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ARTICLE



A cross-cultural mixed methods validation study of the spinal cord injury quality of life basic dataset (SCI QoL-BDS)

Edward J. Rohn^{1,2}✉, Aline J. Hakbijl-van der Wind³, Marcel W. M. Post^{3,4}, Martin Forchheimer⁵, Susan Charlifue⁵, Peter W. New^{6,7,8}, Julia M. D. Greve⁹ and Denise G. Tate²

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STUDY DESIGN: Mixed methods inquiry using cognitive interviews and thematic content analysis.

OBJECTIVES: Cross-validation of the concept of quality of life (QoL) and of the International Spinal Cord Injury Quality of Life Basic Data Set (SCI QoL-BDS) items across five sites in four countries: United States, Australia, Brazil, and the Netherlands. Analysis aimed to uncover patterns, differences, and similarities suggesting conceptual equivalence for overall QoL and the three SCI QoL-BDS items.

SETTING: International, community.

METHODS: Semi-structured cognitive interviews with 51 participants across five sites and four countries. Participants with spinal cord injury/disease (SCI/D) completed the SCI QoL-BDS items and one additional question. Interviews were audio recorded and transcribed. Transcripts were coded using NVivo software. Coded data were analyzed using thematic content analysis. Seventeen themes were identified. Responses by sites were compared for conceptual equivalence.

RESULTS: Across the five sites, equivalence in the conceptual meaning of QoL was found based on the frequent commonalities in terminology employed to describe it. Despite sample differences in terms of demographic and SCI characteristics, participants across all sites replied to the SCI QoL-BDS items in a similar way, suggesting good item equivalence. Qualitatively, the differences noted with respect to the use of themes for each question suggest some variability on how participants with SCI/D describe QoL. In spite of these contextual differences, there is a high degree of commonality not explained by participants' demographic or injury/disease characteristics.

CONCLUSIONS: The SCI QoL-BDS shows good cross-cultural validity among the international sites included in this study.

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INTRODUCTION

The World Health Organization (WHO) defines quality of life (QoL) as an “individual’s perception of their position in life in the context of their culture and value system in which they live, and in relation to their goals, expectations, standards, and concerns” [1]. This definition underscores the subjective nature of QoL as it reflects individuals’ overall perception of and satisfaction with their different experiences. Many have noted the difficulties associated with interpreting the subjective meaning of QoL [2–5]. The WHO definition further implies that meaning and levels of QoL are likely to be different across the globe. Research has shown, for example, significant associations between QoL and societal conditions [6].

The consequences of spinal cord injury or disease (SCI/D) include issues of functional capacity, personal and social relationships, financial loss, loss of bowel and bladder function, sexual function, chronic pain, and lack of accessible environments [7]. Unsurprisingly, these issues impact QoL for individuals with SCI/D

[8, 9]. International comparative studies on QoL among individuals with SCI/D are sparse but show converging results, suggesting similarities in what makes life meaningful that transcend national boundaries [10]. Yet, differences in QoL between countries that could not be completely explained by differences in demographic and SCI/D characteristics point to the potential impact of social and cultural differences [11, 12].

The demand is increasing for QoL research of cross-national comparisons or aggregation of data across societies [13]. Such research is important to inform the development of national policies and international principles to deter stigmatization and discrimination of people with SCI/D. Therefore, it is important to ensure that QoL measures developed in one society are equally valid for use in others [14]. Subjective concepts, such as QoL, require similar understanding and interpretation of meaning to ensure comparability of results. The process of achieving cross-cultural validation is often complex and includes congruency of

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conceptualization and item content, accuracy in translation, and establishment of key metrics such as reliability, validity, and responsiveness to change [15].

Conceptual equivalence (CE) is a key concept in assessing cross-cultural validity of QoL measures [16]. CE refers to whether or not a given domain has similar meaning and salience across different cultures. For instance, emotional and relational domains may have a higher salience for overall QoL in one country than another [17]. This issue is particularly relevant to the International Spinal Cord Injury Quality of Life Basic DataSet (SCI QoL-BDS), developed with the purpose of standardizing the collection and reporting of a minimal amount of information necessary to merge and compare results of studies on QoL across the globe [18]. Preliminary evidence suggests cross-cultural validity of the SCI QoL-BDS [10], but the equivalence of meaning of the SCI QoL-BDS is still in need of research. This study was designed to address cross-cultural CE, while examining response differences across international sites. The purpose of this article is to describe the results of this inquiry.

METHODS

Design

This study utilized a mixed methods approach guided primarily by qualitative methods and using cognitive interviews (CI). CI are used to improve reliability and validity of new measures by showing how respondents interpret concepts and understand the survey questions they are asked [19]. CI are routinely administered as part of questionnaire design, piloting and refinement, and can be particularly helpful when attempting to measure abstract concepts like QoL [20]. Quantitative analyses were complementary. The study was conducted in 2017–2019 as part of a larger validation of the SCI QoL-BDS across five sites across four countries: Ann Arbor and Denver (United States), Melbourne (Australia), São Paulo (Brazil), and Utrecht (the Netherlands) [21]. Each of the five sites recruited 8–12 participants living in the community utilizing a convenience sampling approach. Eligibility criteria included diagnosis of SCI/D,

minimum of 18 years of age, and completion of informed consent. Exclusion criterion was the inability to complete the interview due to cognitive or psychiatric limitations. Trained research interviewers assessed participants' cognitive ability during the recruitment and consent process to assure ability to understand instructions, attend to the questions, and their ability to express their thoughts accordingly. Participants were recruited mainly through affiliated hospitals and clinics at the respective sites. Medical information was made available by these facilities.

CI were conducted to examine similarities in the meaning of QoL and the interpretation of the SCI QoL-BDS questions across sites [22]. CI is a semi-structured method for determining how people understand and respond to questions [23–26]. CI were conducted in person or via phone. Interviews lasted 30–40 min, were audio recorded, and transcribed. Interviews were conducted in the native languages. Responses to the research questions were transcribed and, for the São Paulo and Utrecht sites, translated into English by authors who are fluent in both English and their relevant language. Researchers from each site participated in the design of the interviews and training on qualitative methods used for CI.

Measure

Participants were asked the opening question, "How would you define the concept of QoL?" to elicit their definitions of QoL. This question was followed by the three items of the SCI QoL-BDS. The three items are: (1) Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole during the past 4 weeks? (2) How satisfied are you with your physical health in the past 4 weeks? (3) How satisfied are you with your psychological health, emotions, and mood during the past 4 weeks? All items were rated on a scale of 0 (completely dissatisfied) to 10 (completely satisfied). Each of these questions was followed by semi-standard probes based on the context of respondents' answers in order to gain a better understanding of their perspectives. This process allowed for determination of whether the SCI QoL-BDS items made sense to respondents, if the items were relevant and understood consistently, and if there were circumstances under which it was difficult to respond to them appropriately. These follow-up discussions allowed respondents to identify key areas within the QoL construct that impacted their QoL, providing detailed contexts to their numerical responses. Lastly, they were

Table 1. Demographics, neurological data, and scores on the Spinal Cord Injury Quality of Life Basic DataSet (SCI QoL-BDS).

	Total	Ann Arbor	Denver	Melbourne	São Paulo	Utrecht	Sig
Number of Participants	51	10	8	10	11	12	
Sex %							
Male	59.6%	70.0%	66.7%	60.0%	63.6%	41.7%	$p = 0.678$
Female	40.4%	30.0%	33.3%	40.0%	36.4%	58.3%	
Age mean (SD)	55.9 (12.9)	50.9 (12.0)	61.3 (5.9)	61.0 (10.0)	46.6 (9.9)	60.8 (16.4)	$p = 0.014^a$
Years Since Onset mean (SD)	14.0 (12.9)	16.3 (11.4)	13.9 (16.5)	8.2 (10.1)	17.0 (12.4)	13.6 (12.2)	$p = 0.617$
Years of Schooling mean (SD)	13.8 (4.1)	14.0 (2.4)	15.0 (2.5)	14.9 (4.0)	9.5 (3.8)	15.7 (4.1)	$p = 0.001^b$
Type of Impairment %							
SCI	62.7%	80.0%	66.7%	33.3%	81.8%	50.0%	$p = 0.125^c$
SCD	37.3%	20.0%	33.3%	66.7%	18.2%	50.0%	
Level of Impairment %							
Paraplegia	62.7%	40.0%	66.7%	44.4%	88.9%	66.7%	$p = 0.117$
Tetraplegia	37.3%	60.0%	33.3%	55.6%	11.1%	33.3%	
Scores on SCI QoL-BDS							
Satisfaction with life as a whole mean (SD)	6.2 (1.8)	6.5 (1.4)	5.1 (2.4)	5.8 (1.7)	6.9 (1.6)	6.5 (1.8)	$p = 0.214$
Satisfaction with physical health mean (SD)	6.7 (2.0)	7.1 (1.8)	5.1 (2.3)	5.4 (1.7)	7.7 (2.0)	7.5 (1.0)	$p = 0.003^d$
Satisfaction with psychological health mean (SD)	6.6 (2.4)	7.5 (2.9)	5.7 (2.2)	6.4 (1.5)	6.6 (3.3)	6.8 (1.7)	$p = 0.587$

^aSão Paulo participants are significantly younger than those from Denver ($p = 0.01$), Melbourne ($p = 0.009$), and Utrecht ($p = 0.006$).

^bSão Paulo participants have completed significantly less schooling than those from all other sites: Ann Arbor ($p = 0.005$), Denver and Melbourne ($p = 0.001$), and Utrecht ($p < 0.0005$).

^cPlease note that differences between the number of traumatic (SCI) and non-traumatic cases (SCD) were not statistically significant since Utrecht samples equal numbers of participants from both groups.

^dSão Paulo participants had significantly higher ratings of their physical health than did those from Denver ($p = 0.002$) and Melbourne ($p = 0.004$). Utrecht participants had significantly higher ratings than did those from Denver ($p = 0.004$) and Melbourne (0.008).

Table 2. Theme definitions and examples.

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
<i>Physical factors</i>			
1. Complications and comorbidities	101 (11.1%)	Complications: physical problems related to the SCI/D, e.g., pain, fatigue, or bladder or bowel issues. Comorbidities: physical problems not usually related to SCI/D; e.g., arthritis; high cholesterol.	<i>It's constantly throbbing...sometimes it's hard to grasp and hang onto things...My feet are always numb and throbbing...It's very discomforting and never lets up... It has cut my quality of life in half. I've got a bladder that doesn't work. I've got a bowel that I have no idea what it's doing half the time... I feel like I need to go all the time... you sit on there and nothing happens... It's just all that gets to you.</i>
2. Physical ability and functional limitations	68 (7.5%)	Physical and bodily functions, including physical limitations arising from it; e.g., dependence on others, exercise, transfers, sexuality and general function.	<i>The dependency on others, I have to lower the bar for my physical and mental capacity. Without the SCI I would have more energy, would have been happier. Compared to shortly after the SCI, my independence has deteriorated. I could dress myself, go to bed independently. My wife did not need to help me... I'm older now and it becomes more difficult.</i>
3. Physical health and wellbeing	69 (7.6%)	Overall health of the body, being healthy or sick. It includes also aging with SCI and maintenance of health; e.g., medication, diet, sleep, smoking.	<i>My health is not 100%, it is only 50%. I have a heart monitor, I have a pacemaker, so... I am often tired. And freezing. I'm getting enough sleep, I'm eating alright. I'm looking after myself, but I'm trying to do as much physical activity as I can, just to keep moving. Yeah, I'm doing as much as I can.</i>
<i>Environmental factors</i>			
4. Access and barriers	47 (5.2%)	Accessibility of public spaces and their own living environment. Also includes issues of driving, public transportation and living conditions, e.g., access related to living alone.	<i>Accessibility it's better now, but it has to improve more. There are still many hotels that are not accessible even though they say they are. Prejudice against wheelchair user still exists... When I want to go somewhere, there are always barriers, you can't do everything you could do when you were healthy... When I want to go to a restaurant... I have to check that the place is accessible first. That is a limitation, but if it is accessible then I go, that is freedom for me.</i>
5. Basic resources	16 (1.8%)	Availability of basic needs and financial issues, including funding, income, insurance coverage and financial security, e.g., home, food, money issues.	<i>My basic needs are fulfilled, I eat as much as I want, I have a place to live... all my needs are well taken care of beyond what is necessary... I have nothing because I'm now on long-term disability... my job is to look after my household finances...</i>
6. Caregiving and caregivers	16 (1.8%)	Caregivers: formal and informal assistants who help in daily care and/or transportation. Or caregiving: the quality of care, e.g., satisfaction, relationship with caregiver.	<i>Maybe how we feel having to adapt having people coming into our lives to have to do things for us. Like having carers, having people help wash you or physio and all of those, the changes in your whole lifestyle. The care you get also determines your QoL. I'm very happy w/ our home care. But in cases when you would not be satisfied with the care you get, that would impact your QoL. This is an important aspect.</i>
7. Healthcare systems and services	31 (3.4%)	Includes organization and bureaucracy of care and finances. Or services: availability of medication and medical devices, and access to providers, e.g., psychologist, specialists, surgery scheduling.	<i>The state has also started becoming overly active in making it difficult to find caregivers. Expensive classes, first aid, CPR, DNR... It's difficult to find quality caregivers. I do have a spinal clinical nurse. She rings me once a week, once a fortnight. But she's overseas in Sri Lanka at the moment. And she's been fantastic. And I don't know where they're from... She's organized... She put me onto the right medical and the cheapest medical suppliers... she's been fantastic.</i>
<i>Social factors</i>			
8. Activities, hobbies, and recreation	37 (4%)	Filling time with daily activities, hobbies, sports, or travel. Staying active and the planning in advance of an activity is also included.	<i>I try not to think too much. I have my activities. Today I drive, I go to church, I have my social life always active. That's make me feel good. To go out, to walk, to live well, not have frustrations</i>

Table 2. continued

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
			<i>and resentment. I'm a para-athlete, I have many medals and I love sports. I love to play games... live life.</i>
9. Relationships (immediate)	55 (6%)	Quality and solidarity of relationships with family and family support, including a significant other or romantic partner. Includes the perceived importance and impact on SCI/D.	<i>I still have a loving wife. You know, I still get to see each day and greet it and to conquer it. I think that's a pretty big QoL. I'm still able to hold my grandbabies and see my children. Psychologically, adding everything family, home, it is complicated. So my family, atmosphere is a little tense. It disrupts my psychological balance caused by family complications and fights.</i>
10. Relationships (social)	66 (7.2%)	Quality and solidarity of relationships <u>outside</u> immediate family or romantic relationships, including talk of shared activities with friends and connectedness with others.	<i>Being able to visit my friends... because even though I've got a mobile wheelchair, that will only get me within a five kilometer radius of my house, where I have friends that are 60 or 70 kilometers away, I'm part of a religious community in the village. It's unbelievable what these people do for me... I'm part of this since I moved here 4 years ago. It gives me much strength to go on, praying, reading the bible, taking part in meetings, the sense of togetherness...</i>
11. Work and school	19 (2.1%)	Jobs, gaining or losing employment, volunteer work, time in or away from jobs or school, and how these have been impacted by SCI/D.	<i>When I stopped working, I immediately started searching for volunteer work. You have to get your sense of accomplishment from something... It is satisfactory to hear from people that you do a good job... I recently found a job where I'm in contact with many people... Thanks to my new job, I talk to many people. I do everything to keep my head working. It feels good to help people...</i>
<i>Personal factors</i>			
12. Ability and autonomy	53 (5.8%)	Determination/reflections on freedom/ability to do things, despite disability. This includes meeting expectations from others, (in) dependence, and quality and quantity of desired activities.	<i>The ability to do what I want to do without any sort of impediment. And, for me, my quality of life involves being independently able to move and drive and travel and work and socialize. Just because you're used to being able to do things a certain way, once after you've had the spinal cord injury, you're restricted in that way. It takes longer to do things, and maybe you can't do them as well as you used to, but you still get them done...</i>
13. Coping and adjustment	106 (11.6%)	Psychological responses to disability and their life after injury or disease, including ability to cope, evaluate, have hope, reframe their situation, and recalibrate expectations.	<i>If I could go back and stop the 3-wheeler from flipping on me, I wouldn't do it... because I wouldn't be the man that I am today if it wasn't for that event... You can say, you have so many limitations and you can go nowhere anymore. That is life and you should consider that in the rating, but if you focus on what you can't do anymore, QoL will be low. Considering all my limitations, I feel life isn't that bad...</i>
14. Purpose and identity	97 (10.6%)	Identity, overall philosophy about life, reflections on self-value rather than efficacy or emotionality.	<i>I was always the guy that motivated and the guy that made things happen... I am no longer that person, but you know, there is an acceptance after, but I'm strong willed, I have hope. I can talk normally to other people, not as a sick-person. I've left the being-sick behind me. It would be bad if this would dictate your life and attitude toward life...</i>
<i>Emotional factors</i>			
15. Emotions (negative)	66 (7.2%)	Negative emotional reactions to circumstances, including anxiety, anger, frustration, sadness, and suicidal ideation, caused by all aspects of life.	<i>I struggle everyday with depression. I struggle everyday with anxiety. I struggle everyday with trying to push myself and not giving up and it's very difficult and my emotions are all over the place, mostly sad, mostly mad, because I get mad at it when I can't do things. That's very heartbreaking and it adds to depression for me... thinking that I'm just not good enough or</i>

Table 2. continued

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
16. Emotions (positive)	30 (3.3%)	Positive emotional reactions to circumstances, including happiness and thankfulness, joy, excitement, and being in good spirits, caused by all aspects of life.	<i>it makes me feel less of a person and makes me feel worthless, and it also adds to the anxiety as well.</i>
17. Loss	35 (3.8%)	Reflections on what is no longer in one's life after SCI/D, grief and the feelings of mourning, e.g., loss of independence, relationship, physical function, control, activities.	<i>Nothing's really changed, okay, so I've always been pretty upbeat about all things and always try to have hope and that amplifies your mental attitude. Looking at it from 30,000 feet and how I see my life in different segments and I think the quality of my life is fantastic. I could not have asked for a better life. I'm very happy, very content, I'm on solid ground, I mean I love where I'm at. I'm very happy.</i> <i>I miss feeling in my feet. I miss my favorite cowboy boots. I miss fashion and standing up tall in a crowd and physically commanding attention in a room. I used to be a magnetic personality and I'm not that anymore at all.</i> <i>Life isn't as exciting anymore... Through my work I came across different things, like tickets for soccer games or DJs. Now I don't have enough energy to go with my friends. So, my social life has gone down a bit.</i>

^aNumber of topic codes were tabulated by NVivo. This number reflects the number of text segments to which the topics included in this theme ($N = 912$) were discovered across the entire text of all the interview transcripts. The percentages reflect the frequency of each theme across all coded text of all the interview transcripts, as a function of the total number of topics ($N = 912$).

^bAcronyms: SCI (spinal cord injury), SCI/D (spinal cord injury/disorder), QoL (quality of life), CPR (cardiopulmonary resuscitation), DNR (do not resuscitate).

asked if there were any other issues that were not mentioned by the items that influenced their QoL.

The SCI QoL-BDS was translated using back translation methods recommended by the International DataSets Committee using two native speakers of the required languages (Dutch and Brazilian Portuguese) and English [21, 27, 28]. Translations were adjusted to be contextual and idiomatically meaningful to each site and language.

Analyses

Thematic content analysis was used to uncover patterns within the data, following established approaches in thematic analysis [29, 30]. Four principle authors (EJ Rohn, MWM Post, AJ Hakbijl, and DG Tate) read the interview transcripts to gain an overall sense of the content and quality of the data. These four authors independently identified and coded topics in the data using NVivo, a qualitative data analysis software (NVivo 12) [31]. This software helps organize and find insights in qualitative data using coding functions that link text to codes, facilitating the identification of patterns within the data. Inductive open coding was used to allow meaning to emerge from the participants' own words. Redundant topic codes were collapsed together, resulting in 1067 discrete topics across all the text data. Topics with similar content or expressed ideas were combined further into 39 larger categories of related topics. Of these topical categories, 17 included by far the most topics (912 topics in the top 17; 155 topics across the bottom 22), and were treated as qualitative themes [32, 33]. These themes represented repeated, patterned expressions across multiple respondents, suggesting salient, self-defined feelings, experiences, and values therein [34, 35]. Consensus was reached at each step by teams of two principle authors working together, reviewing the work of the others on the same task, and followed by repeated discussions among all four principle authors [36].

In order to check the frequencies and distributions of themes, NVivo was used to identify the relative percentages of where the text coded at each of the 17 themes intersected with each site and each question item. This percentage represents the amount of text dedicated to discussions of all the topics combined in that theme, across each of the 17 themes. We grouped these themes further by broad components of participants' lives (i.e., physical, environmental, social, personal, and emotional factors) into theme categories to facilitate CE comparisons of broadly related ideas [37]. The frequencies of the themes and theme categories in response to each question (i.e., QoL definition and the three SCI QoL-BDS items) were treated as indicators of salience and the participants' understanding of these questions, allowing comparisons across sites. CE was suggested in cases where similar percentages of themes were found in response to an item, across sites, by each of the items in the measure. The senior authors

held additional lengthy consensus-building discussions to confirm patterns in and across the theme categories, explore meaning in those responses, and examine CE. Those interpretations most strongly supported by the data were deemed credible and were included [32, 36]. As a last step, we examined differences in theme distribution in relation to participant demographic and injury characteristics, to examine whether differences in CE were explainable by these factors.

Quantitative analyses included calculating descriptive statistics for the sample. To assess differences in participants' characteristics as a function of site, queries compared the five sites with analyses by age groups (<50; 50 +), non-traumatic vs. traumatic SCI/D, level of injury (paraplegia; tetraplegia), and time since injury (<10 years; 10+ years). Chi-square tests, ANOVAs, or independent *t*-tests were used, and significance was assessed using a *p* value < 0.05.

RESULTS

Demographic and SCI/D characteristics

The sample included 51 participants, with the number per site ranging from 8 to 12. Most participants were male (60.8%). The mean age was 55.8 and the mean time since injury was 14.2 years. Of the total sample, 64% had traumatic injuries and 60.4% had paraplegia (see Table 1).

Themes related to QoL definition and SCI QoL-BDS

Analysis resulted in 17 themes. These themes, the number of topics in each, their definitions, and corresponding exemplar quotes appear in Table 2. Of the 17 themes, *coping and adjustment*, *complications and comorbidities*, and *purpose and identity* were the most frequently cited across the five sites. In general, the QoL definitions and the three items of the SCI QoL-BDS showed CE across sites in the distribution of themes. We detail specific findings for each of the four items below.

QoL definitions

The first row of Table 3 shows the percentages of the top three themes, in descending order, appearing in the responses to the QoL definition question by site. The percentages of all 17 themes for this item (summing up to 100%) appear in Supplementary Table 1. Overall, the top three themes per site show partial CE in the topics used to define QoL, with only seven of the 17 themes

Table 3. Highest three % referenced themes across the Quality of Life Definition item, each Spinal Cord Injury Quality of Life Basic DataSet (SCI QoL-BDS) item, and all items combined by site^a.

Question	Ann Arbor	Denver	Melbourne	São Paulo	Utrecht
QoL definition	1. Purpose and identity (35.3%) 2. Coping and adjustment (22.5%) 3. Ability and autonomy (15.1%)	1. Purpose and identity (22.6%) 2. Relationships (social) (13.8%) 3. Ability and autonomy (12.1%)	1. Ability and autonomy (20.4%) 2. Physical ability and limitations (18.2%) 3. Relationships (social) (12.4%)	1. Coping and adjustment (35.3%) 2. Ability and autonomy (15.8%) 3. Access and barriers (14.9%)	1. Coping and adjustment (21.4%) 2. Ability and autonomy (16%) 3. Relationships (immediate) (10.5%)
Life as a whole	1. Purpose and identity (16.3%) 2. Loss (12.2%) 3. Physical ability and limitations (10.2%)	1. Loss (20%) 2. Coping and adjustment (16.2%) 3. Purpose and identity (15.1%)	1. Physical ability and limitations (17.7%) 2. Access and barriers (13%) 3. Loss (9.3%)	1. Complications and comorbidities (22.3%) 2. Coping and adjustment (13.4%) 3. Work and school (9.7%)	1. Coping and adjustment (21.9%) 2. Purpose and identity (15.1%) 3. Complications and comorbidities (12.1%)
Physical health	1. Physical health and wellbeing (33.3%) 2. Complications and comorbidities (17.7%) 3. Physical ability and limitations (13.7%)	1. Physical health and wellbeing (16.3%) 2. Loss (15%) 3. Purpose and identity (14.6%)	1. Complications and comorbidities (24.8%) 2. Physical health and wellbeing (24.5%) 3. Physical ability and limitations (13.8%)	1. Complications and comorbidities (30.3%) 2. Emotions (negative) (20.3%) 3. Physical health and wellbeing (9.8%)	1. Complications and comorbidities (19.2%) 2. Coping and adjustment (13.8%) 3. Physical health and wellbeing (9.8%)
Psychological health	1. Coping and adjustment (22.8%) 2. Emotions (positive) (17.3%) 3. Emotions (negative) (14.7%)	1. Emotions (negative) (15.4%) 2. Loss (13.1%) 3. Purpose and identity (11.8%)	1. Emotions (negative) (22.4%) 2. Purpose and identity (17.2%) 3. Relationships (social) (14.5%)	1. Emotions (negative) (21.9%) 2. Relationships (immediate) (13.5%) 3. Healthcare systems and services (12.9%)	1. Coping and adjustment (22.4%) 2. Purpose and identity (20.3%) 3. Relationships (immediate) (14.1%)

^aEach cell represents the top 3 themes referenced for that site and that question. Were all 17 themes included in each cell, the total would equal 100%.

appearing in the top three positions across all five sites. *Ability and autonomy* was cited in the top three by all five sites, suggesting self-efficacy and the ability to do things freely in one's life was a shared common denominator defining QoL. Further, *coping and adjustment* was frequently referenced by three sites and *purpose and identity* was heavily cited by both USA sites. *Physical ability and limitations* (18.2%) and *ability and autonomy* (20.4%) were most emphasized by participants in Melbourne. Finally, Table 4 provides exemplar QoL quotes of each of the top-three themes by site, further illustrating commonalities in how QoL was defined through the exact language used by participants.

In looking at the larger theme categories (see Supplementary Table 1), *personal factors* dominated these definitions across all five sites, albeit with a spread from 33.6 to 65%. *Physical factors* were highly factored in Melbourne (26.6%) and Utrecht (23.3%) responses, *emotional factors* in Ann Arbor responses (19.8%), *social factors* in Denver (20.1%), and *environmental factors* in São Paulo (20.4%).

Satisfaction with life as a whole—item 1

Only six of the 17 themes appeared in the top three positions of responses to the Life as a Whole item across all five sites (see second row of Table 3 and Supplementary Table 2). *Coping and adjustment*, *loss*, and *purpose and identity* each appeared in three of the sites. Overall, the notions of working through SCI/D challenges, mourning the losses from SCI/D, and finding purpose post-SCI/D (successfully or not) were key factors shared across all the sites. That this item was designed to garner a more holistic perspective on life satisfaction (as compared to specific QoL domains in the other two items), it allowed for the most salient items in personal QoL meaning to come to the fore.

The theme categories again show that *personal factors* were high in the definitions across sites, ranging from 15 to 35%, with high instances of *emotional factors* in Ann Arbor (22.1%), Denver (28.1%), Melbourne (21%), and São Paulo (17.9%); and high instances of *physical factors* across all the sites (between 29% in Utrecht to 18% in Denver). Together, similarities in themes suggest a close equivalence in framing responses to this question. However, some variety (for example, Utrecht's low rate of *emotional factors*, 3.8%) suggests local differences in what is included in "life as a whole" definitions.

Satisfaction with physical health—item 2

The second item of the SCI QoL-BDS revealed seven of the 17 themes appearing in the top three positions across the five sites (see third row of Table 3 and Supplementary Table 3). *Physical health and wellbeing* was cited in the top three themes by all five sites, and *complications and comorbidities* by four of the five sites. Themes included in the *personal* and *emotional factors* categories appear in the top three in three sites (Denver, São Paulo, Utrecht). Of note, themes that fall within the *social* and *environmental factors* categories were relatively low or absent.

Returning to the theme categories, the highest percentages appear in *physical factors*, though *personal factors* and *emotional factors* also were cited frequently. Overall, however, this item showed a strong pattern toward the intended focus of the question—physical health and wellbeing—suggesting good understanding cross-culturally, while leaving room for other meaningful issues.

Satisfaction with psychological health—item 3

The third item of the SCI QoL-BDS shows eight of the 17 themes appearing in the top three position across the five sites (see fourth row of Table 3 and Supplementary Table 4). *Emotions* (positive or negative) were cited in the top three in every site but Utrecht, where it was fourth with 13.9%. *Purpose and identity* was cited in three sites. *Emotions (positive)* was cited frequently only in Ann Arbor.

Table 4. Exemplar quotes for the Quality of Life Definition item for the three highest referenced themes by site.

Site	Exemplar Quote
Ann Arbor	Being able to enjoy life, being able to be productive, being able to do the things that you love to do in everyday living. (<i>purpose and identity</i>) I think it determines how well adjusted I am to my spinal cord injury, my living environment, do I have family and friends that I see and interact with. Do I have outside interests... (<i>coping and adjustment</i>) Being able to have the way of living that is able to care for oneself and also do other things that you enjoy. (<i>ability and autonomy</i>)
Denver	Quality of life is if you have a reason to live, I guess. If you're-- quality of life is are you happy with your life. Happy that you're alive. (<i>purpose and identity</i>) Being able to socialize & take part in activities... (<i>relationships social</i>) Being able to do what I want to do. Physically can't do some things anymore. Not on a golf course. (<i>ability and autonomy</i>)
Melbourne	The ability to do what I want to do without any sort of impediment. And, for me, my quality of life involves being independently able to move and drive and travel and work and socialize. (<i>ability and autonomy</i>) It takes longer to do things, and maybe you can't do them as well as you used to, but you still get them done, but it just takes a lot longer. (<i>physical ability & limitations</i>) It really means to be able to interact with society as a whole, in a normal way. So in terms of what I've lost, I've lost a good forty percent of my ability to interact with the rest of the world. (<i>relationships social</i>)
São Paulo	To go out, to walk, to live well, not have frustrations and resentment... I love sports. I love to play games. I like ...parties, to entertain people at home, live life. I'm not complaining because I live well with myself and w/ others. (<i>ability and autonomy; coping and adjustment</i>) Freedom. It is to be able to come & go. (<i>ability and autonomy</i>) But other things are accessibility in the environment especially in this city. When I first got injured my father had to carry me in his lap to bring me to the doctor. We had to ask neighbors to bring me sometimes, but today I am more independent (<i>access and barriers</i>)
Utrecht	But my life is very different now & I still have difficulty accepting that. Because it was just a stupid mistake during a hernia-operation... (<i>coping and adjustment</i>) That you are not limited, or better, that you can deal w/ your physical & mental limitations, if necessary w/ help from others. That you are not limited in doing what you want to do. (<i>ability and autonomy</i>) There are also good things, I have my children & grandchildren, my husband who is always there for me, we have a good life together. (<i>relationships immediate</i>)

All five sites frequently cited themes within the larger *emotional factors* theme category. Further, *personal factors* accounted for over a third of all references in this category across sites. Melbourne and Utrecht referenced *social factors* often, while Denver referenced *environmental factors* and São Paulo referenced *physical health* with surprising frequency.

Demographic and injury characteristics

In an attempt to interpret differences in theme percentages between sites in terms of cross-site sample differences, the same NVivo percentage analyses were conducted for key demographic and injury characteristics. Table 5 shows percentages for these comparisons by theme category (see Supplementary Table 5 for percentages of all 17 themes). No notable differences were apparent, suggesting rough equivalence across the sample.

DISCUSSION

The results of this CI study suggest satisfactory CE of the SCI QoL-BDS, as demonstrated by the largely similar distribution of percentages of themes and theme categories in the responses to the QoL definition and SCI QoL-BDS items across sites. We used CI to establish CE as measured by the SCI QoL-BDS items. By using qualitative methods, our work further provides a unique in-depth perspective on the experiences of QoL across sites reflecting both differences and similarities in the interpretation of the meaning of this concept as defined by those with SCI/D [12, 13, 21].

Our findings suggest that in spite of contextual differences by sites, there are important shared ways of defining QoL and the concept is contextually understood and defined. Results depicted in Tables 3–5 reflect both conceptual similarities and consistency/percentage of common themes used to describe QoL and items, showing a good degree of CE. That a relatively circumscribed group of salient issues emerged across all four interview items suggests key components of QoL transcend some cultural boundaries by virtue of shared experience [10, 11]. Even with the third item (satisfaction with psychological health, emotions

and mood) showing the highest variation in themes, still less than half appeared in the top three positions across all five sites. This spread, however, may suggest something about the contextual variance of individual or cultural definitions of psychological health in particular. Nonetheless, taken as a whole, this study confirms and extends preliminary evidence on the cross-cultural validity of the SCI QoL-BDS [12].

In research on cross-cultural validity of QoL measures, CI are mostly used to test the clarity and appropriateness of a translation for the target audience. Our study was novel in that it attempted to define CE in greater depth and made use of CI to explore similarities and differences in personal meaning of QoL concepts and domains. We could find only one previous study using qualitative analyses to compare the importance of QoL domains across five European countries [38]. That study also showed more similarities than differences across countries but only at a level comparable to our theme categories, without more detailed results. Our in-depth qualitative data allows the participants' own words to demonstrate understanding of the questions. The concepts that emerged in our study were remarkably similar across sites. Further, our data allowed us to demonstrate, rather than assume, that translating these questions into participants' languages is enough to reach equivalence.

Our findings point to the rich complexity of the QoL concept, in ways similar to other studies, and beyond the similarities in theme frequencies across our sites. For example, Rohn, et al.'s recent work on QoL shows similar richness of data. In that work, the paths toward acceptance and coping with SCI/D-related challenges showed similar concerns with self-efficacy, shifting perspectives, physical wellbeing, loss, and social factors [9]. Further, similarities within our themes are seen across Hammell's meta-synthesis of qualitative SCI QoL research [3]. Hammell's synthesis focused on the factors that contribute or detract from QoL across 68 studies and found thematic concepts very similar to our own, though at times with different labels (e.g., body problems, loss, relationships, occupation, and self-worth, to name a few). The overlap between our findings and these studies is considerable. That we

Table 5. Frequency of theme categories across all items by demographic and injury characteristics^a.

Themes	Age < 50 (N = 14)	Age 50 + (N = 37)	SCD (N = 33)	SCI (N = 18)	Paraplegia (N = 28)	Tetraplegia (N = 23)	TSI < 10 yrs (N = 28)	TSI 10 + yrs (N = 23)	Educ < 13 yrs (N = 25)	Educ ^b 13 + yrs (N = 25)
Physical factors ^b	25.7%	24.8%	24.3%	25.5%	23.6%	27%	25.1%	25%	24.6%	22.75%
Environmental factors ^c	11.9%	11%	11.7%	10.9%	13.2%	8.6%	10.2%	12.6%	12.2%	11.1%
Social factors ^d	16.4%	14.8%	17.1%	14%	15.8%	14.5%	15.9%	14.3%	15.8%	20.6%
Personal factors ^e	31.5%	31.3%	32.1%	30.9%	30.7%	32.3%	32.1%	30.4%	29.1%	32.8%
Emotional factors ^f	14.5%	18.1%	14.8%	18.6%	16.6%	17.7%	16.6%	17.7%	18.4%	12.7%

^aFor each column, the total equals 100% of all text collectively coded as belonging to the top 17 themes, as clustered within the larger theme categories, across all sites and for all four items combined. Comparing columns in pairs, per demographic or injury characteristic, illustrates the relatively small impact each of these items had on theme coding, as grouped by theme categories.

^bPhysical factors include the themes complications and comorbidities, physical ability and limitations, and physical health and wellbeing.

^cEnvironmental factors include the themes access and barriers, basic resources, caregiving and caregivers, and healthcare systems and services.

^dSocial factors include the themes activities, hobbies, and recreation, relationships (immediate), relationships (social), and work and school.

^ePersonal factors include the themes ability and autonomy, coping and adjustment, and purpose and identity.

^fEmotional factors include the themes emotions (negative), emotions (positive), and loss.

^gAcronyms and abbreviations: SCD (spinal cord disorder), SCI (spinal cord injury), TSI (time since injury), Educ (education).

endeavored to disarticulate the challenges of the concept from the challenges of cross-cultural understanding now allows the complexity of QoL to come through with less concern that this complexity is the result of cultural differences in understanding the concept.

However, we did expect some differences across sites due to language, socio-economic, and geographical factors influencing participants' interpretation of this concept. In this respect, we expected to see the highest similarities between the two USA sites. While the data for these two sites were quite similar, the similarities do not appear to be greater than those with the other sites. We also did not see large differences between the English and non-English speaking sites. Further, we show that differences in theme distributions and percentages were not explained by the demographic or injury/disease characteristics collected as part of the study. For example, though São Paulo participants were significantly younger than the rest of the sample, and likewise less educated, neither of these demographic factors revealed differences in theme distribution. The distribution of themes within São Paulo, rather, were likely a factor of their experiences with SCI/D and their unique expectations in life as well as the living environment. We note that access and socio-economic were mentioned by this group only when asked to define QoL. Similarly, only they mentioned opportunities for work/school when asked about life as a whole. This pattern is suggestive of the different socioeconomics of São Paulo, where the other sites are all in more developed countries, with full access to rehabilitation.

In general, the patterns of differences around each item were minor and taken together showed good CE across sites. Overall, the themes expressed were congruent with the item domain reflecting themes pertinent to that domain. Most ideas expressed in relation to physical health included physical health, ability, comorbidities, losses (referring to functional losses) while emotions and coping were the main themes used to define psychological health. An intriguing development was the emergence of the range and frequency of social factors in the themes. This emergent factor informed the subsequent adoption of a fourth item in the SCI QoL-BDS focused on social QoL, which we began collecting subsequently in the larger study. The importance of social health as a domain of QoL is not an explicit focus of the current SCI BDS-QoL and future work will elucidate this domain further.

There were several limitations to this study. While CE was found to be good, further research is needed to widen the sample and deepen comparisons across more populations engaged in using the SCI QoL-BDS. Except for the USA, there was only one site per country. This is an especially important limitation in São Paulo, where there is greater access to rehabilitation and other SCI/D resources than much of the rest of Brazil. In addition, the small sample size limits our ability to generalize about potential cross-cultural differences. Finally, in qualitative research, findings are contextual and more highly dependent on the researchers involved. Although consensus was reached, individual idiosyncrasies of training, bias, and insights cannot be ruled out entirely.

In conclusion, we feel confident in recommending the use of the SCI BDS-QoL, with appropriate translation, to collect comparable QoL data across sites internationally, given the overall good CE across the five sites. Having a standard way to assess QoL consistently across different settings, cultures and environments will allow comparison of research results and clinical data worldwide. Our findings shed promising light on the similar conceptualizations of QoL cross-culturally and the sensitivity of this measure to accurately assess QoL for persons with SCI/D around the world.

DATA AVAILABILITY

De-identified datasets used for this portion of the study can be made available upon request based on and following completion of a data sharing agreement.

REFERENCES

1. Szabo S. The World Health Organisation Quality of life (WHOQOL) assessment instrument. *Quality Life Pharmacoeconom Clin Trials*. 1996;355–62.
2. Dijkers MP. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev*. 2005;42:87–110.
3. Hammell KW. Quality of life after spinal cord injury: a meta-synthesis of qualitative findings. *Spinal Cord*. 2007;45:124–39.
4. Post M. Definitions of quality of life: what has happened and how to move on. *Top Spinal Cord Inj Rehabil*. 2014;20:167–80.
5. Post M, Noreau L. Quality of life after spinal cord injury. *J Neurol Phys Ther*. 2005;29:139–46.
6. Ngamaba KH. Determinants of subjective well-being in representative samples of nations. *Eur J Public Health*. 2017;27:377–82.
7. Wood-Dauphinee S, Exner G, Bostanci B, Exner G, Glass C, Jochheim KA, et al. Quality of life in patients with spinal cord injury—basic issues, assessment, and recommendations. *Restor Neurol Neurosci*. 2002;20:135–49.
8. Nevedal A, Kratz AL, Tate DG. Women's experiences of living with neurogenic bladder and bowel after spinal cord injury: life controlled by bladder and bowel. *Disabil Rehabil*. 2016;38:573–81.
9. Rohn EJ, Tate DG, Forchheimer M, DiPonio L. Contextualizing the lived experience of quality of life for persons with spinal cord injury: A mixed-methods application of the response shift model. *J Spinal Cord Med*. 2019;42:469–77.
10. Tate DG, Kalpakjian CZ, Forchheimer MB. Quality of life issues in individuals with spinal cord injury. *Arch Phys Med Rehabil*. 2002;83:S18–25.
11. Geyh S, Ballert C, Sinnott A, Charlifue S, Catz A, D'Andrea Greve JM, et al. Quality of life after spinal cord injury: a comparison across six countries. *Spinal Cord*. 2013;51:322–6.
12. Tate D, Forchheimer M. Review of cross-cultural issues related to quality of life after spinal cord injury. *Top Spinal Cord Inj Rehabil*. 2014;20:181–90.
13. Bullinger M, Schmidt S, Naber D. Cross-cultural quality of life research in mental health. In: *Quality of Life Impairment in Schizophrenia*, Dordrecht, Netherlands: Mood and Anxiety Disorders. Springer; 2007. p. 67–98.
14. Mokkink LB, Prinsen CA, Bouter LM, de Vet HC, Terwee CB. The COSMIN-based Standards for the selection of health Measurement Instruments (COSMIN) and how to select an outcome measurement instrument. *Braz J Phys Ther*. 2016;20:105–13.
15. Patrick DL, Wild D, Johnson E, Wagner T, Martin M. Cross-cultural validation of quality of life measures. In: *Quality of life assessment: International perspectives*. Berlin, Germany: Springer;1994. p. 19–32.
16. Amuyunzu M, Allen T, Mwenesi H, Johnson K, Egasah O, Parker M, et al. The resonance of language: health terms in Kenya. *Qual life Res*. 1995;4:388–9.
17. Schmidt S, Bullinger M. Current issues in cross-cultural quality of life instrument development. *Arch Phys Med Rehabil*. 2003;84:S29–S34.
18. Charlifue S, Post MW, Biering-Sorensen F, Catz A, Dijkers M, Geyh S, et al. International Spinal Cord Injury Quality of Life Basic Data Set. *Spinal Cord*. 2012;50:672–5.
19. Desimone LM, Le Floch KC. Are we asking the right questions? Using cognitive interviews to improve surveys in education research. *Educ Eval Policy Anal*. 2004;26:1–22.
20. Ryan K, Gannon-Slater N, Culbertson MJ. Improving survey methods with cognitive interviews in small-and medium-scale evaluations. *Am J Eval*. 2012;33:414–30.
21. Post MWM, Forchheimer MB, Charlifue S, D'Andrea Greve JM, New PW, Tate DG. Reproducibility of the international spinal cord injury quality of life basic data set: an international psychometric study. *Spinal Cord*. 2019;57:992–8.
22. Herdman M, Fox-Rushby J, Badia X. A model of equivalence in the cultural adaptation of HRQoL instruments: the universalist approach. *Qual Life Res*. 1998;7:323–35.
23. DeWalt DA, Rothrock N, Yount S, Stone AA, Group PC. Evaluation of item candidates: the PROMIS qualitative item review. *Med Care*. 2007;45:12–21.
24. Eremenco SL, Cella D, Arnold BJ. A comprehensive method for the translation and cross-cultural validation of health status questionnaires. *Eval Health Prof*. 2005;28:212–32.
25. Miller K, Mont D, Maitland A, Altman B, Madans J. Results of a cross-national structured cognitive interviewing protocol to test measures of disability. *Qual Quant*. 2011;45:801–15.
26. Willis GB, Miller K. Cross-cultural cognitive interviewing: Seeking comparability and enhancing understanding. *Field Methods*. 2011;23:331–41.
27. Biering-Sorensen F, Alexander MS, Burns S, Charlifue S, DeVivo M, Dietz V, et al. Recommendations for translation and reliability testing of International Spinal Cord Injury Data Sets. *Spinal Cord*. 2011;49:357–60.
28. Post MW, Adriaansen JJ, Charlifue S, Biering-Sorensen F, van Asbeck FW. Good validity of the international spinal cord injury quality of life basic data set. *Spinal Cord*. 2016;54:314–8.
29. Braun V, Clarke V. Using thematic analysis in psychology. *Qualitative Res Psychol*. 2006;3:77–101.
30. Braun V, Clarke V. Reflecting on reflexive thematic analysis. *Qualitative Res Sport Exerc Health*. 2019;11:589–97.
31. QSR International Pty Ltd. NVivo (Version 12). 2018. <https://www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home>.
32. Luborsky MR. The identification and analysis of themes and patterns. In: Gubrium JF, Sankar A, eds. *Qualitative methods in aging research*. Newbury Park, California, USA: Sage Publications, Inc.;1994.
33. Ryan GW, Bernard HR. Techniques to identify themes. *Field methods*. 2003;15:85–109.
34. Bernard HR. *Research methods in anthropology: qualitative and quantitative approaches*. Lanham, Maryland, USA: Rowman & Littlefield; 2017.
35. Lequerica AH, Forchheimer M, Albright KJ, Tate DG, Duggan CH, Rahman RO. Stress appraisal in women with spinal cord injury: Supplementary findings through mixed methods. *Int J Stress Manag*. 2010;17:259.
36. Shenton AK. Strategies for ensuring trustworthiness in qualitative research projects. *Educ Inf*. 2004;22:63–75.
37. Peterson DB. International classification of functioning, disability and health: an introduction for rehabilitation psychologists. *Rehabil Psychol*. 2005;50:105.
38. Sommer R, Bullinger M, Chaplin J, Do J, Power M, Pleil A, et al. Experiencing health-related quality of life in paediatric short stature—a cross-cultural analysis of statements from patients and parents. *Clin Psychol Psychother*. 2017;24:1370–6.

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AUTHOR CONTRIBUTIONS

ER led qualitative data analysis, contributed to development and confirmation of findings, developed Tables 2–5 and supplementary tables, and wrote the paper post-introduction. MP contributed to study design, data collection, data analysis, development and confirmation of findings, and conceptualization and revisions of the paper. AH contributed to data collection, data analysis, development and confirmation of findings, and revisions of the paper. MF led quantitative analysis, contributed to development and confirmation of findings, and revisions of the paper. SC, JMAG, and PN contributed to study design and data collection, and provided feedback on the paper. DT contributed to the design of the study, data collection, data analysis, development and confirmation of findings, conceptualization and revisions of the paper, and wrote the paper introduction.

COMPETING INTERESTS

The authors declare no competing interests.

ETHICS APPROVAL

The research protocol was approved by the University of Michigan Medical School Institutional Review Board, protocol number HUM00126164 and HUM00125769. For the Netherlands, permission to execute the study was granted by the Board of Directors of De Hoogstraat after positive advice of the Institute Review Board on 27 July 2017. For Brazil, the research protocol was approved by the Medical Ethics Committee of the Hospital das Clínicas da Faculdade de Medicina da Universidade de São Paulo in April 2018. Approbation number CAAE:283112917.3.0000.0068. For Australia, the project was approved by the Alfred Hospital Ethics Committee on 14 June 2017 (project no 203/17). We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

ADDITIONAL INFORMATION

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