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Research Summary – Spinal Cord Injury – Quality of Life (SCI-QOL) – Quality of Life

Author Year Country Research Design Setting	Demographics and Injury Characteristics of Sample	Validity	Reliability	Responsiveness Interpretability
Cohen et al. (2018) (pain behavior assessment) Grounded-theory based qualitative item development; large-scale item calibration field-testing; confirmatory factor analyses; graded response model item response theory analyses; statistical linking techniques to transform scores to the Patient Reported Outcome	N=757 SCI % Female: 20.9% Mean age 42.9 years, SD 15.5 years Level: 23.9% Paraplegia complete,18.5% Paraplegia incomplete, 23.1% tetraplegia complete, 34.4% tetraplegia incomplete Etiology: 32.4% motor vehicle accident, 22.3% fall, 11.8% gunshot wound/violence, 6.6% diving, 7.4% other sports, 3.7% medical/surgical accident, 2.6% motorcycle accident,		**Test-retest reliability:** r=0.84 (ICC = 0.83)	**Mean score (SD):** 53.10 (9.89)

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Measurement Information System (PROMIS) metric. Five SCI Model Systems centers and one Department of Veterans Affairs medical center in the United States.	6.2% other or not reported Duration: Mean 6.7 years, SD 9.9 years <1 year (28.9%), 1–3 years (27.6%), >3 years post injury (43.5%)			
Tulsky et al. (2015) (SCI-QOL bladder management scale) Development and Validation study University of Michigan,	N=757 SCI % Female: 20.9% Mean age 42.9 years, SD 15.5 years Level: 23.9% Paraplegia complete,18.5% Paraplegia incomplete, 23.1% tetraplegia complete,	Item/total correlations for bladder complications ranged from 0.38 to 0.60 Item/total correlations for bladder management difficulties ranged from 0.38 to 0.78.	Bladder management difficulties: internal consistency: α=0.91 Bladder complications internal consistency: α=0.72 Bladder management difficulties: Test-retest reliability: r=0.77 (P < 0.01)	

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Kessler Foundation Research Center, the Rehabilitation Institute of Chicago, the University of Washington, Craig Hospital, and the James J. Peters VA Medical Center, Bronx, NY	34.4% tetraplegia incomplete Etiology: 32.4% motor vehicle accident, 22.3% fall, 11.8% gunshot wound/violence, 6.6% diving, 7.4% other sports, 3.7% medical/surgical accident, 2.6% motorcycle accident, 6.2% other or not reported Duration: Mean 6.7 years, SD 9.9 years <1 year (28.9%), 1–3 years (27.6%), >3 years post injury (43.5%)		ICC = 0.76 Bladder complications: Test-retest reliability: r=0.70 (P < 0.01) ICC = 0.69	
[Bertisch et al. (2015)](#) (SCI-QOL PAWB)	N=717 SCI % Female: 22% Mean age 43.0 years, SD 15.3 years		**Internal consistency:** α=0.970	RMSEA = 0.094

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Qualitative feedback from patient and provider focus University of Michigan, Kessler Foundation, Rehabilitation Institute of Chicago, the University of Washington, Craig Hospital and the James J. Peters/Bronx Department of Veterans Affairs hospital.	Level: 25% Paraplegia complete, 20% Paraplegia incomplete, 22% tetraplegia complete, 32% tetraplegia incomplete Ethnicity: 70% Caucasian, 17% African American, 1% Asian, 1% American Indian Duration: Mean 7.1 years, SD 10 years <1 year (27%), 1–3 years (26%), >3 years post injury (47%)			
Kalpakjian et al. (2015) (self esteem) Mixed Methods	N=717 SCI % Female: 22% Mean age 43.0 years, SD 15.3 years			

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Michigan, Kessler Foundation, the Rehabilitation Institute of Chicago, the University of Washington, Craig Hospital, and the James J. Peters/Bronx Department of Veterans Affairs hospital.	Level: 25% Paraplegia complete, 20% Paraplegia incomplete, 22% tetraplegia complete, 33% tetraplegia incomplete Ethnicity: 70% Caucasian, 17% African American, 1% Asian, 1% American Indian Duration: Mean 7.1 years, SD 10 years <1 year (27%), 1–3 years (26%), >3 years post injury (47%)			
[Victorson et al. (2015)](#) *Same data set as Kalpakjian et al. 2015	N=717; Mean (SD), N (%) Female 158 (22%) Male 559 (78%) Age 43.0 years (15.3) Age at injury: 36.1 years (16.8)		**Test-retest reliability:** When comparing the SCI-QOL Resilience CAT at baseline with the CAT score from the 1-2 week follow up	

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Development, validation and psychometric characteristics of the SCI-QOL	Time since injury: 7.1 (10.0) <1 year post injury 196 (27%) 1–3 years post injury 186 (26%) >3 years post injury 335 (47%) Diagnosis: Paraplegia complete 182 (25%) Paraplegia incomplete 143 (20%) Tetraplegia complete 157 (22%) Tetraplegia incomplete 231 (33%) Unknown 4 (0%) Race: Caucasian 505 (70%) African-American 125 (17%)		assessment (n= 245), Pearson's r= 0.79 (P < 0.01) and ICC(2,1) = 0.79 (95% CI: 0.74 to 0.83).	

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	Asian 8 (1%) American Indian/Alaska Native or Native Hawaiian/Pacific Islander 7 (1%) More than one race 9 (1%) Other 50 (7%) Not provided/Refused 4 (1%)			
Tulsky et al. (2015) (SCI-QOL depression scales) Development and Validation study Five SCI Model System centers and one Department of Veterans Affairs	N=716 SCI % Female: 22% Mean age 43.0 years, SD 15.3 years Level: 25% Paraplegia complete, 20% Paraplegia incomplete, 22% tetraplegia complete, 32% tetraplegia incomplete	Correlation with PHQ-9 scores: r = 0.76	**Internal consistency:** α=0.72 **Test-retest reliability:** r=0.80 (ICC = 0.80)	

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medical center in the United States.	Ethnicity: 70% Caucasian, 17% African American, 1% Asian, 1% American Indian Duration: Mean 7.1 years, SD 10 years <1 year (27%), 1–3 years (26%), >3 years post injury (47%)			
Ebrahimzadeh et al. (2013) Validity and reliability study Mashhad University of Medical Sciences, in Mashad, Iran	N=52 SCI Mean age 49.3 years, SD 7.9 years % Incomplete paraplegia: 88.5%		**Internal consistency:** α=0.764	
Tulsky et al. (2011)	N=65 SCI N=42 clinicians			

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Focus Groups Four SCI Model Systems rehabilitation hospitals	% Female: 27.7% Mean age 45.6 years, SD 14.2 years Level: 52.4% paraplegia, 47.7% tetraplegia Ethnicity: 69.2% Caucasian, 20.0% African American, 6.2% Hispanic, 3.1% Native American Duration: Mean 12.6 years, SD 11.5 years Assistive technology use: 84.6% wheelchair, 14.3% cane/crutches/walker, 2.0% none			