised SWBI for SCI would have similar measurement properties to the original, would correlate well with the WHOQOL-BREF,($r = 0.45$–0.75), and would show similar patterns of known-group validity to other QOL instrument in the literature.[9]

The WHOQOL assessment was developed as an international effort to create a cross-cultural, cross-population QOL measure based on a generic theoretical model of QOL.[33,43] The short version, the WHOQOL-BREF, has been assessed by multiple authors.[1,9,38,44] Population-specific versions exist, such as the Taiwan/Hong Kong version with two additional questions of local cultural importance.[38] Although sometimes considered an HRQOL instrument, many questions rate individual subjective satisfaction, thus covering both objective and subjective components of QOL. The WHOQOL-BREF generally supported authors' hypotheses that it would show item-domain validity ($r = 0.41$–0.77),[1] correlate in appropriate domains with other QOL measures such as SF-36 ($r_s = 0.33$–0.78),[38,45] and differentiate between sub-groups such as employment, self-care ability, age, marital status, and

level of injury.[38] Reliability was moderate to high ($\alpha = 0.74$–0.87), with the exception of the social relationships domain, which was consistently lower than the other domains (0.54).[1,38]

Discussion

Definition of QOL
It is evident that there are currently as many definitions of QOL as there are instruments measuring it. We have examined existing literature on 13 QOL instruments that have been investigated in SCI populations. By assembling these instruments for this population, conclusions can be drawn on the broad themes found in QOL investigation, such as subjective versus objective measurement, approaches to QOL definition, and lack of data on cause and effect in SCI QOL.

Measurement properties of instruments
Generally, sufficient investigation has been carried out to validate the use of only a few of the QOL instruments with SCI populations. The WHOQOL-BREF and SF-36 have been extensively used and validated. In the SF-36, concern has been expressed in the SCI community regarding the appropriateness of the use of the term 'walking' in the mobility-related physical questions of the SF-36.[5,19] This concern has been addressed in the SF-36V, which requires further investigation before wide-spread use with SCI populations. The SF-12 and SF-6D also exhibit certain SCI bias and floor effects[5,18] that could easily be removed if they were derived from the SF-36V, as opposed to the original SF-36.

The Qualiveen and PRISM have performed well in all measurement properties,[22,23] likely because of the clarity of results obtained from objective QOL measures, which can be strongly and concretely correlated to health state. Both could use further investigation in SCI populations.

For objective QOL, the SIP68, and for subjective, the QOLP-PD and the SWBI all have very positive supportive evidence and face validity, appropriate for their continued use.[7,9,20] Again, all three require much more investigation, especially those measuring subjective QOL, which are more difficult to validate, given the theoretical nature of the underlying construct.

Disappointing results were obtained for the QLI, the QWB, and the SWLS.[2,5,6] The QLI likely requires alteration to the structure of the importance scale scoring, and potentially domain rearrangement before wide-spread use in SCI populations. The QWB preference-weighted scoring approach, weighing certain symptoms more heavily than others, is founded on data from the general population. It measures HRQOL from a 'decision theory approach,' in which differently weighted symptoms contribute to one final score, which can be applied to any population.[46] This is distinct from the approaches of other QOL instruments, in which a profile is generated composed of measurements in several domains; the QWB correlated only moderately to the physical domain of the psychometric SF-36 instrument.[5] The QWB tells health-care providers very little about the HRQOL of their individual SCI client, as it is intended to offer inter-population comparison, with less sensitivity to clinical change.[46] With respect to the SWLS, it is possible that the brevity and generality of its approach, as well as the wording of several of the questions (for example 'If I could live my life over, I would change almost nothing'), weaken its applicability with SCI population.

Subjective QOL issues
In the field of SCI QOL research, there is controversy over the appropriateness of objective QOL measurements. This is due to the assumptions that these measurements impose on individuals with different life circumstances and ability levels, namely, that all individuals prioritize common life domains and goals, especially those related to measureable outcomes such as financial gain or physical strength, and that success and achievement in these domains and goals are directly proportional to happiness and life satisfaction. Not only this, but it had been found that injury-specific variables such as level or severity of injury do not always affect objective QOL.[5,18] As an alternative, subjective QOL purports to measure outcomes through the point of view of the individual that cannot necessarily be broadly generalized. This issue with the subjective instruments is addressed in various ways. In the QOLP-PD development, Renwick et al.[6] suggested that all individuals value similar elements of life, but may address or achieve these differently.[7] In this and several other subjective QOL instruments, satisfaction with items scores are weighted by scoring the importance of these items to the individual.[2,7] Alternatively, instruments such as the SWLS address QOL without splitting

it into domains or questioning specific aspects of life, resulting in a measurement of overall satisfaction with life only.

Although most objective QOL measures have existed for much longer, and thus have much more published data and utilization, many authors now suggest the use of subjective QOL measures as more appropriate in individuals with SCI.[6,7,9] Scores in objective QOL domains are found to be lower in SCI than in the general population,[1,18] whereas some domains of subjective QOL are equal to the general population, and some are higher.[47] Item bias scores for SCI were higher in the subjective instruments, whereas measurement model scores were higher in the objective instruments. These trends would seem to reflect the differences in QOL models, in which subjective instruments are more highly attuned to the individual's situation, and subjective QOL can vary greatly between individuals. Although objective QOL is more easily measured, such instruments have the potential to miss many aspects of the individual's life.

Clearly, objective and subjective QOL instruments are measuring different constructs, and thus have different conceptualizations of QOL. It may be that, such as the mental and physical component scores of the SF-36, both contribute equally, rather than solely, to the overall QOL score. Or, it could be that, similar to satisfaction and importance scores in many of the instruments, one should be weighted against the other. A mixture of subjective and objective approaches could resolve the existing debate on which is the more appropriate approach to QOL research, or, as Fuhrer stated, 'measures of subjective well-being should be viewed as being complementary with objective indices of people's functioning and life status.'[10]

Conclusions

Overall, there is a wealth of data on SCI QOL. There are numerous promising instruments to measure QOL. Unfortunately, because of a lack of consistent results and definitions, our knowledge pertaining to the QOL among individuals with SCI is still limited. It is important to keep in mind that we are attempting to perform a comparison of different measurement instruments of QOL that are based on different definitions of QOL. A more concrete, universal definition of QOL is required, as is further investigation on the causative and related effects of different aspects of the SCI client's life on QOL. Known-group associations that are examined in a systematic and consistent manner between studies and populations would provide valuable information. With a clear definition of QOL, this type of investigation could be undertaken without the excessive contradictions that exist in the literature at present.

In terms of the instruments included in this review, the disease state-specific HRQOL Qualiveen PRISM, and SIP68 performed very well. The longer, more varied HRQOL SF-36 and subjective WHOQOL-BREF performed moderately well in all areas, with the added bonus of their wide-spread use and the wealth of evidence supporting their outcomes. Several newer subjective QOL instruments also performed

very well, but will need further investigation, including the SWBI and the QOLP-PD. The remaining instruments lacked either SCI-appropriate structure, language, or investigation.

Pending further investigation of some of the very promising, but recently, developed instruments, we would recommend the use of the WHOQOL-BREF, as it addresses both objective and subjective QOL, is based on an international effort to clearly define QOL, and has been well studied in SCI populations with acceptable results. The SF-36V or SIP68 as measures of HRQOL, or the QOLP-PD or the SWBI as measures of subjective QOL, also show promise, but require further investigation before using with confidence. In the context of clinical practice or research, investigators must choose tools based on practice/purpose, and explicitly state their concept of the definition of QOL.

Conflict of interest

The authors declare no conflict of interest.

Acknowledgements

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