Research Review

Spinal cord injury and quality of life measures: a review of instrument psychometric quality

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Introduction: Quality of life (QOL) is often considered the primary endpoint in research, clinical medicine, and health promotion when impairments are incurable or insufficiently understood. For spinal cord injured (SCI) persons extended life spans and the need for life-long follow-up make it important to expand the outcome parameters of medical care and health services to include QOL measures.

Study design: Review.

Objectives: The aim of this study was to evaluate QOL research in SCI persons from the perspective of current criteria for instrument psychometric quality developed by Medical Outcomes Trust (MOT).

Methods: Relevant articles were extracted from the Medline, Cinahl, and PsycLit databases for approximately a recent 30-year period (1966–1999). The keyword ‘spinal cord injuries’ was cross-indexed with ‘quality of life’, ‘personal satisfaction’ and ‘life satisfaction’. A total of 105 articles were identified and 46 met our inclusion criteria: (a) report of original research; (b) evaluation of QOL by self-report questionnaires or scales; and (c) publication in English.

Results: The quality of the research designs varied widely. Most of studies were cross-sectional with limited study populations. The number of instruments or different combinations of instruments nearly equalled the number of studies conducted. Most questionnaires were condition-specific and only used by the developers. The variety of instruments and the diversity of their core content made results difficult to compare, and evaluations and conclusions unpredictable and sometimes contradictory. The low psychometric standard of many instruments used further aggravates the interpretation of results.

Conclusion: To improve future research in special populations such as the SCI, the MOT criteria for review of QOL instruments should be further disseminated and applied to reach desirable consensus of a limited number of standardised generic and condition-specific QOL measures.

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Introduction

As healthcare has improved, life expectancy following spinal cord injury (SCI) has increased. Spinal cord injured patients treated and followed in specialised units now have an almost normal life expectancy.¹ Living with disability therefore becomes a life-long process for many injured persons, with a different set of problems presenting themselves at different stages in life.² Extended life spans and the need for life-long follow-up make it important to expand the outcome parameters of

medical care to better understand and promote physical, psychological, and social well-being after an SCI.

A number of different approaches have been used throughout the years to define and describe quality of life (QOL) in the SCI population. Earlier meta-analyses published by Evans *et al*³ and Dijkers⁴ emphasise the difficulties in drawing general conclusions from SCI QOL research due to the wide variety of research designs, analyses, interventions, and sample characteristics. This criticism is not, however, unique to SCI research. For example, Staquet *et al*⁵ report that important information is often missing from clinical trials where QOL assessment is

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incorporated. They conclude that the psychometric properties of the instruments used are not well established and that missing data and the number of patients treated are rarely documented.

In recent years, clinical research incorporating QOL measurements has developed rapidly. The need to further develop medical care, improve outcomes of rehabilitation and find cost-effective management demands more comprehensive outcome assessments. A multidimensional approach calls for a holistic view of the individual. The QOL concept is, however, hard to define due to its multi-dimensional nature. A universal definition has not been adopted but the broad concept of QOL has been operationalised and assessed by generic and disease-specific measurements. Self-assessment questionnaires, comprising questions about different life domains, are often used nowadays to evaluate patients' QOL. Other methods of assessing QOL are single-item measures or overall ratings on visual analogue scales.

The purpose of this review is to evaluate QOL research in SCI persons from the perspective of current criteria for instrument psychometric quality. Methodological issues related to instrument selection are discussed with the aim of improving the quality of health care services for the SCI population.

Methods

Research strategy

Relevant articles were extracted from the Medline, Cinahl, and PsycLit databases. The keyword 'spinal cord injuries' was cross-indexed with 'quality of life', 'personal satisfaction' and 'life satisfaction'. The keywords were indexed as major subject headings or major topics in order to identify articles specifically focusing on QOL issues. Medline searches identified 71 articles published between 1966 and December 1999. Searches in the Cinahl database produced an additional 18 articles published between 1982 and December 1999. Finally, 16 articles published between 1974 and December 1999 were found in PsycLit. Thus, a total of 105 articles were identified.

Review criteria

Two persons reviewed the abstracts. The following criteria determined the final selection of the articles reviewed:

- Report of original research
- Evaluation of QOL by self-assessment questionnaires
- Publication in English

The process yielded a total of 46 articles included in this review.

Articles were first assigned to one of the following four different classes based on the comprehensiveness of the instruments:

- Single-item measures
- Specific instruments
- Generic multi-item instruments
- Generic multi-item and specific instruments

A checklist was developed to evaluate the articles according to the Instrument Review Criteria developed by the MOT (Table 1).

The criteria were considered to be met when the following conditions were satisfied:

Reliability: Indicated by cited references or statistical tests conducted (accepted minimal standard for internal consistency reliability coefficients $\alpha = 0.70$). Test-retest information required when repeated measures were used.

Validity: Content; construct- and criterion-related validity expressed either by references or by the statistical methods used in the study.

Responsiveness: Empirical evidence, preferably by calculated effect sizes, eg, standardised response means, when a longitudinal design was adopted.

Interpretability: Comparative data available from defined reference populations.

Practicality: Information provided on at least one aspect of both respondent and administrative burden.

Cross-cultural applicability: Methods used to achieve conceptual and linguistic equivalence for translated versions of the original instrument.

Results

Single-item measures

A single-item measure was used to assess QOL in two studies.^{6,7} No information on the psychometric properties of the measure was given (Table 2).

Specific instruments

QOL was assessed by either condition- or study-specific instruments in 15 studies.^{8–22} Information about the main psychometric features of these measures is shown in Table 3.

Condition-specific instruments were used in ten studies^{9,10,12,13,17–22} and study-specific instruments were used in five.^{8,11,14–16} The condition-specific Life Situation Questionnaire (LSQ) or a revised form of the LSQ was used in all but one of the studies.^{9,12,13,17–22} Discrepancies between the number of items used and scales developed in the different versions of LSQ aggravates data analyses and interpretation. The other condition-specific questionnaire used was the Spinal Cord Injury Quality of Life Questionnaire (SCI QL-23), which was derived from a comprehensive general

Table 1 Main psychometric features of health-related quality of life instruments

Concepts	Definitions
Reliability	For example, internal consistency (Cronbach's α), reproducibility (test-retest correlation)
Validity	For example, content-related (acceptable to patients, relevant to clinicians or other focus groups), construct-related (concurrent or predictive-known groups or events analysis), criterion-related (concurrent or predictive known groups or events analysis)
Responsiveness	For example, sensitivity to clinically relevant changes (effect sizes-standardised response means)
Interpretability	For example, reference values (patient and general population databases)
Practicality	For example, respondent burden (self or proxy report), administrative burden (alternative forms)
Cross-cultural applicability	For example, translation criteria (conceptual and linguistic equivalence), psychometric evaluation (source instrument comparison)

Instrument Review Criteria of the Medical Outcomes Trust 1995. From Sullivan *et al* (1999)¹⁰², with permission.

Table 2 Studies including single-item measures. Review of psychometric properties

Author/ Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Inter- pretability	Cross-cultural applicability
Vaidyanathan <i>et al.</i> (1998) ⁶ Longitudinal	0–100 point scale	QOL Sexuality Urinary continence	–	–	–	–	n.a.
Stensman (1994) ⁷ Longitudinal	0–10 imaginary scale	QOL	–	–	–	–	n.a.

n.a. = not applicable

battery of well-established questionnaires in combination with a set of study-specific questions.²³ In two studies the same name was given to two distinct study-specific questionnaires.^{11,15}

Generic multi-item instruments

Thirteen different generic multi-item instruments were used in ten studies.^{24–33} The psychometric properties of the generic multi-item instruments are summarised in Table 4. The same set of instruments was used in two reports.^{26,30} The remaining studies contained a combination of one or several other generic multi-item instruments.

The Sickness Impact Profile 68 used by Post *et al*^{27,34} is a shortened version of the original SIP comprising 136 items.³⁵ In the study by Anke *et al*³¹ a cut-off point indicating psychological distress was proposed to interpret individual scores.³⁶ Practicality and respondent-administrative burden, were not addressed in any of these articles.

Generic multi-item and specific instruments in combination

In 19 studies, QOL was assessed by generic multi-item instruments in combination with specific instruments.^{23,37–54} The psychometric properties of the instruments, evaluated in terms of the seven attributes found in Table 1, are summarised in Table 5. A total of 25 different generic multi-item instruments and 32 specific instruments appeared in the studies. Different

combinations of instruments were used in each study. A variety of different specific instruments (study-specific, condition-specific, modified generic instruments, modified sub-scales of generic instruments, and single items from generic instruments) were applied in the studies.

The interpretability of the instrument scores, ie, their relationship to clinically recognised conditions or the need for specific treatments, were reported using The Center for Epidemiological Studies Depression Scale in the studies by Coyle *et al*^{44,45} and The Hospital Anxiety and Depression Scale in the studies by Lundqvist *et al*.^{23,48} Neither the practicality of the instruments used nor various aspects of administrative respondent burden, as defined in Table 1, was reported in any of the studies.

Discussion

Quality of life is a multidimensional concept, and the research efforts to assess QOL in SCI persons are multifaceted. As shown in this review, a wide variety of research designs has been used in QOL research throughout the years; the number of different instruments or combinations of instruments nearly equals the number of studies conducted. This is primarily due to conceptual difficulties—a universal definition of the QOL concept has not been adopted and the terminology used varies between researchers.

The variety of instruments and their core content make results difficult to compare, evaluations unpre-

Table 3 Studies including specific instruments. Review of psychometric properties

<i>Author/Study design</i>	<i>Instrument</i>	<i>Dimensions</i>	<i>Reliability</i>	<i>Validity</i>	<i>Responsiveness</i>	<i>Interpretability</i>	<i>Cross-cultural applicability</i>
Hall <i>et al.</i> (1999) ⁸ Cross-sectional	High Quadriplegia Questionnaire	Assistance/care Respiratory support Equipment costs Psychosocial information Overall QOL	—	—	n.a.	—	n.a.
	Modified version of Level of Free Time Activities Scale	Time utilisation	—	—	n.a.	—	n.a.
	Nine items from Rosenberg's Self Esteem Scale	Self-esteem	0.85 ^c	—	n.a.	—	n.a.
Krause (1998) ⁹ Cross-sectional	Life Situation Questionnaire-Revised (LSQ-R)	Engagement	0.85 ^a (mean)	—	n.a.	—	n.a.
		Negative emotions Health problems Career opportunities Finances Living circumstances Interpersonal relations Medical instability Fitness Adjustment					
Kreuter <i>et al.</i> (1998) ¹⁰ Cross-sectional	Spinal Cord Injuries Quality of Life Questionnaire (SCI QL-23)	Functioning Mood state Problems re injury Global QOL	23	23	n.a.	—	n.a.
Kuo (1998) ¹¹ Longitudinal	Quality of Life Index (QLI)	Sensation of a full bladder	—	—	—	—	n.a.
		Urinary continence Smooth voiding without dysuria Residual urine sensation Free urination					
Krause <i>et al.</i> (1997) ¹² Cross-sectional	Multidimensional Adjustment Profile (MAP)	General satisfaction	0.78 ^a (mean)	40	n.a.	—	n.a.
		Career satisfaction Home satisfaction Interpersonal satisfaction Emotional distress Skills deficit Physical discomfort Dependency Financial limitations Adjustment					

continued

Table 3 Continued

<i>Author/Study design</i>	<i>Instrument</i>	<i>Dimensions</i>	<i>Reliability</i>	<i>Validity</i>	<i>Responsiveness</i>	<i>Interpretability</i>	<i>Cross-cultural applicability</i>
Krause (1997) ¹³ Longitudinal	Revised version of LSQ	General satisfaction Economic satisfaction Emotional distress Dependency Health problems Medical instability Adjustment	0.78 ^a (mean)	—	—	—	n.a.
Liguori <i>et al.</i> (1997) ¹⁴ Cross-sectional	Study-specific Questionnaire	UTI information Bladder management Functioning Productivity Life satisfaction Global QOL	—	—	n.a.	—	n.a.
Lin <i>et al.</i> (1997) ¹⁵ Cross-sectional	Quality of Life Index (QLI)	Physical mobility Psychosocial adjustment Environment and transportation Education Economics	0.6 ^b	—	n.a.	—	—
White <i>et al.</i> (1992) ¹⁶ Cross-sectional	Study-specific Questionnaire	Twelve areas of life	—	—	n.a.	—	n.a.
Krause <i>et al.</i> (1992) ¹⁷ Longitudinal	Revised version of LSQ	Activity General satisfaction Economic satisfaction Active recreation Quiet recreation Emotional distress Dependency Health problems Medical instability Adjustment	18	—	—	—	n.a.
	Three dimension of Multidimensional personality Questionnaire (MPQ)	Positive Affectivity Negative Affectivity Constraint	—	—	—	—	n.a.
Krause (1992) ¹⁸ Cross-sectional	Revised version of LSQ	General satisfaction Economic satisfaction	0.86 ^b 0.76 ^b 0.80 ^c	—	n.a.	—	n.a.
	MPQ	Fourteen dimensions	—	—	n.a.	—	n.a.

continued

Table 3 Continued

Author/Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Interpretability	Cross-cultural applicability
Krause et al. (1992) ²⁰ Cross-sectional	Revised version of LSQ	General satisfaction Economic satisfaction Emotional distress Dependency Health problems Adjustment Life satisfaction Problem areas Adjustment Life satisfaction Psychosocial adjustment Vocational adjustment Medical adjustment Overall adjustment	0.76 ^a (mean)	—	n.a.	—	n.a.
Crewe et al. (1988) ²¹ Cross-sectional	Modified version of LSQ		—	—	n.a.	—	n.a.
Krause et al. (1987) ²² Cross-sectional	LSQ		—	—	n.a.	—	n.a.

^aCronbach's alpha; ^bInternal reliability; ^cTest-retest reliability; n.a. = Not applicable. References are given in superscript numbers

dictable and conclusions sometimes contradictory. The low psychometric standard of many of the instruments used further aggravates the interpretation of results. It is a fundamental scientific principle to establish and secure the reliability and validity of the measurement techniques. The purpose of the QOL instrument is to provide quantified assessments which are amenable to scoring index construction and statistical analysis. Several important criteria must be fulfilled in order to establish the psychometric properties of an instrument (Table 1).

Single-item measures

The single-item measurement assesses a global overall rating of perceived QOL. When global ratings are used, QOL becomes unidimensional and undefined. No further information regarding specific areas of life are provided. Quality of life indicators like this are hard to interpret and their value is questionable when used alone.

Several methodological differences were found between studies that used single-item measurements. In most studies recordings were either made on study-specific response formats^{6,7} or on visual analogue scales.^{23,48,52} Defined response categories were also used.⁵³ The scales were often labelled with different descriptors and anchor points, and the way of asking the participants to rate their perceived global QOL differed. Participants were generally not asked to rate their perceived QOL within a time frame.⁷

In the two studies that assessed QOL with single-item measures a longitudinal design with repeated measurements was adopted^{6,7}. Since the psychometric properties of the ratings used were not stated, it is questionable whether a true change can be detected and interpreted when information concerning test-retest reliability and responsiveness of the measure is unavailable. It is important to know how well an instrument reflects true change over time, especially when used to evaluate the effects of an intervention.

Specific instruments

Specific instruments are important in order to detect differences for specific conditions. The specific instruments summarised here were designed either for clinical use^{10,23} or for capturing different dimensions of QOL in studies of SCI persons. In the five studies using a study-specific questionnaire alone the psychometric properties of the instruments were not presented.^{8,11,14–16} The main problem with the use of a single study-specific instrument is the fact that it is study-specific. Consequently, comparisons with the general population are not possible, effect sizes are not calculated, information on cross-cultural applicability is not available, and the instruments cover different dimensions. The interpretation of results is thus questionable due to the unknown psychometric quality of the applied instruments.

Table 4 Studies including generic multi-item instruments. Review of psychometric properties

<i>Author/Study design</i>	<i>Instrument</i>	<i>Dimensions</i>	<i>Reliability</i>	<i>Validity</i>	<i>Responsiveness</i>	<i>Interpretability</i>	<i>Cross-cultural applicability</i>
Dijkers (1999) ²⁴ Cross-sectional	Satisfaction With Life Scale (SWLS)	Life satisfaction	0.80–0.89 ^a 0.54–0.83 ^b	55	n.a.	Various samples	n.a.
	Craig Handicap Assessment and Reporting Technique (CHART)	Dimensions of handicap	56,57	56,57	n.a.	Various samples Stroke patients	n.a.
	Functional Independence Measure (FIM)	Disability	58–61	58–61	n.a.	–	n.a.
Gianino <i>et al.</i> (1998) ²⁵ Longitudinal	Ferrans and Powers Quality of Life Index	Health and functioning Socio-economic Psychological Family	0.93 ^a /0.81 ^b	0.75 ^d	–	–	n.a.
	Sickness Impact Profile (SIP136)	Overall SIP Physical dimension Psychosocial dimension	0.94 ^a /0.92 ^b	35	–	–	n.a.
	Generic fifteen dimensional self-administered instrument (15D)	15 health related dimensions Perceived overall health status	62 –	62 –	n.a. n.a.	General population –	n.a. –
Post <i>et al.</i> (1998) ²⁷ Cross-sectional	Visual Analogue Scale (VAS) 0–100						
	Life Satisfaction Questionnaire SIP68	General life satisfaction Eight life domains Physical functioning	0.74 ^a 0.89 ^a /0.97 ^b	63 34	n.a. n.a.	General population General population	– –
		Psychological functioning Social functioning	0.80 ^a 0.87 ^a				
Post <i>et al.</i> (1998) ²⁸ Cross-sectional	Life Satisfaction Questionnaire	General life satisfaction Eight life domains	63,64	63,64	n.a.	General population	–
Westgren <i>et al.</i> (1998) ²⁹ Cross-sectional	Swedish SF-36 Health Survey	Eight domains	65–67	65–67	n.a.	General population Different patient groups	65
Kannisto <i>et al.</i> (1998) ³⁰ Cross-sectional	Generic fifteen dimensional self-administered instrument (15D)	15 health related dimensions	62	62	n.a.	General population	n.a.
	Visual Analogue Scale (VAS) 0–100	Perceived overall health status	68,69	68,69	n.a.	–	–
	General Health Questionnaire (GHQ 20)	Subjective well-being Psychological distress	36	36	n.a.	General population	–
Chubon <i>et al.</i> (1995) ³² Cross-sectional	Life Situation Survey (LSS)	QOL	0.70–0.90 ^a 0.91 ^b	70	n.a.	General population Different patient groups	n.a. –
Katz <i>et al.</i> (1987) ³³ Cross-sectional	Human Service Scale (HSS)	Seven areas of life	0.63–0.98 ^c	71	n.a.	–	–

^aCronbach's alpha; ^bTest-retest correlation; ^cSubscale homogeneity; ^dCriterion validity; n.a. = not applicable. References are given in superscript numbers

Table 5 Studies including generic multi-item and specific instruments in combination. Review of psychometric properties

Author/Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Interpretability	Cross-cultural applicability
Manns <i>et al.</i> (1999) ³⁷ Cross-sectional	Quality of Life Profile: Physical and Sensory Disabilities Version (QOLP-PSD)	QOL	0.97 ^a	72–74	n.a.	—	n.a.
	Craig Handicap Assessment and Recording Technique (CHART)	Dimensions of handicap	56	56	n.a.	—	n.a.
	Leisure Time Exercise Questionnaire	Physical activity	75	75	n.a.	—	n.a.
Richards <i>et al.</i> (1999) ³⁸ Cross-sectional	Satisfaction with Life Scale (SWL)	Life satisfaction	55	55	n.a.	—	n.a.
	Occupation Scale and items from Mobility Scale of the CHART	Occupation Mobility	—	—	n.a.	—	n.a.
	Single item from SF-36 Health Survey	Self-perceived health	—	—	n.a.	—	n.a.
	Motor component of Functional Independence Measure (FIM)	Disability	58	58	n.a.	—	n.a.
Vogel <i>et al.</i> (1998) ³⁹ Cross-sectional	SWL	Life satisfaction	55	55	n.a.	—	n.a.
	Life Satisfaction Index A (LSIA)	Life satisfaction	76	76	n.a.	—	n.a.
	CHART	Physical independence Mobility Occupation Social integration Economic self-sufficiency Ten areas of life	56	56	n.a.	—	n.a.
Krause <i>et al.</i> (1997) ⁴⁰ Cross-sectional	Study-specific Questionnaire	50 statements	—	—	n.a.	—	n.a.
	Acceptance of Disability Scale	General satisfaction	0.93 ^b /0.86 ^c	77	n.a.	—	n.a.
	Multidimensional Adjustment Profile (MAP)	Carrier satisfaction	0.89 ^a	–0.39–0.71	n.a.	—	n.a.
		Home satisfaction					
		Interpersonal satisfaction	0.66 ^a				
		Emotional distress					
		Skills deficit					
		Physical discomfort	0.51 ^a				
		Dependency	0.63 ^a				
		Financial limitations					
Lundqvist <i>et al.</i> (1997) ²³ Cross-sectional	Sickness Impact Profile (SIP136)	Adjustment Overall SIP Physical dimension Psychosocial dimension	0.83 ^a 35	35	n.a.	—	—
	Visual Analogue Scale (VAS)	Overall QOL	78	78	n.a.	—	—
	Mood Adjective Check List (MACL)	Pleasantness/ unpleasantness	79	79	n.a.	—	n.a.
		Activation/deactivation					
		Calmness/tension					

continued

Table 5 Continued

Author/Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Interpretability	Cross-cultural applicability
Boschen <i>et al.</i> (1996) ⁴¹ Cross-sectional	Hospital Anxiety and Depression Scale (HAD)	Anxiety	80	80	n.a.	—	—
	SCI Problem Scale	Depression	48	48	n.a.	—	n.a.
		Perceptions of dependence complications, social stigma					
	Sexual Interest and Satisfaction Scale	Seven items	81	81	n.a.	—	n.a.
	James Locus of Control Scale	General beliefs	0.86 ^a	82	n.a.	—	n.a.
	Self-concept Semantic Differential Scale	Adjustment	0.93 ^a	83	n.a.	—	n.a.
	Wellbeing						
	Latitude of Choice Scale	Activities	114	84	n.a.	—	n.a.
	Items from Canadian QOL Survey	Life satisfaction	0.89 ^a	—	n.a.	—	n.a.
	Residential Choice Scale	Residential satisfaction					
Warren <i>et al.</i> (1996) ⁴² Cross-sectional	LSIA	Residential choice	0.68 ^a 76	— 76	n.a.	—	n.a.
		Zest for life			n.a.	—	n.a.
		Mood tone					
		Congruence between desired and achieved goals					
	Two items from FIM	Memory independence	—	—	n.a.	—	n.a.
		Bowel independence					
	Family Satisfaction Scale	Family satisfaction	—	—	n.a.	—	n.a.
	LSS	QOL	0.87 ^a /0.91 ^a	70	n.a.	General population Different patient groups	n.a.
Coyle <i>et al.</i> (1994) ⁴⁴ Cross-sectional	Three scales from a revised version of General and Well-being Scale	Anxiety	0.88 ^a	—	n.a.	—	n.a.
		Depression	(mean)				
		Positive well-being					
	Social Health Battery (SHB)	Social participation	—	—	n.a.	—	n.a.
	Life 3 Measure	Life satisfaction	0.85 ^d	0.39–0.73 ^e 85–87	n.a.	—	n.a.
	Centre for Epidemiological Studies Depression Scale (CES-D)	Depression	0.87 ^a /0.86 ^c		n.a.	Community sample	n.a.
	Rosenberg's Self-Esteem Scale	Attitudes	0.85 ^a	88	n.a.	—	n.a.
	Mastery Scale	Construct of mastery	0.86 ^a	89	n.a.	—	n.a.
	Activity of Daily Living Scale 35-items	Activity	0.86 ^a	90	n.a.	—	n.a.
		Leisure satisfaction	0.79 ^a	—	n.a.	—	n.a.
		Family satisfaction	0.70 ^a				
		Socio-economic satisfaction	0.57 ^a				
	Two single items	Health satisfaction	—	—	n.a.	—	n.a.
		Accessibility					

continued

Table 5 Continued

Author/Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Interpretability	Cross-cultural applicability
Coyle <i>et al.</i> (1993) ⁴⁵ Cross-sectional	SWL	Life satisfaction	0.77 ^a /0.82 ^d	0.57–0.68 ^{85,86}	n.a.	Students	n.a.
	CES-D	Depression	0.86 ^a /0.86 ^d		n.a.	—	n.a.
	Modified sub-scale of Psychosocial Adjustment to Illness Scale	Social time activities Leisure time activities	—		n.a.	—	n.a.
Fuhrer <i>et al.</i> (1992) ⁴⁶ Cross-sectional	LSIA-A	Zest for life Mood tone Congruence between desired and achieved goals	76,91	76	n.a.	General population	n.a.
	CHART	Mobility Social integration Occupation	56	56	n.a.	—	n.a.
	Self-report version of FIM	Independence in activities of daily life	92	92	n.a.	—	n.a.
	Social Support Scale	Total support	93	—	n.a.	—	n.a.
	Likert type scale	Health	—	—	—	—	n.a.
	Three items from Perceived Stress Scale	Perceived control	—	—	n.a.	—	n.a.
	Study-specific Questionnaire	Life satisfaction	—	—	n.a.	—	n.a.
	LSIA-A	Zest for life Fortitude Physical, psychological, social self-concept	0.76 ^a	94	n.a.	—	n.a.
	CES-D	Mood tone Depression Hopefulness	0.84–0.90 ^a	0.50–0.70 ^f	n.a.	—	n.a.
Lundqvist <i>et al.</i> (1991) ⁴⁸ Cross-sectional	Self-assessed health status	Wellbeing	93	—	n.a.	—	n.a.
	Social Support Scale	Support satisfaction	0.90 ^a	—	n.a.	—	n.a.
		Total support					
	SIP136	Overall SIP	35	35	n.a.	General population women	95
		Physical dimension					
	VAS	Psychosocial dimension	96	96	n.a.	—	n.a.
	MACL	Overall QOL	79	79	n.a.	General population	n.a.
		Pleasantness/unpleasantness					
		Activation/deactivation					
	HAD	Calmness/tension Anxiety	80	80	n.a.	—	—
	SCI Problem Scale	Depression Perceptions of dependence, complications, social stigma	0.86 ^a	48	n.a.	—	n.a.

continued

Table 5 Continued

<i>Author/Study design</i>	<i>Instrument</i>	<i>Dimensions</i>	<i>Reliability</i>	<i>Validity</i>	<i>Responsiveness</i>	<i>Interpretability</i>	<i>Cross-cultural applicability</i>
Nieves <i>et al.</i> (1991) ⁴⁹ Cross-sectional	Coping Effectiveness Questionnaire	Coping effectiveness	0.90 ^a	0.68 ^g	n.a.	—	n.a.
	Revised version of Pandilla/Grant's Quality of Life Index	Psychological well-being Physical well-being Body image concerns Diagnosis and treatment responses Social concerns	—	—	n.a.	—	n.a.
Boschen <i>et al.</i> (1990) ⁵⁰ Cross-sectional	James Locus of Control Scale	General beliefs	82	82	n.a.	Students General population	n.a.
	29 items from Canadian QOL Survey	Life satisfaction Residential satisfaction	—	—	n.a.		n.a.
Dunnum (1990) ⁵¹ Cross-sectional	Life Satisfaction in the Elderly Scale (LSES)	Social contacts	97	97	n.a.	—	n.a.
		Mood					
		Self-concept					
		Meaning					
		Daily activities					
		Health					
		Goals					
		Finances					
		Barthel Index	98	98	n.a.	—	n.a.
		Single items	—	—	n.a.	—	n.a.
Siösteen <i>et al.</i> (1990) ⁵² Cross-sectional	SIP136	Transportation	35	35	n.a.	—	—
		Overall SIP					
	VAS	Physical dimension					
		Psychosocial dimension	99	99	n.a.	—	—
	MACL	Overall QOL	79	79	n.a.	—	n.a.
		Pleasantness/unpleasantness					
	HAD	Activation/deactivation					
		Calmness/tension	80	80	n.a.	—	—
	Self-care and Mobility Index	Depression					
		Physical function	0.79 ^a	—	n.a.	—	n.a.
Yerxa <i>et al.</i> (1986) ⁵³ Cross-sectional	Cantril Ladder	Accessibility of the environment	—	—	—	—	n.a.
		General life satisfaction	100	100	n.a.	—	n.a.
	Rotter I-E Scale	Perception of internal and external control	101	101	n.a.	—	n.a.
		Recorded occupations during eight days	0.37–0.88 ^b 0.27–0.74 ^d	—	n.a.	—	n.a.
	Modified Activity Configuration Log						

continued

Table 5 Continued

Author/Study design	Instrument	Dimensions	Reliability	Validity	Responsiveness	Interpretability	Cross-cultural applicability
Decker et al. (1985) ⁵⁴ Cross-sectional	The Satisfaction with Performance Scaled Questionnaire (SPSQ)	Home management skills	—	—	n.a.	—	n.a.
		Social problem solving skills	—	—	n.a.	—	n.a.
	Two single questions LSIA-A CES-D	Community problem solving skills	—	—	n.a.	—	n.a.
		Overall life satisfaction	0.76 ^a	0.78–0.99 ^g	n.a.	General population	n.a.
		Psychological well-being	0.83 ^a	85	n.a.	—	n.a.
Social Support Scale	Perceived Control Scale	Depression	0.54 ^d	—	—	—	—
		Instrumental support	0.77 ^e	—	—	—	—
		Affective support	0.70 ^a	—	n.a.	—	n.a.
Single item	Single item	Cognitive support	—	—	n.a.	—	n.a.
		Perceived control	0.81 ^a	—	n.a.	—	n.a.
Health status	Health status	Health status	—	—	—	—	n.a.
		Health status	—	—	—	—	n.a.

^aCronbach's alpha; ^bInternal consistency; ^cSplit-half reliability; ^dTest-retest correlation; ^eConvergent validity; ^fConcurrent validity; ^gConstruct validity; n.a. = not applicable. References are given in superscript numbers

Only two condition-specific instruments, SCI QL-23²³ and LSQ⁴⁰, have been validated. There is a need for carefully constructed condition-specific instruments that can capture dimensions of specific interest for the SCI population, especially for clinical use. Most of the specific instruments were created for a specific purpose in a single study. The evaluation of the psychometric properties of the reviewed instruments was generally poorly stated and should be improved. The use of condition-specific instruments are recommended in combination with generic measures.

Generic multi-item instruments

The use of generic multi-item instruments, which measure general aspects of physical and/or mental health, functioning and well-being, enhance standardised methods when assessing QOL. A disadvantage to the exclusive use of generic measures is that condition-specific areas of life are often not sufficiently covered and floor and ceiling effects may be more common in patients with SCI than among persons in the general population. Thus, generic multi-item instruments might not distinguish those individuals with limitations caused by SCI. On the other hand, comparisons with persons from the general population and/or other patient groups are informative. The interpretability of data is strengthened when results can be compared between different SCI study populations and between SCI and non-SCI control populations. Multi-national studies require that the instruments have cross-cultural applicability. Cultural and language adaptations of the generic multi-item instruments were only reported and addressed in two studies, the Swedish versions of the SF-36 Health Survey and the SIP.^{29,48} The procedures for language adaptations should be pointed out and explained. Several forward and backward translations, psychometric evaluation, and field tests are necessary to ensure comparability with the original instrument.

A variety of different generic instruments have been used in QOL research, making comparisons of results difficult. Quality of life is sometimes defined either as the degree of subjective well-being and psychological distress³¹ or by a broader set of dimensions covering physical function, physical and emotional role function, social function, bodily pain, mental health, vitality, and general health, ie, the health dimensions of the SF-36 Health Survey.^{29,48}

The reliability and validity of the generic instruments used are stated but there is not always evidence that they were tested on an SCI population. It is proposed that standardised well-established generic questionnaires, tested on the SCI population, be used in future research.

Combination of generic multi-item and specific instruments

The combination of generic multi-item and specific instruments unites general standardised methods and

more specific areas of interest for a multidimensional approach. Most of the specific instruments used in combination with the generic instruments were either modified generic instruments or study-specific instruments. The lack of condition-specific instruments as a complement to the broader generic instruments is noteworthy.

The number of questionnaires and items used in each study increased with the use of a set of multidimensional instruments. However, the respondent and administrative burden of the battery is seldom addressed. It is important to state the time necessary to complete and administer the form, and the need for any special resources when the instrument is filed and analyzed. Furthermore, the instrument should not cause any emotional or physical constraint to the respondents. Administrative burden can also involve information about acceptable levels of missing data. With the use of comprehensive measurements, the practicality of the measurement must be discussed. Quality of life measurement at the clinical level needs validated comprehensive instruments with a reasonable amount of respondent and administrative burden.

Conclusion

Quality of life research in SCI subjects needs to improve from a methodological standpoint. Many scientists and clinicians are creating their own instruments in the course of their research. It is important to use instruments that are already proven reliable and valid. If new instruments are to be developed for a specific study the psychometric properties of the instrument need to be determined and tested. It is important to use high-quality standardised outcome measurements in order to detect and compare results from interventions. Consensus about the use of a limited number of standardised QOL measures (generic, condition-specific, overall ratings) is desirable in order to improve contemporary and future research.

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