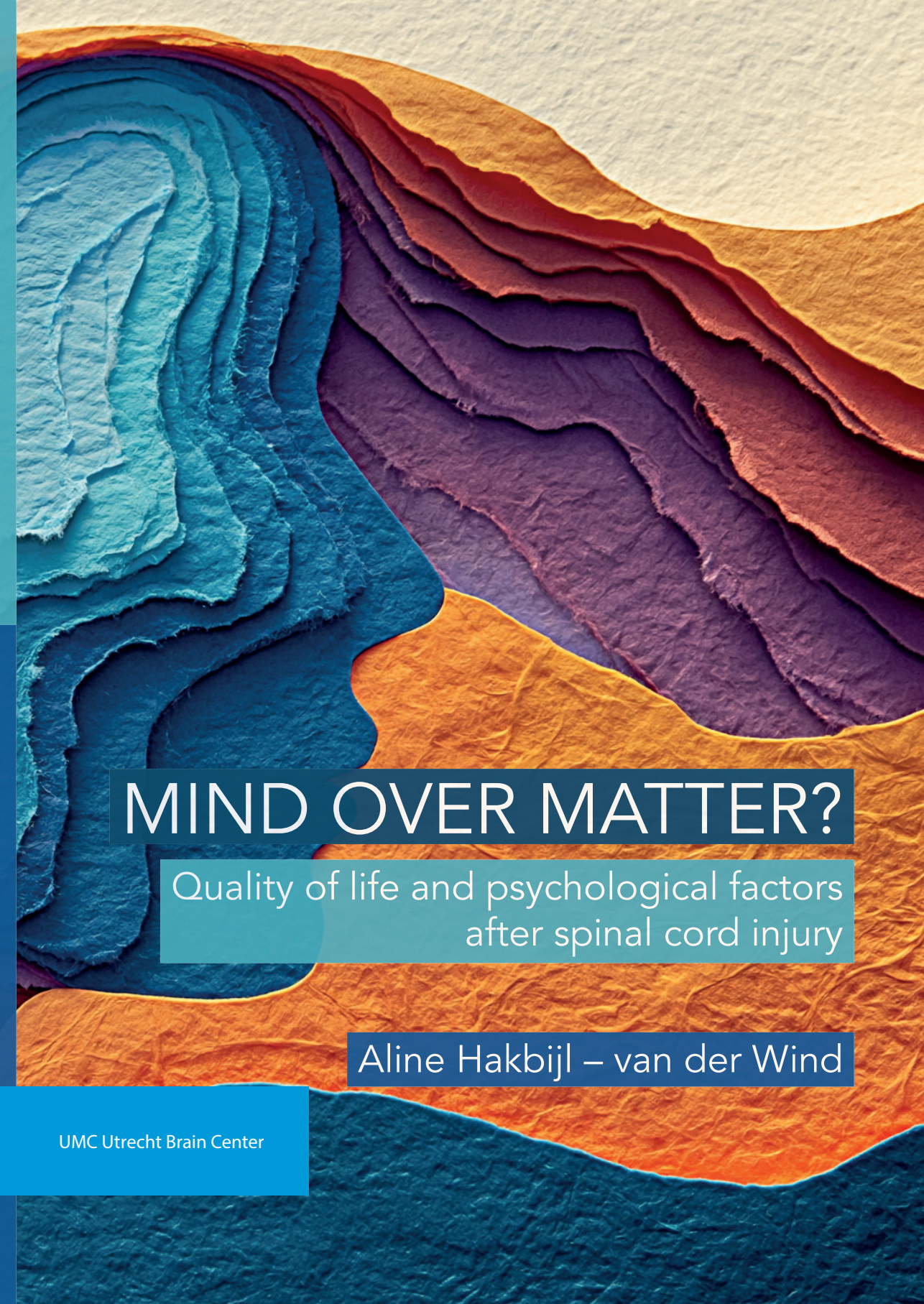




MIND OVER MATTER?

Quality of life and psychological factors
after spinal cord injury

Aline Hakbijl – van der Wind

UMC Utrecht Brain Center

Mind over Matter?

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The colorful cover reflects the multitude of psychological factors and the various facets that influence quality of life. Insight into these factors can help guide the healthcare team in supporting the personal journey that each rehabilitation patient goes through and in understanding how quality of life is experienced, which is visualized in the window to the future.

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Mind over Matter?

Quality of life and psychological factors after spinal cord injury

Mind over Matter?

Kwaliteit van leven en psychologische factoren na een dwarslaesie
(met een samenvatting in het Nederlands)

Proefschrift

ter verkrijging van de graad van doctor
aan de Universiteit Utrecht
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ingevolge het besluit van het College voor Promoties
in het openbaar te verdedigen op

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CHAPTER 1

General introduction

Sam, a young man, husband, father, and truck driver, sustained a spinal cord injury (SCI) in a car accident. Upon arrival at the hospital, he immediately felt the loss of motor function and sensation in his legs and was overwhelmed by the intense physical and emotional shock. The consequences of his injury included severe pain, limited mobility, and dysfunction of his bowel and bladder. After initial stabilization in a trauma center, Sam was transferred to a specialized SCI rehabilitation center.

Sam's future was uncertain—he feared he could no longer work as a truck driver and struggled with the possible loss of his roles as a husband and father. His dependency on help from others led to feelings of depression and frustration. Throughout his rehabilitation, he remained motivated to regain independence, especially in self-care and mobility. Support from his psychologist, a close friend, and Laura, his nurse, was helpful. Laura provided not only clinical care but also emotional support helping Sam manage his concerns and focus on his present life. By addressing the emotional side of his care, Laura helped Sam move beyond feelings of shame and focus on making progress.

After three months of intensive rehabilitation, Sam returned home, working with his family to adapt to a new way of life. Despite challenges, including truck driving and shifting family dynamics, Sam remained grateful to be alive. This thesis focuses on quality of life in people with SCI and highlights the relevance of psychological factors in understanding adjustment during rehabilitation, informed by empirical findings and existing literature.

Spinal cord injury (SCI) is a neurological condition with loss of function distal to the location of the injury. The injury can be located in the spinal cord itself, which is part of the central nervous system, or in the cauda equina. The amount of damage can vary, resulting in minimal to complete loss of functions. The level and severity of SCI is classified according to the International standards for Neurological Classification of SCI resulting in a level and scale of (in)completeness.¹ It can result in impairment of motor, sensory, and autonomic functions, including sexual, urinary and defecation functions. As a consequence, many physical activities such as walking, carrying objects, eating and self-care, and social activities such as sports, work and leisure can be affected. Furthermore, people with SCI are prone to seriously disabling secondary health conditions, such as poor sleep quality, (shoulder)pain, spasticity and pressure ulcers.² Compared to the general population, other health conditions such as diabetes, dyslipidaemia and myocardial infarction are more frequent, earlier in life and more severe in the SCI population.^{3,4}

Theoretical understanding of the impact of SCI

The primary and secondary physical health consequences of SCI urge people with SCI to deal with and adapt to their new situation. Most people manage to incorporate these changes into their lives, experience favorable quality of life (QoL), like Sam in the case above. However, some people experience difficulties in adjusting to their new situation and develop psychological secondary health conditions, like depression or anxiety.⁵⁻⁷ Support from rehabilitation professionals during rehabilitation can play a crucial role in promoting positive adaptation. Nevertheless, psychological challenges may arise both during inpatient rehabilitation and in the period afterwards. It is important to know that having more secondary health conditions is significantly related to more psychological burden and lower QoL in chronic SCI population.²

Some theoretical background can help to understand the different outcomes of people with SCI. The international Classification of Functioning, Disability and Health (ICF) model is a framework that classifies the consequences of primary and secondary health conditions at the level of an individual's functioning (**Figure 1.1**).⁸ The ICF model describes the impact of SCI on the individual at three levels: body functions and structure or impairments, activities, and participation, which

are intertwined with environmental and personal factors (such as living area, gender, educational level and psychological factors). All these factors vary from individual to individual and may explain differences in individuals' functioning and have impact on the level QoL.^{9–11}

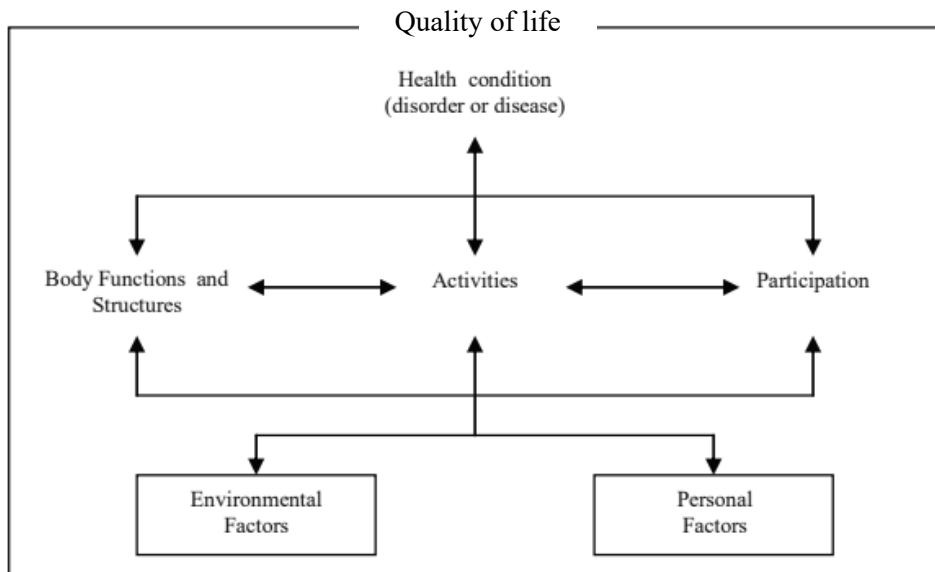


Figure 1.1. Interactions between the components of ICF,⁸ combined with a modified version by McDougall J.¹¹

Concept of Quality of Life

QoL is defined by the World Health Organization as 'the 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'.¹² It is a multifaceted concept, encompassing both internal and external factors such as physical health, mental well-being, and social support, and reflecting how individuals react to and are impacted by their circumstances and relationships.^{13–15} In line with this definition, QoL is considered an umbrella term. In this thesis we focus on different aspects of QoL, such as life satisfaction and mental health.

Assessing QoL can be challenging due to the complexity of capturing QoL-related constructs, leading to a plethora of measures of QoL.^{16,17} As a result, it is difficult to compare QoL outcomes across individuals, centers, countries and cultures. This is why the SCI QoL-Basic Dataset (SCI QoL-BDS) was developed, as part of the international SCI Datasets.¹³ The aim of these datasets is to facilitate data

sharing between both healthcare professionals and researchers, and to inform the development of national policies and international guidelines.¹⁸ To achieve these goals (comparing QoL outcomes and sharing data) confirmation of the globally equivalent meaning of the SCI QoL-BDS was needed, which is part of this thesis. During the study into the globally equivalent meaning of the SCI QoL-BDS, the importance of social life for QoL was emphasized, which was not a specific item in this measurement. Therefore, we conducted further research on the importance of the social life and how to incorporate this in the existing SCI QoL-BDS.

QoL is shown to recover from lower levels immediately after the event, to slightly higher levels in the longer term, although average QoL ratings in SCI remain lower compared to the general population.^{10,17} Psychological adjustment after SCI is associated with demographic characteristics (such as gender and marital status), injury-related factors (such as neurological level and age at injury), but also with certain psychological factors, such as self-efficacy and purpose in life).^{10,19–21} Interventions to support the restoration of QoL can be applied during admission to rehabilitation. Therefore, healthcare professionals need to conduct accurate screening and must have knowledge of predictive factors for the development of QoL. In this way, they can support people with SCI adapt to their new situation. We know that psychological factors can help restore QoL. However, little is known about how life satisfaction develops during and after inpatient rehabilitation and how psychological factors influence this development.

Back to practice: Rehabilitation care

The goal of the rehabilitation team is to create an environment in which the individual can recover optimally. In ICF terms, this includes focus on the health conditions as the SCI themselves, body structures and functions. But also the focus on the impact of the health conditions on the individuals' life, by evaluating and supporting activities and participation, and strengthening environmental and personal factors. The goal for the individual is to restore QoL, by an optimal self-reliance, self-direction and social participation, integrated in the rehabilitation.^{22,23} Perhaps, most people initially think that this is the role of the psychologist, for whom QoL is the "core business". They focus on the diagnosis and treatment of cognitive, emotional and behavioral problems and play an important role in coaching other team members in their interactions with the individual with SCI. But in practice, all disciplines are involved in psychological care. It is just through

the collaboration of all team members in influencing protective factors that the QoL of people with SCI can be restored. This introduction started with a casus about Sam. The successful rehabilitation was possible through the collaborative effort of the team. For example: the medical treatment and overview of the rehabilitation process by the physiatrist, the psychological treatment by the psychologist, the personal “click” with the nurse Laura and practical and mental support of the nursing team, the physical training and mental support by the physiotherapist and occupational therapist to be independent in transfers and dressing, and the incorporation of Sam’s wife and children in the rehabilitation by all disciplines. Although not all of these interventions were directly aimed to promote his QoL, they supported indirectly his QoL. For example, by improving self-care skills, Sam was able to gain a sense of independence and mastery, which are key components of QoL.²⁴ These connections between rehabilitation objectives and QoL highlights the importance of healthcare professionals’ understanding of psychological, social, and physical factors in rehabilitation practice.

From my background as a SCI nurse, I feel that the role of the rehabilitation nurse is particularly important for people admitted to the rehabilitation center. This discipline has the most contact outside office hours and can observe them and their social networks in these moments, while acting as the “ears and eyes” of the rehabilitation team. For example: they observe whether the individual is still able to take care of themselves at the end of the day with less energy. And outside office hours, this discipline provides support, both physically and mentally.²⁵ This thesis highlights the importance of social participation and psychological factors in the development and restoration of QoL. Nurses can use this knowledge in their daily practice by supporting psychological resources throughout the day. Knowing that this will contribute to the restoration of QoL can motivate nurses to prioritize psychological support in daily busy rehabilitation care.

Aim of the thesis

The aim of this thesis is to gain a better understanding of QoL after SCI in order (1) to provide healthcare professionals with a practical measurement instrument to measure QoL and (2) to provide detailed knowledge on how QoL can be influenced. This will be done by answering the following research questions: 1) What is the meaning of quality of life for individuals with SCI across five different

countries, and how is this reflected in the interpretation of the SCI QoL-BDS, particularly regarding the social dimension? 2) How are psychological factors related to the QoL in people with SCI?

Outline of the thesis

To achieve the overall objective, the following studies were executed. The thesis consists of two parts. The first part consists of studies about the meaning of QoL and the validation of the SCI QoL-BDS. The second part will focus on psychological factors and their relationship with QoL. Together, these chapters provide a comprehensive perspective on how different aspects of QoL can be understood, measured, and influenced in people with SCI.

Part 1: Quality of life in spinal cord injury

In **Chapter 2**, the cross-cultural validity of the SCI QoL-BDS was analyzed at an international level in a qualitative interview study (USA, Australia, Brazil, the Netherlands).

In **Chapter 3**, the addition of an item about the social domain to the SCI QoL-BDS was investigated through an international ICF-linking study.

Part 2: Psychological factors in quality of life

In **Chapter 4**, the associations between psychological factors and QoL and mood in people with SCI were systematically reviewed in the scientific literature published between 2011 and 2023.

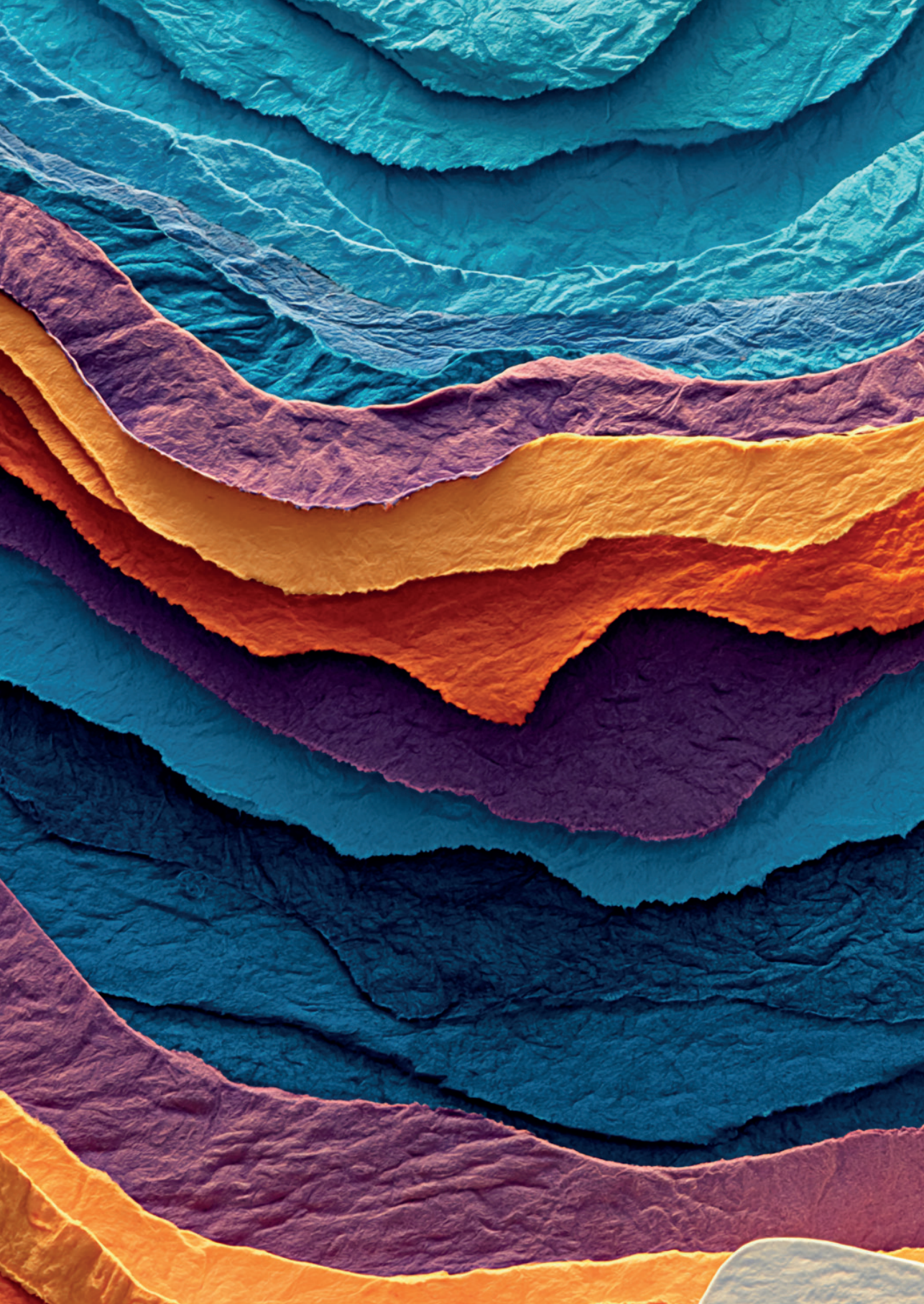
In **Chapter 5**, the development of QoL from admission up to four years after discharge was examined in a Dutch SCI population. This dataset was also used to assess the effect of various psychological factors in order to identify the most important ones.

The results of Chapters 2–5 are discussed in **Chapter 6**.

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PART 1

Quality of life
in spinal cord injury

CHAPTER 2

A cross-cultural mixed methods validation study of the Spinal Cord Injury Quality of Life Basic Data Set (SCI QoL-BDS)

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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 commonalty 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.

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 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 Data Set (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 to 40 minutes, 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 cognitive interviews.

Measure

Participants were asked the opening question, "How would you define the concept of quality of life?" 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 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 Data Sets 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 Hakkijl, 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

Table 2.1. Demographics, neurological data, and scores on the Spinal Cord Injury Quality of Life Basic Data Set (SCI QoL-BDS)

Number of participants		Total	Ann Arbor	Denver	Melbourne	São Paulo	Utrecht	Sig
		51	10	8	10	11	12	
Sex, %								
Male		59.6%	70.0%	66.7%	60.0%	63.6%	41.7%	
Female		40.4%	30.0%	33.3%	40.0%	36.4%	58.3%	p=.678
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=.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=.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=.001 ^b
Type of impairment, %								
SCI		62.7%	80.0%	66.7%	33.3%	81.8%	50.0%	
SCD		37.3%	20.0%	33.3%	66.7%	18.2%	50.0%	p=.125 ^c
Level of impairment, %								
Paraplegia		62.7%	40.0%	66.7%	44.4%	88.9%	66.7%	
Tetraplegia		37.3%	60.0%	33.3%	55.6%	11.1%	33.3%	p=.117
Scores on SCI QoL-BDS, mean (SD)								
Satisfaction with life as a whole		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=.214
Satisfaction with physical health		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=.003 ^d
Satisfaction with psychological health		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=.587

^a São Paulo participants are significantly younger than those from Denver (p=.01), Melbourne (p=.009), and Utrecht (p=.006).

^b São Paulo participants have completed significantly less schooling than those from all other sites: Ann Arbor (p=.005), Denver and Melbourne (p=.001), and Utrecht (p<.0005).

^c Please 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.

^d São Paulo participants had significantly higher ratings of their physical health than did those from Denver (p=.002) and Melbourne (p=.004). Utrecht participants had significantly higher ratings than did those from Denver (p=.004) and Melbourne (.008)

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 <.05.

Results

Demographic and SCI/D characteristics

The sample included 51 participants, with the number per site ranging from 8–12. 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 2.1**).

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 2.2**. 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 2.3** 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 **Appendix 2.1**. Overall, the top three themes per site show partial CE in the topics used to define QoL, with only seven of the 17 themes 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 2.4** 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.

Table 2.2. Theme definitions and examples

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
Physical factors			
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.	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.
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.	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.
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.	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.

Table 2.2 continues on next page.

Table 2.2. Continued

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
Environmental factors			
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.	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.
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.	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...
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.	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.
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.	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.

Social factors		
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 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 and resentment. I'm a para-athlete, I have many medals and I love sports. I love to play games... live life.
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 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.
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. 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...
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. 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...

Table 2.2 continues on next page.

Table 2.2. Continued

Theme	Discrete topics in each theme ^a	Definitions ^b	Exemplar quotes
Personal factors			
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.	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...
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.	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...
14. Purpose and identity	97 (10.6%)	Identity, overall philosophy about life, reflections on self-value rather than efficacy or emotionality.	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 towards life...

Emotional factors		
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 struggle every day with depression. I struggle every day with anxiety. I struggle every day 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 it makes me feel less of a person and makes me feel worthless, and it also adds to the anxiety as well.
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. 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.
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 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. 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.

^a Number 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).

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

Table 2.3. Highest three % referenced themes across the Quality of Life Definition item, each Spinal Cord Injury Basic Data Set (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%)

^a Each 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%.

Table 2.4. 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. (purpose and identity) 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... (coping and adjustment) Being able to have the way of living that is able to care for oneself and also do other things that you enjoy. (ability and autonomy)
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. (purpose and identity) Being able to socialize & take part in activities.... (relationships social) Being able to do what I want to do. Physically can't do some things anymore. Not on a golf course. (ability and autonomy)
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. (ability and autonomy) 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. (physical ability & limitations) 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. (relationships social)
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. (ability and autonomy; coping and adjustment) Freedom. It is to be able to come & go. (ability and autonomy) 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 (access and barriers)
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... (coping and adjustment) 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. (ability and autonomy) There are also good things, I have my children & grandchildren, my husband who is always there for me, we have a good life together. (relationships immediate)

In looking at the larger theme categories (see **Appendix 2.1**), 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 2.3** and **Appendix 2.2**). *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 2.3** and **Appendix 2.3**). *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 2.3** and **Appendix 2.4**). *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.

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 2.5** shows percentages for these comparisons by theme category (see **Appendix 2.5** 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}

Table 2.5. 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)	Para- plegia (N=28)	Tetra- plegia (N=23)	TSI <10 yrs (N=28)	TSI 10+ yrs (N=23)	Educ <13 yrs (N=25)	Educ ^e 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%

^a For 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.

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

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

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

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

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

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

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 2.3-2.5** 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 towards 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 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, socioeconomic 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 socioeconomic 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.

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Ethical 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.

Competing interests

The authors declare that they have no conflict of interest.

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Appendices

For Appendices 2.1–2.5, see:

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CHAPTER 3

The social dimension of quality of life following spinal cord injury or disease: An international ICF-linking study

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Study: International Classification of Functioning, Disability and Health (ICF) linking study.

Objective: Analyze cognitive interview data using the ICF as an analytic framework, to examine aspects of social life relevant to quality of life (QoL) according to people with spinal cord injury or disease (SCI/D). This study builds upon results of an international study about the cross-cultural validity of the International SCI QoL Basic Data Set (QoL-BDS).

Setting: Four specialized outpatient clinics in SCI/D rehabilitation, from the US, Brazil and Australia.

Methods: Analysis of qualitative data from 39 cognitive interviews with SCI/D patients at least one year post onset. Participants were asked to define their concept of QoL, overall life satisfaction, physical health and psychological health, and other relevant matters. Four independent researchers coded text fragments related to the items, and fragments were linked to ICF chapters d6–d9, following established linking rules.

Results: The proportion of text referring to social life was 35.8% (definition QoL), 24.9% (QoL life as whole), 6.0% (physical health) and 34.9% (psychological health). The most frequent ICF categories were d760 *Family relationships*, d770 *Intimate relationships* and d920 *Recreation and leisure*. Most frequent responded social topics to the 'other issues' item were d770 *Intimate relationships*, d760 *Formal relationships*, and d870 *Economic self-sufficiency*.

Conclusion: The importance of social life aspects to the QoL was highlighted based on responses of SCI/D patients, clearly demonstrated through the ICF linking process. Adding a satisfaction with social life item to the QoL-BDS has made this instrument a more comprehensive measure.

Introduction

Spinal cord injury or disease (SCI/D) often results in sensory and motor dysfunction,¹ leading to significant consequences for quality of life (QoL), physical and mental health and social functioning.^{2,3} QoL has been defined by the World Health Organization as 'the individual's overall perception of and satisfaction with how things are in their life'.⁴ It is a multifaceted concept, involving reactions to and impact on one's circumstances and relations, including both internal and external factors, such as physical health, mental health issues and social support.⁵⁻⁷ People with SCI/D experienced lower levels of QoL early after SCI, which generally improves over time, but to a level that typically remains substantially below that of the general population.^{8,9} Therefore, evaluating the lived experience of people with SCI/D is an important outcome, in the acute setting, as well as during and after the rehabilitation process.¹⁰

QoL means many things to different people. Although many instruments to evaluate QoL among individuals with SCI/D are available consistency in defining the concept cross culturally and its domains is rarely addressed. In addition, most of these measures are long and complex.¹¹ The SCI QoL Basic Data Set (QoL-BDS) was developed as a brief QoL measure for use in clinical practice and research, making it possible to measure QoL across SCI populations in a standardized way.⁵ The QoL-BDS includes three questions on satisfaction during the previous four weeks with (1) life as a whole, (2) physical health, and (3) psychological health.⁵ Prior research in inpatient and community settings provided evidence of its cross-cultural validity,¹² convergent and discriminant validity,^{13,14} inter-rater reliability¹⁵ and psychometric properties.¹⁶

The current study expands upon the results of an international cognitive interview study on the cross-cultural validity of the QoL-BDS.¹² Those authors showed that a considerable part of QoL was determined by aspects of social life, such as hobbies and recreation, relationships, work and school.¹² This importance aligns with reported associations between such social factors and QoL.^{2,8,17,18} However, the social dimension was beyond its initial scope. As such, there is a clear need for a more detailed analysis of this aspect of QoL utilizing that data.

With the approval of the International Classification of Functioning, Disability and Health (ICF) by the World Health Organization, there is a universally accepted

framework to classify and describe functioning from both the patient's and health professional's perspectives.¹⁹ With this study, we want to revive the discussion about the importance of a fourth item addressing satisfaction with social life on the QoL-BDS. Such an item would make it easier to find, analyze, and compare these social aspects across populations, and make the QoL-BDS a more comprehensive measure to QoL. The ICF framework provides that conceptual schema that we need to examine and explore this further. Therefore, the aim of the present study was to re-analyze the cognitive interview data to explore aspects of social life relevant to QoL according to people with SCI/D data, using the ICF as an analytical framework. This approach will enable us to broaden our understanding of their social lives, ultimately contributing to improving their QoL.

Methods

Study design

This study involved secondary data analysis of previously-collected text-based cognitive interview data. We performed an ICF-linking study, utilizing data from 39 cognitive interviews (CI) performed in 2017–2019 as part of a larger study validating the QoL-BDS.¹² CI is a proven method used to improve reliability and validity of new measures by determining how participants interpret concepts and understand survey questions they are asked.²⁰ CI is particularly helpful when attempting to measure abstract concepts like social participation.²¹ We used data from participants from four sites across three countries: Ann Arbor, Michigan and Denver, Colorado (United States), Melbourne (Australia) and São Paulo (Brazil). Participants included in these interviews provided a broad spectrum of QoL perspectives from participants with SCI/D living in different geographical regions under different economic and cultural environments.

Participants

Participants were included if they had SCI/D for at least one year, were at least 18 years old, were able to communicate in the language spoken in their country and completed written informed consent prior to the interview. Trained research assistants ensured that none had cognitive or psychiatric limitations that prohibited them from completing a screening questionnaire and obtained informed consent. They all had knowledge about rehabilitation of SCI/D.

Procedure

A convenience sampling approach was used for recruitment of 8–11 participants at each site. Participants were recruited mainly through affiliated hospitals and clinics at the respective sites. Medical information was made available by these facilities. The interviews were conducted in the participants' native language via phone or in person (choice was made by the participant), lasted 30–40 minutes, were audio recorded, and transcribed. Responses to the research questions were transcribed and, for São Paulo, translated into English by an author who is fluent in both English and Brazilian Portuguese. Researchers from each site participated in the design of the interviews and training on qualitative methods used for CI.

Instruments

Each interview began with an introduction to the study and a few questions on participant and SCI/D characteristics: age, gender, years since onset, years of schooling, cause of SCI, and affected body parts. Thereafter, participants were asked to provide their definition of QoL: "How would you define the concept of quality of life?", followed by the SCI QoL-BDS. The QoL-BDS comprises three questions, asking participants to indicate satisfaction with their life as a whole, with their physical health and with their psychological health in the past 4 weeks. Each question is answered using a numeric rating scale between 0 (completely dissatisfied) to 10 (completely satisfied).⁵ Lastly, participants were asked if there were any other issues relevant to their QoL. Responses related to social life were spontaneous comments provided by the study participants. Each question was followed by semi-standard probes, inviting participants to elaborate on their ratings. These probes allowed participants to identify key areas that impacted their QoL and provided context to their numerical responses.

Data analyses

As part of the previous qualitative analysis,¹² inductive open coding was used to reveal and categorize information on aspects mentioned by the participants as part of, or relevant to, their QoL. In that analysis, four authors (AH, ER, DT and MP) first read the interview transcripts to gain an overall sense of the content and quality of the data, independently identified topics in the data, and together discussed these codes and their application until consensus was reached. This resulted in a total of 1517 discrete topics across all the verbatim transcripts. Further analysis resulted in the formulation of themes that characterized the data.

Throughout and following this coding process, AH, ER, DT and MP discussed resulting topics and themes to the point of consensus was reached. A full description of these findings appear in our previous study.¹²

To then substantiate the relevance and potential value of a social life item in the QoL-BDS, we applied the ICF as a theoretical reference framework. The ICF is a universally accepted reference framework, intended to link data and increase comparability of content.²² The ICF comprises four components: *Body Functions*, *Body Structures*, *Activities and Participation* and *Environmental Factors*. Within the component *Participation* social related items are arranged hierarchically.^{23,24} This framework made it able to compare meaningful concepts from the CI to ICF categories most related to social participation. In this study we defined participation in social life as the involvement in social roles and activities outside the home that provide interaction with others.^{25,26} All topics were reviewed again in their context within the transcripts and treated each topic identified as a meaningful concept unit, reflecting the essence of what participants are saying.²²

Meaningful concepts were classified as belonging to social life if they could be linked to categories in the chapters d6–d9 of the ICF,²² that are widely considered as demarcations of participation.^{23,27} These chapters are: d6 *Domestic life* (e.g. d649 *household tasks*), d7 *Interpersonal Interactions and Relationships* (e.g. d740 *formal relationships*), d8 *Major life areas* (e.g. d839 *education*), and d9 *Community, social and civic life* (e.g. d930 *religion and spirituality*).

Linking was performed following a set of formal rules and procedures.²² Each meaningful concept was allocated to the best fitting second-level ICF category in chapters d6–d9. For example: “*I’ve got children and grandkids and that sort of thing*” was identified as meaningful concept text and this concept was linked to the second-level category d760 *Family relationships*. If information provided was not specific enough or could not be linked to a second-level category, we linked it to an “unspecified” or “other specified” category.²² Finally, all meaningful concepts that could not be linked to categories in chapters d6–d9 or were not definable at all, were classified as ‘non-social’. Linking was performed using the qualitative data analysis software MaxQDA 2022 (VERBI Software, Berlin, Germany).

To ensure the reliability of the linking, the first iteration was conducted by two authors who were familiar with the ICF (AH and CvL). They read and linked the first

20 concepts together and after that they linked 100 concepts independently and compared the results. AH then linked the remaining concepts and CvL randomly checked 10%. All disagreements were discussed and resolved by consensus. Results are presented as percentages, representing the amount of text labeled as a meaningful concept that could be linked to the selected ICF chapters, relative to the total amount of text labeled as any meaningful concept. This process was repeated across all questions and per question within the interview.

Results

Characteristics of the 39 participants are presented in **Table 3.1**. Most participants were male (64.1%), and paraplegic (61.5%). The mean time since injury was 14.1 years. Participants' average ratings of the QoL-BDS questions were 6.2 (SD 1.8), 6.4 (2.2), and 6.6 (2.6), respectively (**Table 3.1**).

Table 3.1. Demographics, disease characteristics, and scores on the spinal cord injury – quality of life basic data set

Participants characteristics	Total (n=39)
Site, (%)	
Ann Arbor	10 (25.6)
Denver	8 (20.5)
Melbourne	10 (25.6)
São Paulo	11(28.2)
Sex, (%)	
Male	25 (64.1)
Female	14 (35.9)
Age, mean (SD)	54.4 (11.4)
Years since onset, mean (SD)	14.1 (12.7)
Years of education, mean (SD)	13.2 (4.0)
Type of impairment	
SCI	26 (66.7)
SCD	13 (33.3)
Level of impairment, (%)	
Paraplegia	24 (61.5)
Tetraplegia	15 (38.5)
Scores on SCI QoL-BDS ^a , mean (SD)	
Satisfaction with life as a whole	6.2 (1.8)
Satisfaction with physical health	6.4 (2.2)
Satisfaction with psychological health	6.6 (2.6)

^a Numeric rating scale 0 (completely dissatisfied) to 10 (completely satisfied).

Linking results are summarized in **Table 3.2**. Percentages show text linked to the four ICF chapters together and per chapter, and the top three ICF second-level categories, appearing in the responses to the interview questions. Detailed results

are shown in **Appendix A**. Across all questions, most meaningful concepts were linked to chapter d7 *Interpersonal interactions and relationships* and less text to chapter d6 *Domestic life*. In each question, d760 *Informal social relationships*, d770 *Intimate relationships*, d845 *Acquiring, keeping and terminating a job* and d920 *Recreation and leisure* were mentioned. Hereinafter, the results are described per question, illustrated with quotes from the interviews.

Table 3.2. Distribution of the chapters and highest three % referenced ICF categories

	Total ^a %	d6 ^a	d7 ^a	d8 ^a	d9 ^a	Top three categories ^b
Definition of QoL	35.8%	1.3	18.2	2.9	13.4	d920 Recreation and leisure (6.1) d770 Intimate relationships (4.5) d999 Community, social and civic life, unspecified (4.2)
Life as a whole	24.9	2.7	11.5	5.6	5.1	d760 Family relationships (5.1) d920 Recreation and leisure (4.6) d770 Intimate relationships (3.3)
Physical health	6.0	0	4.1	0.5	1.4	d770 Intimate relationships (3.1) d920 Recreation and leisure (1.4) d760 Family relationships (1.0)
Psychological health	34.9	0.2	25.5	1.9	7.3	d760 Family relationships (14.4) d770 Intimate relationships (6.9) d950 Political life and citizenship (3.3)
Other issues	39.6	0.8	20.2	10.0	8.6	d770 Intimate relationships (5.8) d740 Formal relationships (4.3) d870 Economic self-sufficiency (4.0)

^a Percentages of the amount of text labeled as a meaningful concept that could be linked to the selected ICF chapters, relative to the total amount of text labeled as a meaningful concept.

^b Each field represents the highest three % referenced categories for that question. The percentages are shown in brackets.

Concept of QoL

In the responses to this question, participants' meaningful concepts closely related to d7 *Interpersonal interactions and relationships*, as they commented on the quality of such relationships. For example, regarding d770 *Intimate relationships* they mentioned, "I still have a loving wife", or in contrast, "She tells me that she is doing me a favor by staying with me". Considerable text was linked to chapter d9 *Community, social and civic life*, especially to d920 *Recreation and leisure* and d930 *Religion and spirituality*. These relate to the ability to engage in pre-injury or post-injury sports and hobbies, and how a SCI/D changed spending time on daily activities and travel, e.g.: more time to do things, but conversely difficul-

ties in traveling. Also, the importance of religious activities and being part of a community are part of the meaningful concepts.

Satisfaction with life as a whole

Compared to the other questions, more meaningful concepts were related to d8 *Major life areas* and d6 *Domestic life*. This was found especially related to d650 *Caring for household objects*, showing things that participants cannot do anymore in or around the house due to the SCI, for example e.g. *"I can't even replace a lightbulb in my home"*.

The focus of the meaningful concepts linked to chapter d7 *Interpersonal interactions and relationships* were related to changes in relationships due to SCI/D: *"The communication with the family, that gets broken down between me and the family and you end up just feeling distance..."* (d760 *Family relationships*).

In chapter d8 *Major life areas* concepts were most linked to d845 *Acquiring, keeping and terminating a job*. These meaningful concepts showed the importance of having a job for QoL, e.g. *"I feel very fortunate with what's going in my life...a job..."*.

Also in this question, most meaningful concepts within chapter d9 *Community, social and civic life* were linked to d920 *Recreation and leisure*. A participant related this explicitly to the situation in the past: *"There is a lot of things that I would like to be better like walking, dancing, & going shopping. Right now I am limited on the things that I enjoyed in the past. My husband has to walk the dog alone now and I can't do that anymore either"*.

Satisfaction with physical health

In this question, by far the fewest meaningful concepts (6% in total) are linked to a predefined chapter relevant to social life. Most text is linked to d770 *Intimate relationships*, where the influence of the physical impairments are linked to social life. E.g.: *"I'm not young. I would like to date a woman within my range. I want to be perfect when it comes to dating someone you might end up marrying and for that you have to be normal. And I'm not normal"*. Text on physical health was also linked to d920 *Recreation and leisure*, as quoted: *"Yesterday we played cards for 3 hours. My physical health is great"*.

Satisfaction with psychological health

The most meaningful concepts are linked to d7 *Interpersonal interactions and relationships*, especially d760 *Family relationships*. Here the meaningful concepts explained how relationships influenced mood, e.g., the happiness by seeing (grand)children, and numbers of contact moments.

Topics defined in the categories of chapter d8 *Major life areas* and d9 *Community, social and civic life* were linked to satisfaction with psychological health. These categories were about how work, sports, religion, or activities in the community affected mood "*I gave a rating of 9 and not 10 because I can't get a job*" (d845 *Acquiring, keeping and terminating a job*), "*I was depressed after the accident, but by being involved in sports ... I got better*" (d920 *Recreation and leisure*) or "*But then what's going on in our society at the moment. Those different issues that are putting worry into everybody's mind*" (d950 *Political life and citizenship*).

Other issues

In response to the question to other issues, participants addressed other topics they felt were relevant to their QoL. A number of these topics could be linked to ICF categories in the chapters d6–d9.

Most text was labeled to d7 *Interpersonal interactions and relationships* mostly to d740 *Formal relationships*, such as colleagues, and d770 *Intimate relationships*. In d770 *Intimate relationships* the concepts specified the importance of sexuality and how altered sexuality due to SCI affects their mood. For example: "*The thing that it bugs me a lot is the sexuality.*"

Considerable text was linked to chapter d8 *Major life areas*, especially to d870 *Economic self-sufficiency*. For example: "*I think financial health, financial stability, is something that I think everyone deals with no matter what bracket they're in*". Meaningful concepts explain the importance of this by relating it to the availability of special aids, housing or house adjustments, and transport.

Topics related to work and employment were much more frequently mentioned in response to the other issues question compared to the other questions. When we merged the categories d845 *Acquiring, keeping and terminating a job*, d850 *Remunerative employment*, d855 *Non-remunerative employment*, and d859 *Work and employment, other specified and unspecified*, they accounted for 4.2% in total.

Discussion

This study aimed to explore aspects of social life relevant to QoL according to people with SCI/D by re-analyzing cognitive interview data about participants' meaning of QoL and answers on the QoL-BDS. We found that aspects of social life are prominent in participants' answers to the questions regarding defining QoL, life as a whole, psychological health, and other aspects. This finding reflects the relative salience of these issues for people defining and experiencing QoL. They are best reflected in aspects concerned with d920 *Recreation and leisure*, d770 *Intimate relationships* and d760 *Family relationships*. When asking about other issues that may relate to meaningful concepts, the most frequently mentioned categories are d770 *Intimate relationships*, d740 *Formal relationships* and d870 *Economic self-sufficiency*. These social categories are not covered by the initial version of the QoL-BDS.⁵ A social life item was considered during the development of the QoL-BDS, but the decision was made to not include that item to avoid overlap with the simultaneously developed International SCI Activities and Participation Basic Data Set.²⁸

Many meaningful concepts were linked to d770 *Intimate relationships*, d760 *Family relationships* and d920 *Recreation and leisure*. The importance of recreation and leisure for peoples with SCI/D has been reported elsewhere, but consistently ranked lower than other social or physical health domains.^{9,18} Therefore, it is not surprising that in our study the most meaningful concepts were linked to d7 *Interpersonal relationships*, especially with family and intimates.^{9,18} Other aspects relevant to participant's QoL further showed the importance of employment and economic self-sufficiency. The inclusion of these topics is highlighted in previous studies.^{2,9} Results of this study indicated that people are thinking about their social life when answering questions about their life as a whole, physical, and psychological life. Clinicians should recognize that the responses to each item of the QoL-BDS may be influenced by other factors, such as social participation. This suggests that people do not see their lives as separate themes, but as one intertwined whole. These topics are highly salient when people consider and evaluate their QoL. However, measuring QoL in different areas is necessary for comparison. It is impossible to measure the social aspects of QoL across populations without incorporating a separate item into the QoL-BDS.

Findings from this exploratory study suggested that a specific question in the QoL-BDS related to satisfaction with people's social life is essential to understand people's QoL and make it easier to find, analyze and compare social aspects across populations. It is also useful in clinical practice. Using the 4-item QoL-BDS makes it possible for clinicians to separate the most important aspects of QoL, and herewith the ability to deploy targeted interventions and resources to improve people's QoL. Additionally, other analyses conducted as a part of this study using Rasch analysis showed minimal differences in psychometric properties between the 3-item and proposed 4-item QoL-BDS (including the question of satisfaction with social life), and supported the validity of the 4-item.¹⁶

Strengths and several limitations to this study should be noted. The strength of rooting this work in qualitative data lies in its capacity to more fully describe what life is like after SCI/D, pointing investigators towards what is salient to people with lived experience rather than relying on a priori assumptions.²⁹ In using the ICF to link these qualitative data, we enable enhanced comparability of health information and structuring data from open-ended questions in a consistent manner.^{22,30}

There were limitations to this process, however. First, linking meaningful concepts was partly done by two researchers. To increase reliability, the findings were randomly checked, doubts discussed, and consensus was reached by a research team familiar with the interview transcripts. Second, although the ICF is an internationally accepted and common language, there is no consensus about which categories are related to participation, and how participation is related to social concepts.³¹ The choice to use the ICF chapters d6–d9 as the definition of social participation, reflected what is commonly accepted by professionals and individuals with SCI/D.^{23,24} Third, during the process of selecting and transcribing text from interviews, there was no step in place to have participants themselves review and confirm the validity of data. However, member checking was done by research assistants during the interview by summarizing responses and confirming their interpretation of what participants said. Finally, the sample consisted mainly of older males, but was comparable with the international SCI/D population.^{3,32} This may have influenced the results because being male and being older are associated with lower levels of perceived social support.³³

Conclusion

This ICF-linking study explored aspects of social life related to the QoL of people with SCI/D, using data from our previous validation study of the QoL-BDS. While the QoL-BDS captures important aspects of QoL, i.e., 'life as a whole', 'physical health' and 'psychological health', people do think about their social lives when rating these other domains. Results from this study confirm the importance and intertwined relationship of social participation with QoL and support the added question regarding satisfaction with one's social life to the QoL-BDS. By linking the ICF domains to qualitative data, this study demonstrates how an additional social life item may facilitate a more robust survey measure of social life normally only captured in qualitative data. By understanding these elements, healthcare workers can better comprehend the lived experiences of people with SCI/D, and contribute to enhancing their overall QoL.

Data availability

The data analyzed during the current study are available from the corresponding author on reasonable request.

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Ethical approval

The research protocol was approved by the University of Michigan Medical School Institutional Review Board, protocol number HUM00126164 and HUM00125769 and the HCA HealthONE Institutional Review Board for Craig Hospital, protocol number 1036454-11. 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.

Competing interests

The authors declare that they have no conflict of interest.

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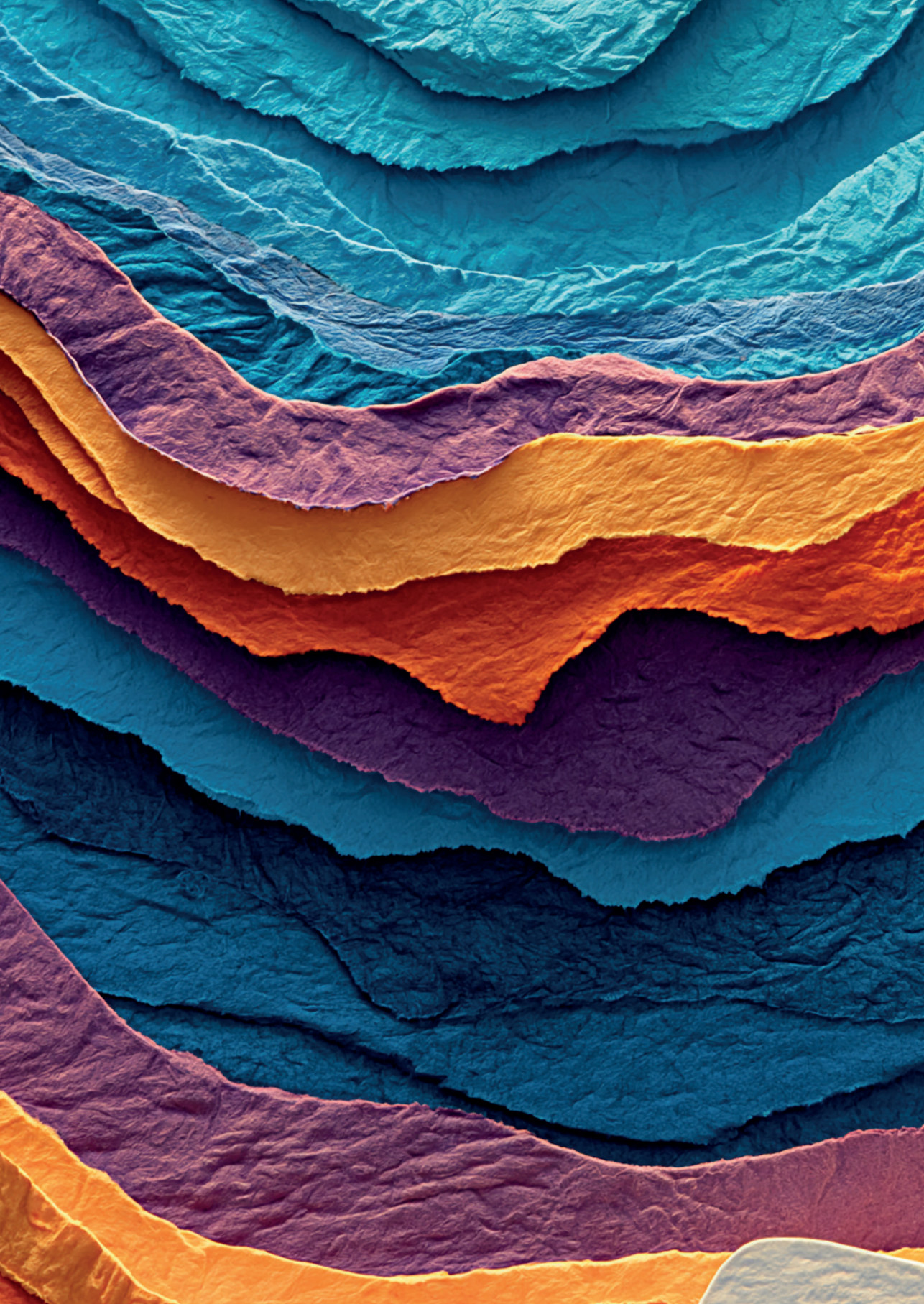
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Appendix

Appendix A

See <https://www.nature.com/articles/s41393-023-00954-7#Sec16>







PART 2

Psychological factors
in quality of life

CHAPTER 4

Associations between psychological factors and quality of life ratings in individuals with spinal cord injury: Update of a systematic review

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Submitted for publication

Objective: To update a systematic review on the relationship between psychological factors and Quality of Life (QoL) in individuals with Spinal Cord Injury (SCI) covering literature after the previous review.

Data sources: Pubmed, Embase, PsychINFO and CINAHL were searched for articles published between December 2010 and January 2023.

Study selection: Studies were included if they involved individuals with SCI, assessed psychological factors using standardized questionnaires, and reported correlation or regression coefficients with mental health (depression, anxiety, PTSD) or subjective well-being (life satisfaction, psychological well-being).

Data extraction: Two reviewers independently extracted data using ASReview. Study quality was assessed with the Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies.

Data synthesis: Of 1568 unique records, 66 met the inclusion criteria. Compared to our previous review, fewer studies focused on stable traits (e.g. locus of control, sense of coherence, personality, spirituality), whereas more attention was given to dynamic, potentially modifiable factors (e.g. purpose in life, self-efficacy, and resilience). Stronger correlations between attribution of blame, personality, and resilience with QoL and mental health were found. Consistent associations were confirmed for locus of control, sense of coherence, positive affect, hope, purpose in life, self-worth, emotion-focused coping, appraisals and QoL. Evidence remains limited for negative affect, spirituality, problem-focused coping, and post-traumatic growth.

Conclusion: Psychological factors play a clear role in QoL after SCI. These findings highlight the importance of systematically addressing psychological functioning within rehabilitation, as several modifiable factors are consistently associated with QoL outcomes. Future research should improve reporting, prioritize longitudinal designs, and use consensus-based terminology to enhance conceptual clarity.

Introduction

Spinal cord injury or disease (SCI/D) is a relatively rare condition, with an annual global incidence of 40 to 80 cases per million.¹ It has long-term consequences across physical, social, occupational, and psychological domains, requiring psychological adjustment to maintain quality of life (QoL).^{2,3} Individuals with SCI/D generally report lower QoL than the general population,^{4,5} making QoL improvement an essential goal and a key outcome in rehabilitation.⁶

Psychological factors play an important role in both adjustment to SCI and perceived QoL.^{2,7,8} Over a decade ago, systematic reviews explored this relationship,^{8,9} with Peter et al. focusing on positive psychological factors or psychological resources, and Van Leeuwen et al. reviewing all studied psychological factors.^{8,9} These reviews found that several psychological factors, including higher levels of locus of control, sense of coherence, self-worth, hope, purpose in life, positive affect, self-efficacy, appraisals, and acceptance, were consistently associated with higher QoL.⁸⁻¹¹ They also reported that higher levels of self-efficacy and self-esteem were linked to lower anxiety and depression.¹² At the same time, the reviews showed inconsistent associations for locus of control, attribution of blame, spirituality, personality, appraisals, passive coping, and emotion focused coping, while active problem-focused coping styles showed no significant correlation with QoL.⁹ According to these reviews, long-term QoL appeared most influenced by self-efficacy, sense of coherence, spirituality, purpose in life and threatening appraisals.⁸ Inconsistencies across studies highlight the need for improved study quality and more longitudinal research with adequately large samples.⁸⁻¹¹ Since then, numerous studies have investigated these associations, and additional systematic reviews have been published, though typically focused on specific factors such as self-efficacy and acceptance.^{10,12} However, no recent review has provided a comprehensive synthesis of the relevance of psychological factors for QoL after SCI.

A better understanding of how psychological factors influence QoL can support healthcare professionals in improving rehabilitation strategies and identify research gaps. Given the growing body of literature, we expected that recent studies provided more insight into the associations between psychological factors and QoL. Therefore, this study aims to update the evidence on the relationship between psychological factors and QoL in individuals with SCI by systematically

reviewing studies published between December 2010 and January 2023 and comparing findings with the previous review.⁹ We hypothesized that: 1) psychological factors previously linked to QoL, namely sense of coherence, purpose in life and locus of control (LOC), self-worth, hope, positive and negative affect, posttraumatic cognitions, would continue to show consistent associations with QoL in individuals with SCI; and 2) these factors would be examined more extensively, providing a better understanding of their relationship with QoL.

Methods

Operationalization of concepts

QoL is a multidimensional concept and consensus on a definition is lacking in the literature. Like in the previous review, we focus on the psychological component of QoL, which we split into two elements: a cognitive component that comprises subjective well-being (SWB; including life satisfaction and psychological well-being), and an emotional component that encompasses mental health. Mental health, while closely related to subjective well-being, refers more narrowly to an individual's state of mind, characterized by psychological and emotional responses to life events, including depression, anxiety, post-traumatic stress, and emotional distress.¹³ The categorization of measures used in the included studies according to these concepts is displayed in **Table 4.1**.

Independent variables

The independent variables in this study were psychological factors, which refer to the internal mental processes and states that influence behavior (such as thoughts, emotions, and personality traits), and contribute to the maintenance of health and well-being.¹³ Psychological factors were primarily organized based on the previous review, as displayed in **Table 4.2**.⁹ Resilience was added as an additional factor, and positive psychological factors were further subdivided to better align with current literature, as the previous classification did not fully reflect recent findings. Wherever possible, we adhered to the definitions provided in the American Psychological Association (APA) dictionary.¹³ When no APA definition was available, alternative definitions were constructed based on existing literature.

Table 4.1. Quality of life: operationalization and questionnaires

	Outcome	Questionnaires
Subjective well-being	Life satisfaction	WHOQOL-BREF: World Health Organization Quality of Life Scale – psychological subscale ^{14–20} ; SWLS: Satisfaction With Life Scale ^{21–29} ; SWLS 5 item version ^{30,31} ; SCI-QOL BDS: Spinal Cord Injury-Quality of Life Basic Data Set ^{32–36} ; 2LS: 2 Life Satisfaction Questionnaires ^{37,38} ; LSQ: Life Satisfaction Questionnaire ³⁹ ; SEIQoL-DW: Schedule for the Evaluation of Individual Quality of Life-Direct Weighting ⁴⁰ ; WHOQoL-5: World Health Organization Quality of Life Assessment, 5 item version ³⁴ ; combined index of Acknowledgement and Adjustment subscales of the RIDI ⁴¹ ; Subjective Happiness Scale ²⁵ ; Neuro-QOL-PAWB-sf: Quality of life in neurological disorders: positive affect and well-being short form ⁴² ; Ryff Scales of Psychological Wellbeing-18 ²⁴ ; 54-item Ryff Scales of Psychological well-being medium form ⁴³ ; SWBI: Sense of Well-Being Inventory ⁴⁴ .
	Psychological well-being	SF-8: Medical Outcomes Study 8-Item Short Form Health Survey, VA version – mental health subscale ²⁶ ; SF-12: Medical Outcomes Study 12-Item Short Form Health Survey – mental health subscale ^{22,45} ; SF-36: Medical Outcomes Study 36-Item Short Form Health Survey – mental health subscale ^{15,37,40,46–50} ; RAND-36-item health survey 1.0 ⁵¹ .
Mental Health	Anxiety	HADS-A: Hospital Anxiety (and Depression) Scale ^{17,20,25,33–35,52–58} ; GAD-7: Generalized Anxiety Disorder ^{23,32,36} ; Beck Anxiety Inventory ²⁵ ; DASS-21: (Depression) Anxiety Stress Scale ⁵⁹ ; PRO-A-SF: Patient reported Outcome Measurement Information System Item Bank v1.0- Emotional Distress-Anxiety-Short form ⁶⁰ .
	Depression	PHQ-8: Patient Health Questionnaire ^{36,61,62} ; PHQ-9 ^{23,25,28,31,32,42,63–68} ; HADS-D: Hospital (Anxiety and) Depression Scale ^{7,17,20,33–35,52–58,69} ; CES-D: Center of Epidemiologic Studies Depression Scale ^{39,41,70,71} ; CES-D Version 10 ⁷² ; BDI: Beck Depression Inventory ^{30,42,73} ; PRO-D-SF: Patient reported Outcome Measurement Information System version 1.0 Item Bank Depression Short form ⁶⁰ ; PRO-D-SF Version 2.0 ⁴³ ; PROMIS SCI-QOL item bank version 1.0, subscale Depression ⁷⁴ ; ADS-K: Allgemeine Depressionsskala Kurzform ⁷⁵ ; DASS-21: Depression (Anxiety Stress) Scale ⁵⁹ ; GDS-15: Geriatric Depression Scale ⁷⁶ ; POMS: Profile of Mood status, subscale depression ⁷⁷ .
	Post-traumatic stress and emotional distress	IES-R: Impact of Events – Revised ⁵⁴ ; IES-6 ⁷⁸ ; PPTSD-R: Purdue Posttraumatic Stress Disorder-Revised Scale ^{41,70} ; PSS-4: Perceived stress scale-4 ⁷² ; PSS-10: Perceived stress scale-10 ²⁴ ; PC-PTSD: 4-item Primary-Care Post Traumatic Stress Diseases ⁶² .

Search strategy

A literature search was conducted across multiple databases: Embase, PsychINFO, Pubmed and CINAHL (Cumulative Index to Nursing and Allied Health Literature), with the search string details provided in **Appendix A**. All results were imported into Mendeley, and duplicate records were removed prior to screening. Two researchers (AH and SD) independently screened titles and abstracts, aided by the ASReview machine learning software tool.⁸⁴ First, AH and SD together labeled five relevant and five irrelevant papers based on psychological factors and outcome variables. The tool then used Artificial Intelligence to assist in

Table 4.2. Psychological Factors: operationalization and questionnaires

Operationalization of psychological factor		Questionnaires
1. Locus of control	A construct that is used to categorize people's perceptions of how much control they have over the conditions of their lives ¹³ .	The Pearlin and Schooler Mastery Scale ^{53,79} ; Pmnac: Perceived manageability Scale (subscale of the needs assessment checklist) ¹⁷ ; MHLC scale: Multidimensional Health Locus of Control scale ⁷⁰ .
2. Attribution of blame	The assessment of an individual's attribution of accountability for his/her SC ⁸⁰ .	IEQ: Injustice Experience Questionnaire ^{22,28,49,61} ; HSF: Heartland Forgiveness Scale ^{24,30} ; Combined Gorsuch and Hao and Behavior Assessment system ²⁹ ; Self-blame domain of the COPE ⁷ .
2a. Blame	Willfully putting aside feelings of resentment toward an individual who has committed a wrong, been unfair or hurtful, or otherwise harmed one in some way ¹³ .	
2b. Forgiveness		
3. Sense of coherence	The degree to which a person experiences that his/her life situation is comprehensible, manageable and meaningful ⁸¹ .	SOC: Sense of Coherence scale ¹⁷ ; SOC-13: Sense of Coherence 13-item version ⁷⁶ ; OLO: Orientation to Life questionnaire ⁴¹ .
4. Personality	The enduring configuration of characteristics and behavior that comprises an individual's unique adjustment to life ¹³ .	EPQ-RSS: Eysenk Personality Questionnaire-Revised Short Scale ³⁷ ; DS-14: Type D Scale-14 ⁴⁷ .
5. Affect	Any experience of feeling or emotion, e.g. suffering, elation, complex sensations of feeling, and pathological emotional reactions ¹³ .	STAXI-II: State Trait Expression, Inhibition ^{61,62} ; PANAS: Positive and Negative Affect Schedule ^{30,42} ; PROMIS SCI-QOL item bank version 1.0, subscale positive affect and Well-Being ⁷⁴ .
5a. Positive	Positive affect reflects feelings of joy, excitement and vigour ⁸² .	
5b. Negative	Negative affect indicates feelings of anger and despair ⁸² .	

6. Hope	The expectation that one will have positive experiences or that a potentially threatening or negative situation will not materialize or will ultimately result in a favorable state of affairs ¹³ .	THS: Trait Hope Scale ^{27,30,39,41} .
7. Purpose in life	The mental sense of a goal or aim in the process of living or in existence itself ¹³ .	PIL: Purpose in life ^{7,18,31,79} ; PIL-SF: Purpose in life-short form ^{33,35,55,78} ; LOT-R Life Orientation Test-Revised ^{55,79} ; LOT-R-6 Modified 6-item version of Life Orientation Test-Revised ³³ ; Life Orientation Scale ⁵¹ .
8. Spirituality	A concern for or sensitivity to things of the spirit or soul ¹³ .	Religion domain of the COPE ^{7,18,22} ; ISS: Intrinsic spirituality Scale ⁴⁵ ; FACIT-sp: Functional Assessment of Chronic Illness Therapies-Spiritual ⁴² ; SWBS: Spiritual well-being scale ⁴⁸ ; Importance of religion on a 1-5 Likert scale ²² ; Religious belief, dichotomous ¹⁹ .
9. Self-worth		
9a. Self-esteem	The degree to which the qualities and characteristics contained in one's self-concept are perceived to be positive ¹³ .	RSES: Rosenberg Self-Esteem Scale ^{27,30} ; Dimension of Self-concept ⁷³ ; Self-distraction domain of the COPE ⁷ ; State Self-esteem ⁴⁵ .
9b. Self-efficacy	An individual's subjective perception of their capability to attain desired results ¹³ .	GSES: General Self Efficacy Scale ^{7,16,18,23,33,35,44,78,79} ; Modified 5-item version of the GSES ⁵⁵ ; MSES: Moorong Self-Efficacy Scale ^{15,23,27,28,46,53,65,77} ; Selection of questions GSES and MSES ⁴⁹ ; UW-SES-6: University of Washington Self-Efficacy Scale 6-item version ^{14,58} ; Sherer's Self-efficacy scale ^{37,38} ; Self-efficacy for managing chronic disability 6-item scale, abbreviated version of the Chronic Disease Self-Efficacy Scale ⁴⁸ ; LCDESES-6: modified Lorig Chronic Disease Self-Management Style ⁴⁴ ; Cha's Korean General self-efficacy scale ²¹ .

Table 4.2 continues on next page.

Table 4.2. Continued

	Operationalization of psychological factor	Questionnaires
10. Resilience	The process and outcome of successfully adapting to difficult or challenging life experiences, especially through mental, emotional, and behavioral flexibility and adjustment to external and internal demands ¹³ .	CD-RISC: Connor-Davidson Resilience Scale ^{19,44,54,60,64,65,68,76} ; CD-RISC-2 ²⁴ ; CD-RISC-10 ^{60,67} ; Spinal Cord Injury Quality of Life Resilience Short form ³⁶ ; PROMIS SCI-QOL item bank version 1.0 subscale resilience ⁷⁴ .
11. Coping	The use of cognitive and behavioral strategies to manage the demands of a situation when these are appraised as taxing or exceeding one's resources or to reduce the negative emotions and conflict caused by stress ¹³ .	Brief COPE ^{7,17,18,25,32,41,55,70,75} ; SCL-CSQ: Spinal Cord Lesion-related coping strategies questionnaire ^{17,32} ; CISS: Coping Inventory for Stressful Situation ⁴⁰ ; Alcohol/Drug use ⁶⁵ ; SCL-CSQ: Spinal Cord Lesion-Related Coping Strategies, subscale acceptance ^{20,27} , subscale social reliance and fighting spirit ⁶⁰ ; TAACS: The assimilative-accommodative Coping Scale ^{57,69} ; Brandtstätter and Renner's 15-items tenacious goal pursuit and flexible goal adjustment scales ⁴³ ; PCI: Proactive coping inventory ⁷² ; ADS: Acceptance of Disability Scale ⁷¹ .
11a. Active problem-focused coping	A stress-management strategy in which a person directly works to control a stressor through appropriately targeted behavior, embracing responsibility for resolving the situation using one's available internal resources ¹³ .	
11b. Passive coping	A stress-management strategy in which a person absolves them self of responsibility for managing a stressor and instead relinquishes control over its resolution to external resources, such as other people and environmental factors ¹³ .	
11c. Emotion-focused coping	A stress-management strategy in which a person focuses on regulating their negative emotional reactions to a stressor ¹³ .	

12. Appraisals	The cognitive evaluation of the nature and significance of a phenomenon or event ¹³ .	ALE: Appraisal of Life Events ^{7,17,18,55,78} ; ADAPSS-sf: Appraisals of Disability Scale Primary and Secondary Scale-short form ^{26,52,63} ; ICQ: Illness Cognition Questionnaire ^{37,79} ; Subdomain fear, loss, catastrophic negativity of the ADAPSS-SF ^{26,52,63} ; RIDI: Reactions to Impairments and Disability Inventory ^{24,41} ; PROMIS SCI-QOL item bank version 1.0; subscale grief/loss ⁷⁴ ; AAQ-M, Acceptance and action Questionnaire, subscale acceptance ⁸² ; AAQ-II: Acceptance and Action Questionnaire-II ⁵⁹ ; ADS-R: Acceptance Disability Scale-revised ²¹ ; Illness perception questionnaire, modified ³¹ .
12a. Positive		
12b. Negative		
13. Posttraumatic growth	Trauma-related thoughts and beliefs ⁸³ . Positive or negative psychological changes that occur after experiencing trauma or highly challenging situations ¹³ .	PTCI: Posttraumatic Cognitions inventory ⁷⁵ ; PTGI: Post Traumatic Growth ^{19,54} ; PTGI-42: Post traumatic depreciation, paired format posttraumatic growth inventory ^{25,34,35,64} ; PTGI-SF: Post traumatic growth inventory short form ³⁴ .
13a. Posttraumatic cognitions		
13b. Posttraumatic growth		
14. Other		BEQ: Body Experience questionnaire ⁵⁶ ; Social comparison scale ⁷⁹ .

finding relevant text. Screening criteria were both predetermined and data-driven. Reviewers stopped reviewing after at least one-hundred irrelevant papers in a row.⁸⁵ Inter-rater agreement (Cohen's kappa) between both raters for selection of titles and abstracts was 0.55, indicating moderate agreement.⁸⁶ The percentage agreement was 93.1%. The relatively low kappa value, despite the high percentage agreement, is likely explained by the skewed distribution of inclusion and exclusion decisions. Disagreements were resolved through discussion, with a third reviewer (CvL) consulted in three cases.

Selection

After selecting title and abstracts, full-text papers were included if they met the following criteria 1) reported a quantitative association between one or more psychological factors and QoL, 2) included participants aged 18 year or older, 3) focused on individuals with a SCI, 4) were written in English, and 5) were published in peer-reviewed journals.

Studies were excluded if they: 1) were qualitative reports, case studies, or systematic reviews, 2) included $\geq 30\%$ of participants with other diagnosis without separate results for SCI, or 3) measured only a physical component of QoL (e.g. physical health, or satisfaction with functional independence). As this paper updates a previous review, the search period was set from 29 November 2010 to 19 January 2023. Studies reporting the same correlation of a psychological factor from the same study groups in multiple articles were only included once.

Critical appraisal

The Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies (OCCSS) developed by the U.S. National Institutes of Health was utilized to evaluate the study quality.⁸⁷ The OCCSS includes 14 criteria and has a final global rating of poor, fair, or good. A rating of 'poor' is given if less than 7 of the criteria are answered with 'yes'. A rating of 'fair' is given if 7 to 11 of the criteria are answered with 'yes', and a rating of 'good' is given if more than 11 of the criteria are answered with 'yes'. Rather than relying solely on the number 'yes' answers, we related the answers to the potential risk of bias for the decisive final rating, as intended in the OCCSS. Two raters (AH and SD) independently assessed study quality. Disagreements were discussed, with a third researcher (CvL) consulted when necessary. Studies were not excluded based on quality rating.

Data synthesis

Relevant data were extracted and tabulated, including sample characteristics (e.g., sample size, age, gender, type and time of injury), study details (e.g. country, study setting, study design, time of measurement), psychological factors, QoL measures, and key findings of the study. Bivariate Pearson's and Spearman correlation coefficients were the preferred statistics for analysis as regression coefficients are difficult to compare across studies. If these correlations were not reported in the article, the authors were contacted, with a reminder sent after 2 weeks if no response was received. Correlations were considered as weak (<0.3), moderate ($0.3\text{--}0.5$), or strong (>0.5).⁸⁸ In longitudinal studies that not report correlation coefficients, other indicators of associations were extracted instead, such as standardized β -coefficients, changes in R^2 , differences between means and multi-variable results. However, these were not used in the main results description, as they are less directly comparable to the bivariate correlations. For readability the results were grouped into mental health (consisting of depression, anxiety and post-traumatic stress) and SWB (consisting of life satisfaction and psychological well-being). These grouped results are presented in **Appendix B**. Due to the broad research question and study heterogeneity, meta-analysis was not feasible. Psychological factors were categorized based on predefined overarching themes.

Psychological factors were classified as consistently related to mental health or SWB if most bivariate associations were statistically significant, and the majority were moderate ($0.3\text{--}0.5$) or strong (>0.5). Variables were considered inconsistently related to mental health or SWB if only some associations were statistically significant or most were weak. If all or nearly all associations were non-significant, a factor was classified as unrelated to mental health or SWB. Study quality was not used to weight the results in the synthesis.

Results

After removing duplicates, 1568 new articles were screened for inclusion, of which 703 were screened by a human and the others automatically excluded by AI software. Of these, 104 articles were selected for the full-text review and assessed for eligibility, with 66 studies met the eligibility criteria. **Figure 4.1** shows a PRISMA flow diagram outlining the search and selection process.

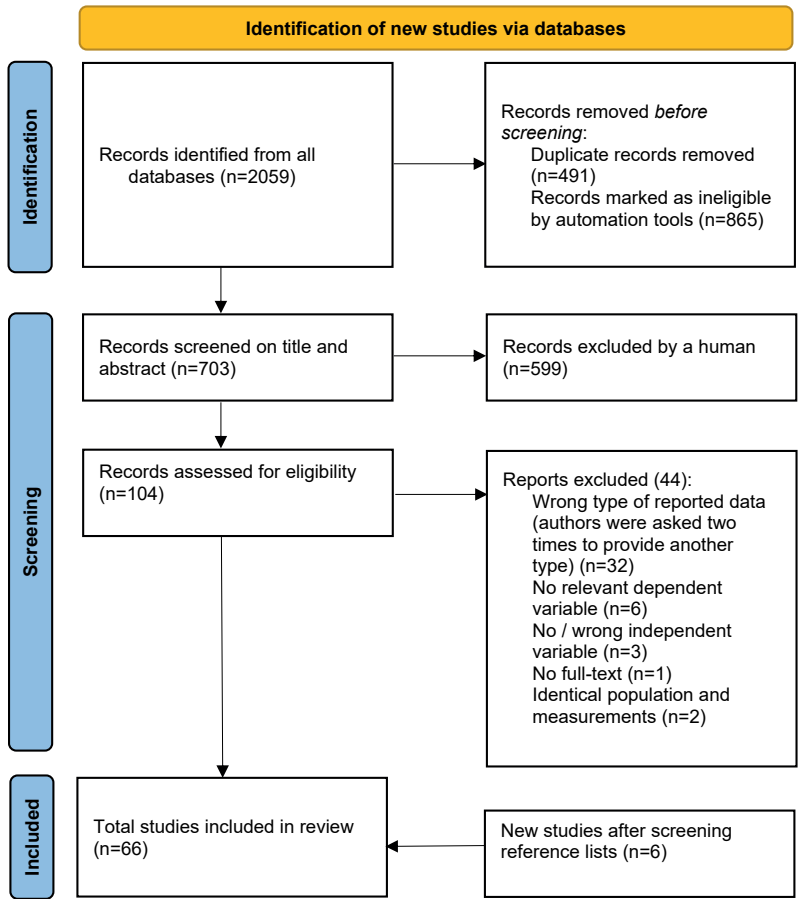


Figure 4.1. PRISMA flow chart.
From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: An updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71.

Study characteristics

Sample sizes of the included studies ranged from 9 to 1579, with a median of 141 participants. All studies showed a majority of male participants, and mean age ranged from 31.1 to 63.0 years. Time since injury ranged extensively from 1.5 months to 26.2 years post-injury, with a median of 90 months (IQR 1.5; 176). Most studies were conducted in Western developed countries, and 18 (27%) used a longitudinal study design. The instruments ranged from single-item global assessments to detailed inventories. Psychological factors and SWB were examined in 35 studies, while 49 investigated psychological factors and mental health. Most studies examined multiple associations between these outcomes. Study characteristics of the included studies are presented in **Table 4.3**.

Table 4.3. Characteristics of included studies

Author, year	Total N of individuals with SCI	Age (y, mean)	Country	Setting	Study design
Aaby, 2022 ³²	453	56.6	Denmark	Community	Cross-sectional
Ahn, 2021 ²¹	142	41.1	South Korea	Community	Cross-sectional
Aparicio, 2019 ³³	370	53.8	Switzerland	Inpatient	Cross-sectional
Aparicio, 2021 ⁵⁵	207	51.9	Switzerland	Inpatient	Longitudinal
Arewasikporn, 2019 ⁴³	214	58.3	USA	Community	Longitudinal
Bhattarai, 2018 ⁶⁵	82	34.8	Nepal	Community	Cross-sectional
Bhattarai, 2020 ⁴⁴	102	34.3	Nepal	Community	Cross-sectional
Bjork, 2022 ⁷⁴	33	32.5	USA	Community	Longitudinal
Bombardier, 2012 ⁶⁶	244	43.1	USA	Community	Cross-sectional
Brazeau, 2018 ³⁰	67	44.7	Canada	Inpatient	Longitudinal
Chlan, 2011 ²²	298	31.1	USA	Community (former pediatric SCI program)	Cross-sectional
Cijsouw, 2017 ¹⁴	261	48.5	The Netherlands	Community	Cross-sectional
Coker, 2019 ²³	40	52.0	USA	Community	Longitudinal
Cornish, 2022 ²⁴	312	33.0	USA	Community	Cross-sectional
Craig, 2013 ⁷⁷	70	47.1	Australia	Community	Cross-sectional
Craig, 2014 ⁴⁶	107	47.1	Australia	Community	Cross-sectional
Craig, 2022 ¹⁵	1579	57.5	Australia	Community	Cross-sectional
Diemen, 2017 ⁵⁶	134	54.2	The Netherlands	Inpatient	Longitudinal
Diemen, 2018 ⁵⁷	113	55.5	The Netherlands	Inpatient	Longitudinal
Diemen, 2021 ⁵⁸	268	55.6	The Netherlands	Inpatient	Longitudinal
Dodd, 2015 ⁶⁷	106	43.8	USA	Inpatient	Cross-sectional
Dorsett, 2017 ³⁹	47	45.7	Australia and New Zealand	Inpatient	Longitudinal
Driver, 2016 ⁶⁸	44	39.8	USA	Inpatient	Longitudinal
Eaton, 2018 ⁵²	371	53.0	United Kingdom	Inpatient	Cross-sectional
Ekechukwu, 2017 ⁴⁵	52	36.2	Nigeria	Community	Cross-sectional

Table 4.3 continues on next page.

Table 4.3. Continued

Author, year	Total N of individuals with SCI	Age (y, mean)	Country	Setting	Study design
Eroglu, 2022 ⁴⁷	105	33.8	Turkey	Inpatient and outpatient	Cross-sectional
Goraczko, 2021 ¹⁶	9	39.8	Europe, USA	Community (outstanding athletes)	Cross-sectional
Hajjaghababaei, 2018 ⁴⁸	213	33.7	Iran	Community	Cross-sectional
Han, 2022 ⁵⁹	92	43.3	USA	Community	Cross-sectional
Huang, 2015 ⁷³	135	43.3	Taiwan	Community	Cross-sectional
January, 2015 ²⁵	161	33.2	USA	Community (former pediatric SCI program)	Cross-sectional
Jiao, 2012 ⁷¹	100	37.7	China	Community	Cross-sectional
Jørgensen, 2017 ⁷⁶	122	63.0	Sweden	Community	Cross-sectional
Kennedy, 2012 ¹⁷	232	40.0	United Kingdom, Switzerland, Germany, Ireland	Inpatient	Longitudinal
Kifley, 2022 ⁴⁹	1579	57.0	Australia	Community	Longitudinal
Kivisild, 2014 ⁵¹	80	43.1	Estonia	Community	Cross-sectional
Krause, 2014 ³¹	208	36.0	USA	Inpatient	Cross-sectional
Kunz, 2017 ³⁴	141	53.5	Switzerland	Inpatient	Cross-sectional
Kunz, 2019 ³⁵	206	53.8	Switzerland	Inpatient	Longitudinal
Kunz, 2021 ⁷⁸	269	53.2	Switzerland	Inpatient	Longitudinal
van Lankveld, 2011 ⁶⁹	130	56.2	The Netherlands	Community	Cross-sectional
van Leeuwen, 2012a ³⁷	143	45.3	The Netherlands	Community	Cross-sectional
van Leeuwen, 2012b ³⁸	162	39.9	The Netherlands	Community	Longitudinal
van Leeuwen, 2015 ⁵⁰	60	46.4	The Netherlands	Inpatient	Longitudinal
Livneh, 2011 ⁷⁰	95	47.5	USA	Outpatient	Cross-sectional
Livneh, 2014 ⁴¹	95	47.5	USA	Outpatient	Cross-sectional
McDonald, 2018 ²⁶	262	58.0	USA	Community (veterans)	Cross-sectional

Mignogna, 2015 ⁶³	98	56.2	USA	Community (veterans)	Cross-sectional
Mikolajczyk, 2021 ³⁶	187	57.0	International (mainly from the USA)	Community	Cross-sectional
Miller Smedema, 2017 ²⁷	235	44.6	USA	Community	Cross-sectional
Min, 2014 ⁶⁴	37	41.5	South Korea	Community	Cross-sectional
Monden, 2019 ⁶¹	74	47.6	USA	Inpatient	Cross-sectional
Monden, 2020 ²⁸	225	52.9	USA	Community	Cross-sectional
Munce, 2016 ⁵³	24	53.3	Canada	Community	Cross-sectional
O'Shea, 2014 ⁷²	238	44.6	USA	Community	Cross-sectional
Peter, 2014 ¹⁸	516	53.1	Switzerland	Community	Cross-sectional
Peter, 2015 ⁷	516	53.1	Switzerland	Community	Cross-sectional
Pincock, 2020 ⁶⁰	34	45.0	USA	Community	Cross-sectional
Sauri, 2014 ²⁰	511	50.6	Spain	Community	Cross-sectional
Schönenberg, 2012 ⁷⁵	102	41.3	Germany	Community	Cross-sectional
Tramonti, 2014 ⁴⁰	40	54.3	Italy	Community	Cross-sectional
Trost, 2017 ⁶²	53	47.6	USA	Inpatient	Cross-sectional
Wang, 2017 ⁵⁴	300	45.8	China	Community	Cross-sectional
Wang, 2019 ¹⁹	300	45.8	China	Community	Cross-sectional
Wilson, 2016 ⁴²	204	41.2	USA	Inpatient, outpatient and community	Cross-sectional
Webb, 2010 ²⁹	140	39.9	USA	Community	Cross-sectional

Study quality

Of the 66 studies, 9 were rated as *poor*, 36 as *fair*, and 21 as *good*. Agreement between raters on methodological quality was moderate (Cohen's Kappa = .41). Recurring quality issues included the absence of a longitudinal design (n=54), lack of sample size justification, power description or variance and effect estimates (n=44), and low participation rates (n=42). Fewer studies failed to report the study population clearly (n=26) or control for confounding variables (n=22). A detailed summary of the ratings and quality issues is provided in **Appendix C**.

Data synthesis

In this section, an overview is presented of the relationships between psychological factors and mental health/SWB. **Table 4.4** provides a summarizing overview, and **Appendix B** provides more detailed information. The measures used in the studies are presented in **Tables 4.1** and **4.2**. The results of this review were compared to those of the 2012 review and are presented in **Table 4.5**.

Locus of control (LOC)

LOC was consistently associated with mental health (3 studies)^{17,53,70} and SWB (2 studies).^{17,50} Higher LOC was significantly and consistently associated with lower levels of anxiety and depression and higher SWB, and non-significantly associated with PTSS.^{17,50,53,70} Notably, only one study used a dedicated LOC scale, which did not find significant correlations.⁷⁰ The other studies used conceptually related measures of perceived manageability¹⁷ or mastery^{50,53} (**Table 4.2**). LOC was consistently associated with higher levels of SWB up to 2 years post-injury.¹⁷ Evidence on LOC was therefore strong, with consistent associations with better mental health and higher SWB, although findings for PTSS were less clear.

Attribution of blame

Attribution of blame (consisting of self-blame, perceived injustice and forgiveness) was consistently associated with depression and PTSS (5 studies)^{7,24,28,61,62} and SWB (4 studies).^{24,28,29,49} Self-blame and perceived injustice were associated with higher levels of depression. Forgiveness was associated with lower levels of PTSS and higher levels of SWB. All of these studies used cross-sectional study designs. Evidence on attribution of blame was therefore consistent, with self-blame and perceived injustice linked to poorer mental health and forgiveness linked to better mental health and SWB.

Sense of coherence (SOC)

SOC was found to be consistently associated with mental health (3 studies).^{17,41,76} Higher SOC was related to lower levels of depression, anxiety, and PTSS.^{17,41,76} Two studies reported associations between SOC and life satisfaction,^{17,41} and one of them found that SOC predicted higher levels of life satisfaction at 2 years post-injury.¹⁷ Evidence on SOC was therefore strong, with consistent associations with better mental health and higher life satisfaction.

Personality

Personality characteristics were not examined in relation to mental health. Three significant associations with SWB were reported (2 studies), showing that neuroticism and type D personality (a combination of negative affectivity and social inhibition) were consistently related to lower SWB.^{37,47} Evidence on personality was therefore limited, with neuroticism and type D personality consistently associated with lower SWB.

Affect

Affect was found to be associated with depression and PTSS (3 studies)^{61,62,74} and SWB (2 studies).^{30,42} Across studies, 9 out of 11 associations between affect and mental health, and all associations between affect and SWB, were statistically significant. Almost all studies reported significant associations between positive affect and lower levels of depression and higher life satisfaction,^{30,42,74} whereas negative affect was generally associated with higher levels of depression, PTSS, and lower life satisfaction.^{30,42,61,62} In two studies, the subdomain 'anger' was measured. Anger was significantly associated with PTSS, while 2 out of 6 weak associations between state and trait anger and depression were found.^{61,62} Evidence on affect was therefore moderate to strong, with positive affect consistently associated with better mental health and SWB, and negative affect showing generally adverse associations.

Hope

Hope was associated with depression and PTSS (3 studies)^{30,39,41} and SWB (4 studies).^{27,30,39,41} It was significantly associated with depression and PTSS in 2 out of these studies,^{30,39,41} and consistently associated to higher levels of SWB.^{27,30,39,41} Hope was found to be longitudinally associated with better mental health and higher SWB.³⁰

Table 4.4. Correlations between psychological factors and mental health and QoL, summary

Determinant	Mental health		Subjective well-being	
	Correlation (r)	Ref.	Correlation (r)	
1. Locus of Control				
	-.29* ^{L4} / -.39* ^{L4} -.07 to .20 -.39* / -.46*	Kennedy, 2012 ¹⁷ Livneh, 2011 ⁷⁰ Munce, 2016 ⁵³	.44* ^{L4} .41* to .43* ^{L3}	Kennedy, 2012 ¹⁷ Leeuwen, 2015 ⁷⁹
2 Attribution of blame				
2a. Blame	.20* .34* .45* .44* / .60*	Peter, 2015 ⁷ Monden, 2021 ²⁸ Monden, 2019 ⁶¹ Trost, 2017 ⁶²	-.50* -.51*	Kifley, 2022 ⁴⁹ Monden, 2021 ²⁸
2b. Forgiveness	-.46* / -.59* / -.60*	Cornish, 2022 ²⁴	.26* to .39* / .55* to .72* # .26* / .28*	Cornish, 2022 ²⁴ Webb, 2010 ²⁹
3. Sense of coherence				
	-.55* / -.51* -.56* / -.71* β -.54* ^R	Kennedy, 2012 ¹⁷ Livneh, 2014 ⁴¹ Jørgensen, 2017 ⁷⁶	.59* .33*	Kennedy, 2012 ¹⁷ Livneh, 2014 ⁴¹
4. Personality				
			-.51* -.36* / -.50*	Eroglu, 2022 ⁴⁷ Leeuwen, 2012 ³⁷
5. Affect				
5a. Positive affect	-.84*	Bjork, 2022 ⁷⁴	.45* to .51* ^{L4} .58*	Brazeau, 2018 ³⁰ Wilson, 2017 ⁴²
5b. Negative affect	.18 / .25* ^{II} .24 to .50* ^{II}	Monden, 2019 ⁶¹ Trost, 2017 ⁶²	-.21* to -.46* ^{L4} -.42*	Brazeau, 2018 ³⁰ Wilson, 2017 ⁴²
6. Hope				
	-.23* to -.36* ^{L4} -.35* -.00 / -.39*	Brazeau, 2018 ³⁰ Dorsett, 2017 ³⁹ Livneh, 2014 ⁴¹	.42* to .58* ^{L4} .60* .26* .33* / .43* #	Brazeau, 2018 ³⁰ Dorsett, 2017 ³⁹ Livneh, 2014 ⁴¹ Smedema, 2017 ²⁷

7. Purpose in life	- .27* L3 to -.42* L3 # ‡ - .42* to -.62* # - .44* - .22* / -.26* L3 - .62* β -.46* L2 † / β -.52* L2 R † ‡	Aparicio, 2021 ⁵⁵ Aparicio, 2020 ³³ Krause, 2014 ³¹ Kunz, 2021 ⁷⁸ Peter, 2015 ⁷ Kunz, 2019 ³⁵	.49* / .54* # .43* .58* .26 to .59* L3 .58* β .58* L2 R †	Aparicio, 2020 ³³ Kivitsid, 2014 ⁵¹ Krause, 2014 ³¹ Leeuwen, 2015 ⁷⁹ Peter, 2014 ¹⁸ Kunz, 2019 ³⁵
	- .04 .02	Bhattarai, 2018 ⁴⁵ Peter, 2015 ⁷	.12* to .17* # -.06 .02 .47* / .76* # β .89* R / β .26* R	Chlan, 2011 ²² Peter, 2014 ¹⁸ Wang, 2019 ¹⁹ Wilson, 2017 ⁴² Hajjaghababaei, 2018 ⁴⁸
8. Spirituality				
9. Self-worth	- .23 to -.49* L4 - .38* / -.41* .02	Brazeau, 2018 ³⁰ Diemen, 2017 ⁵⁶ Huang, 2015 ⁷³	.41* to .64* L4 .48* β -.32* R	Brazeau, 2018 ³⁰ Smedema, 2017 ²⁷ Ekechukwu, 2017 ⁴⁵
	- .32* L3 / -.33* L3 ‡ - .36* / -.42* - .49* - .58* - .21 to -.69* L3 - .64* - .38* to -.64* / -.26 to - .44* L4 - .25 / -.74* L1 - .23* / -.26* L3 - .39* - .32* / -.56* - .54* β -.34* L2 / β -.37* L2 R ‡	Aparicio, 2021 ⁵⁵ Aparicio, 2020 ³³ Bhattarai, 2018 ⁴⁵ Bombardier, 2012 ⁶⁶ Coker, 2019 ²³ Craig, 2013 ⁷⁷ Diemen, 2021 ⁵⁸ Driver, 2016 ⁶⁸ Kunz, 2021 ⁷⁸ Monden, 2021 ²⁸ Munce, 2016 ⁵³ Peter, 2015 ⁷ Kunz, 2019 ³⁵	.57* to .75* .33* .55* .46* .18 to .52* L3 .48* .36* / .46* .79* .52* .33* / .52* ¶ .25 to .48* L3 .53* .48* .39* β .39* L2 R β .05* L5 R ¶	Ahn, 2021 ²¹ Aparicio, 2020 ³³ Bhattarai, 2021 ⁴⁴ Cijssouw, 2017 ¹⁴ Coker, 2019 ²³ Craig, 2014 ⁴⁶ Craig, 2022 ¹⁵ Goraczko, 2021 ¹⁶ Kifley, 2022 ⁴⁹ Leeuwen 2012 ³⁷ Leeuwen 2015 ⁷⁹ Monden, 2021 ²⁸ Peter, 2014 ¹⁸ Smedema, 2017 ²⁷ Kunz, 2019 ³⁵ Leeuwen, 2012 ³⁸

Table 4.4 continues on next page.

Table 4.4. Continued

Determinant	Mental health	Ref.	Subjective well-being
	Correlation (r)		Correlation (r)
10. Resilience			
	-.50*	Bhattacharai, 2018 ⁶⁵	.33*
	-.78*	Bjork, 2022 ⁷⁴	.53* / .57*
	-.40*	Dodd, 2015 ⁶⁷	.69*
	-.26 / .69* / -.44* ^{L1}	Driver, 2016 ⁶⁸	.53*
	-.58* / -.62*	Mikolajczyk, 2021 ³⁶	
	-.61*	Min, 2014 ⁶⁴	
	-.62* / -.75*	Pincok, 2020 ⁶⁰	
	-.34* to -.51*	Wang, 2018 ⁶⁴	
11. Coping			
11a. Active Problem focused coping			
	-.41* to -.30*	Aaby, 2022 ³²	.41* / .50*
	-.24* ^{L2} / -.45* ^{L2}	Aparicio, 2021 ⁵⁵	.15 to .38* [#]
	-.23* ^{L4} to -.41* ^{L4}	Diemen, 2018 ⁵⁷	.25 ^{L4} to .35* ^{L4}
	-.08 to .02	January, 2015 ²⁵	.42* / .47*
	-.32* ^{L4} to .10 ^{L4}	Kennedy, 2012 ¹⁷	.25*
	-.20* to -.42*	Lankveld, 2011 ⁶⁹	.36*
	-.12 to .10 [§]	Livneh, 2011 ⁷⁰	.17 / .26
	-.12 to .21* [§]	Livneh, 2014 ⁴¹	β .42* ^{L5} / β .31* ^{L5 R #}
	-.54* / -.56*	O'Shea, 2014 ⁷²	
	-.41* to .01	Peter, 2015 ⁷	
	-.29* / -.43*	Sauri, 2014 ²⁰ Schöenberg,	
	-.38* to .11	2014 ⁷⁵	
	β -.03* ^{L5} / β -.15* ^{L5 R #}	Arewasikporn, 2019 ⁴³	

11b. Passive problem focused coping	22* L2 / .35* L2 .26* to .29* .22 L4 to .36 L4 -.02 L2 / -.03 L2 .65* / .65* .06 to .45* .21* / .27* .44*	Aparicio, 2021 ⁵⁵ January, 2015 ²⁵ Kennedy, 2012 ¹⁷ Kunz, 2021 ⁷⁸ Livneh, 2011 ⁷⁰ Peter, 2015 ⁷ Sauri, 2014 ²⁰ Schönenberg, 2014 ⁷⁵	-.26* / -.31* # -.20 L4 / -.23 L4 -.14* / -.39* -.22* .30 / .45*	January, 2015 ²⁵ Kennedy, 2012 ¹⁷ Peter, 2014 ¹⁸ Sauri, 2014 ²⁰ Tramonti, 2014 ⁴⁰
	-35* / -.41* -.08 / .02 -.57* -.28* L4 / -.41* L4 -.45* to .12* -.40* / -.53* β -.29* R	Aaby, 2022 ³² January, 2015 ²⁵ Jiao, 2012 ⁷¹ Kennedy, 2012 ¹⁷ Peter, 2015 ⁷ Sauri, 2014 ²⁰ Jørgensen, 2017 ⁷⁶	.38* .38* / .36* # .35* L4 -.12* / .30* 48* .40* -.21 / -.46*	Aaby, 2022 ³² January, 2015 ²⁵ Kennedy, 2012 ¹⁷ Peter, 2014 ¹⁸ Sauri, 2014 ²⁰ Smedema, 2017 ²⁷ Tramonti, 2014 ⁴⁰
12. Appraisals				
12a. Positive appraisals	-.12* / -.12* -.49* -.22 L4 / -.29* L4 -.07 / -.17* # -.21* / -.05 -.30*	Aaby, 2022 ³² Cornish, 2022 ²⁴ Kennedy, 2012 ¹⁷ Krause, 2014 ³¹ Livneh, 2014 ⁴¹ Peter, 2015 ⁷	.09 .53* to .70* .46* / .73* # .45* L4 .15* / .18* # .25* to .56* .22 to .69* L3 .30*	Aaby, 2022 ³² Ahn, 2021 ²¹ Cornish, 2022 ²⁴ Kennedy, 2012 ¹⁷ Krause, 2014 ³¹ Leeuwen, 2012 ³⁷ Leeuwen, 2015 ⁷⁹ Peter, 2014 ¹⁸
	.47* to .54* L3 .65* .60* to .63* .27* / .41* .36* to .47* L4 .41* L3 / .43 L3 .69* .42* / .45*	Aparicio, 2021 ⁵⁵ Bjork, 2022 ⁷⁴ Eaton, 2018 ⁵² Han, 2022 ⁵⁹ Kennedy, 2012 ¹⁷ Kunz, 2021 ⁷⁸ Mignogna, 2015 ⁶³ Peter, 2015 ⁷	-.43* / .50* L4 -.51* / -.59* -.43* L3 to -.55* L3 -.50* to -.66* -.73* -.41* / -.48*	Kennedy, 2012 ¹⁷ Leeuwen, 2012 ³⁷ Leeuwen, 2015 ⁷⁹ McDonald, 2018 ²⁶ Mignogna, 2015 ⁶³ Peter, 2014 ¹⁸
12b. Negative appraisals				

Table 4.4 continues on next page.

Table 4.4. Continued

Determinant	Mental health	Ref.	Subjective well-being
	Correlation (r)		Correlation (r)
13. Posttraumatic growth			
13a. Posttraumatic cognitions	.55* / .57* .38* to .70* β .37* L2 R † / β .48* L2 R †	Kunz, 2017 ³⁴ Schönenberg, 2014 ⁷⁵ Kunz, 2019 ³⁵	-.40* / -.46* # β -.33* L2 R † Kunz, 2017 ³⁴ Kunz, 2019 ³⁵
13b. Posttraumatic growth	.04 / .10 .10 / .28* -.48* -.12* to -.40* β -.03* L2 R † / β -.26 L2 R †	January, 2015 ²⁵ Kunz, 2017 ³⁴ Min, 2014 ⁶⁴ Wang, 2018 ⁵⁴ Kunz, 2019 ³⁵	.18* / .27* # -.03 .46* β .15* L2 R † January, 2015 ²⁵ Kunz, 2017 ³⁴ Wang, 2019 ¹⁹ Kunz, 2019 ³⁵
14. Other			
Social comparison			
Alienation	.47* / .52*	Diemen, 2017 ⁵⁶	-.64* to .25 / -.40* to .12 Leeuwen, 2015 ⁷⁹

^L Longitudinal study (all non-L are cross-sectional studies), ¹up to 3 months post injury, ²up to 6 months post injury, ³up to 1 year post injury, ⁴up to 2 years post injury, ⁵up to 5 years post injury.
^R Study reports only multivariate regression coefficients.
[†] Regression from latent change score, path analysis, latent class growth analysis, logistic regression or logistic regression class membership.
^{‡, §, ||} Consist (partly) the same study population.
[#] Used two different outcome measurements.

Table 4.5. Results compared with 2010 review

Determinant	Van Leeuwen et al. ⁹	Updated review	Change compared to review Van Leeuwen et al.*	Total [†]
1. Locus of control	11/20	6/12	/	17/32
2. Attribution of blame	7/13	18/18	++	25/31
3. Sense of coherence	11/11	6/6	/	17/17
4. Personality	6/15	3/3	++	9/18
5. Affect	14/17	11/15	/	25/32
6. Hope	6/6	7/9	-	13/15
7. Purpose in life	4/4	17/17	/	21/21
8. Spirituality	6/16	5/9	+	11/25
9. Self-worth	20/24	31/41	/	51/65
10. Resilience [‡]		17/17		17/17
11a. Active problem focused coping	18/77	37/60	++	55/137
11b. Passive problem focused coping	45/78	22/31	++	67/109
11c. Emotion focused coping	43/66	19/23	++	62/89
12. Appraisals	30/57	54/57	++	84/114
13. Post-traumatic growth	7/8	15/19	/	15/20

The number before the slash indicates the number of significant associations. Number after the slash indicates the total number of associations found. Blank spaces indicate no data available.

* '/' indicates ≤10% change; '+' or '-' indicates 10–25% change; '++' indicates ≥25% change.

† This is the sum of studies in the review by Van Leeuwen (2012)⁹ and the present review.

‡ Variable not examined in previous review.

Purpose in life

Purpose in life was found to be associated with mental health (6 studies)^{7,31,33,35,55,78} and SWB (6 studies).^{31,33,35,50,51,89} It was consistently associated with lower levels of mental health and higher SWB.^{7,31,33,35,50,51,55,78,89} Additionally, purpose in life was found to be a predictive factor for reduced levels of depression, anxiety and post-traumatic stress, as well as for improved SWB.^{35,50,55,78} Associations between life orientation and depression, anxiety and QoL showed similar results and were likewise identified as a predictive factor for higher SWB.^{30,50,55}

Spirituality

Spirituality was studied in relation to depression (2 studies)^{7,65} and SWB (5 studies).^{19,22,48,89,90} No significant associations were found with depression.^{7,65} Regarding SWB, 7 associations with religious spirituality were reported, 5 of which were statistically significant, indicating that higher levels of religious spirituality were associated with better SWB.^{19,22,48,89,90} Only one study reported a regression coefficient for both existential and religious spirituality in relation to psychological

well-being.⁴⁸ All studies applied a cross-sectional study design. Overall, spirituality was positively associated with higher SWB, while findings regarding its association with depression were unrelated.

Self-worth

Self-worth, encompassing self-esteem and self-efficacy, was examined in relation to mental health (16 studies)^{7,23,28,30,33,35,53,55,56,58,65,66,68,73,77,78} and SWB (18 studies).^{7,14–16,18,21,23,27,28,30,33,35,37,38,44,46,49,50} Across studies, 59 associations were found, of which 51 were statistically significant.^{7,14–16,18,21,23,27,28,30,33,35,37,38,44,46,49,50,53,55,56,58,65,66,68,73,77,78}

Self-esteem was mostly consistently and significantly associated with lower levels of depression and anxiety, and higher SWB.^{27,30,45,56,73} Self-efficacy has been studied more intensively, with nearly all longitudinal and cross-sectional studies reporting significant associations with reduced mental health and higher SWB.^{7,23,28,33,44,53,55,58,66,68,77,78} Evidence on self-worth was therefore strong, particularly for self-efficacy, with consistent associations across both mental health and SWB outcomes.

Resilience

Resilience was examined in relation to mental health (8 studies)^{36,60,64,65,67,68,74,91} and SWB (4 studies).^{19,26,36,44} Nearly all 12 associations with mental health, as well as the 5 associations with SWB, were statistically significant.^{19,26,36,44,60,64,65,67,68,74,91} Depression and life satisfaction were the most frequently studied outcomes. Higher resilience was consistently associated with lower levels of depression, anxiety and PTSS, as well as higher levels of SWB.

One association with depression stemmed from a longitudinal study design, where the relationship with depression was not significant at baseline but demonstrated a strong association three months later.⁶⁸ All studies examining SWB employed cross-sectional designs. Evidence on resilience was therefore strong, with consistent findings across both mental health and SWB outcomes.

Coping

The relationship between various coping styles and mental health and QoL showed inconsistencies. Active problem-focused coping was examined in relation with mental health (13 studies)^{7,17,20,25,32,41,43,55,57,69,70,72,75} and SWB (8 studies).^{17,18,20,25,32,40,41,43} Across studies, 20 out of 43 associations with mental health and 3 out of 17

associations with SWB were not statistically significant.^{7,17,18,20,25,32,40,41,43,55,57,69,70,72,75} The subdomain of social and instrumental support was unrelated to mental health in eight associations.^{7,25,41,70,75} Nevertheless, higher levels of active problem-focused coping were associated with lower levels of depression and anxiety and higher levels of SWB. Evidence on active problem-focused coping was therefore mixed, especially for mental health, but it was linked to lower depression and anxiety and better SWB. Evidence for social and instrumental support was limited.

Passive problem-focused coping was found to be examined in relation with mental health (8 studies)^{7,17,20,25,55,70,75,78} and SWB (5 studies).^{17,18,20,25,40} These associations demonstrated a weak relationship with mental health and SWB. Approximately one-third of the associations were not significant: 6 out of 20 associations for mental health and 3 out of 11 associations for SWB.^{7,17,18,20,25,40,55,70,75,78} However, most studies indicated that higher levels of passive problem-focused coping were linked to higher levels of depression and anxiety, and lower levels of SWB. Longitudinal studies generally showed weaker associations for this coping style compared to cross-sectional studies.^{55,78} Notably, one study found a positive association between avoidance and SWB, using the CISS avoidance subscale, which assesses distraction and social diversion rather than denial. This suggests that, in this context, avoidance may reflect functional coping strategies that temporarily support well-being, rather than maladaptive avoidance.⁴⁰ Overall, evidence on passive problem-focused coping was therefore limited and mostly indicative of negative associations with mental health and SWB.

Emotion-focused coping was examined in relation with depression and anxiety (7 studies)^{7,17,20,25,27,32,71} and SWB (7 studies).^{17,18,20,25,27,32,40} In nearly all studies, higher levels of emotion-focused coping were significantly associated with lower levels of depression and anxiety and higher QoL.^{7,17,18,20,25,27,32,40,50,71} Regarding mental health, 3 out of 13 associations were not significant, two of which originated from the same study.²⁵ Regarding SWB, 1 out of 10 associations was not significantly associated.⁴⁰ Results in the opposite direction were reported for the specific subfactors venting and emotional support, as well as for emotion-focused coping measured with the CISS.^{18,40} Evidence on emotion-focused coping was therefore moderately strong, with generally consistent associations with better mental health and SWB outcomes.

Appraisals

Appraisals were found to be examined in relation with mental health (12 studies)^{7,17,24,31,32,47,52,55,59,63,74,78} and SWB (10 studies).^{17,18,21,24,26,31,32,37,50,63} The most frequently studied outcomes were depression and life satisfaction. Across studies, 2 out of 29 associations for positive appraisals and 1 out of 28 for negative appraisals were not statistically significant.^{7,17,18,21,24,26,31,32,37,41,50,52,55,59,63,74,78} Negative appraisals (e.g. threat, loss, fear) were consistently associated with higher levels of mental health and lower SWB. Positive appraisals (e.g. challenge, acceptance) were strongly associated with reduced mental health and higher SWB. Overall, the evidence on appraisals was therefore strong, showing clear and consistent relationships with both mental health and SWB.

Posttraumatic growth

Posttraumatic growth, encompassing both posttraumatic cognitions and posttraumatic growth, was found to be examined in relation with mental health (6 studies)^{25,34,35,64,75,91} and SWB (4 studies).^{25,34,35,91} Among the associations between posttraumatic growth and mental health, 10 out of 13 were statistically significant.^{25,34,35,64,75,91} Findings regarding the relationship between posttraumatic growth and SWB were moderate consistent, with 5 out of 6 associations being statistically significant. Studies focusing on posttraumatic cognitions consistently reported associations with higher levels of depression and anxiety, and lower life satisfaction. In contrast, studies focusing on posttraumatic growth (specific PTG measures) reported only about half of the associations as significant. Overall, evidence on posttraumatic growth was therefore moderate. While posttraumatic cognitions were consistently associated with lower mental health, findings for the PTG subdomain were more mixed.

Comparison with previous review

Several differences emerge when comparing patient characteristics between this review and the 2012 review. The median sample size increased from 87 to 142 participants. The population in the present review is older, with a mean age of 49 years compared to 38 years previously. The mean time since injury increased from 64 months to 97 months.

Compared to the review by Van Leeuwen,⁹ the current review identified more associations for consistently related determinants hope, purpose in life, self-

worth, appraisals and posttraumatic cognitions. Additionally, more associations were found for the inconsistently related determinant attribution of blame.⁹ In contrast, fewer associations were observed in the current review for the consistently related determinants locus of control and sense of coherence, as well as for inconsistently related determinants personality, spirituality, and passive and emotion-focused coping.

Discussion

This systematic review examines the relationship between psychological factors and QoL in individuals with SCI. We included 66 studies, published between 2010 and 2022, expanding the understanding of these relationships. The first hypothesis, that psychological factors previously related to QoL remain consistently associated with QoL in individuals with SCI, was fully supported. Locus of control, sense of coherence, positive affect, hope, purpose in life and self-worth were consistently related to mental health and SWB. The second hypothesis, that psychological factors inconsistently related to QoL in prior reviews would be more thoroughly studied and better understood, was partially supported. Blame attribution, personality (although less frequently studied), resilience (added as a psychological factor in this update), emotion-focused coping and appraisals were mostly consistently associated with mental health and SWB after SCI. While active and passive problem focused coping styles showed stronger associations with mental health and SWB, they remained inconsistent. Negative affect and posttraumatic growth continued to show mixed results and spirituality remained underexplored. Since 2010, 16 of the 66 new studies used a prospective longitudinal design. Their findings were largely consistent with those of cross-sectional studies.

Comparison with previous review

Several differences emerge when comparing patient characteristics in this review to those reported in the 2012 review. Participants in the current review are older, although comparable to those in other studies.⁹² Time since injury has increased, which is expected given that individuals with SCI are generally aging over time.^{93,94}

Fewer studies have focused on relatively stable traits, such as locus of control, sense of coherence, personality and spirituality.^{95–98} In contrast, more research

has been conducted on dynamic factors that are more amenable to change, such as affect, purpose in life, self-efficacy, and resilience.^{99–101}

Regarding appraisals, the inclusion of acceptance in this review revealed a more consistent relationship with QoL. Greater acceptance is consistently linked to better SWB and reduced mental health.¹⁰ Although coping styles were studied less frequently, recent research has shifted towards active problem-focused coping, including flexible goal adjustment and tenacious goal pursuit, which are more strongly associated with QoL than social and instrumental support.⁵⁷ Measurement instruments used in recent studies remain similar to those in the 2012 review.

Consistent determinants

Consistent associations regarding e.g. locus of control, sense of coherence, personality, positive affect, hope, purpose in life, self-worth, and resilience, may contribute to better adaptation by fostering psychological flexibility.¹⁰² In contrast, attribution of blame shows reversed associations, demonstrating that these hinder SWB and/or mental health.

Negative appraisals are more strongly associated with poorer mental health, likely because they activate cognitive mechanisms that underlie vulnerability to psychological distress. In contrast, locus of control, personality, and negative affect are more strongly related to SWB, as they represent broader, stable factors that shape overall QoL.^{103,104}

Inconsistent determinants

Psychological factors inconsistently related to mental health include, coping, positive appraisals and posttraumatic growth, while inconsistent determinants for SWB include spirituality, coping, and posttraumatic growth. These inconsistencies arise from non-significant or weak associations, likely due to variations in measurement approaches and analytic methods. For example, different aspects of locus of control and appraisals may be assessed, or multiple constructs may be collapsed into a single measure.^{32,70}

Posttraumatic growth also showed inconsistencies, as two studies using the same population found no significant associations with mental health. This may be due to moderating factors such as subsequent psychological and health changes influencing the relationship between posttraumatic growth, mental health, and

SWB.^{25,34} Similarly, coping styles and appraisals showed inconsistencies, likely due to the diversity of coping strategies and how these strategies are measured. Some studies collapsed multiple coping styles into one category, such as combining “active coping” with “use of instrumental support”.²⁵ While we grouped similar terms for clarity, this approach led to minor differences within categories. For example, “fighting spirit” was included under the category “active/proactive coping”.¹⁷ Another potential explanation for the inconsistent associations between active problem-focused coping and mental health or SWB is that, in situations where goals are blocked—such as after SCI—actively adjusting life circumstances to personal preferences may be ineffective. In contrast, adjusting personal preferences and goals to match situational changes may be more effective and more positively associated with adjustment.¹⁰⁵

Time since injury may influence the presence of these psychological factors. As time passes after SCI, individuals typically develop more adaptive coping strategies and realistic appraisals, shifting from reactive coping (e.g., emotion-focused or passive coping) to more adaptive approaches.^{17,41} However, we did not find a clear relationship between the time since injury and the strength of these associations.

Stable traits like personality and enduring coping styles shape responses to SCI. For example, individuals with certain personality traits (e.g., higher emotional stability) may adopt adaptive coping strategies, leading to better outcomes, while those with more passive coping, such as higher neuroticism may struggle with adjustment.¹⁰⁶

Unrelated determinants

Spirituality was the least studied psychological factor and the only one unrelated to mental health and SWB. While the literature distinguishes between religious and existential spirituality, all studies in this review focused on religious spirituality. In contrast, the previous review found only weak associations for religious spirituality, while existential spirituality showed a significant relationship in one study.⁹

Methodological limitations of the included studies

Although the sample sizes have improved since the 2012 review, the methodological quality of most studies remained fair. The main limitations included a predominance of cross-sectional study designs, insufficient justification or descrip-

tion of sample sizes and power analyses, and low participation rates (**Appendix C**). Cross-sectional designs limit causal inferences, and unclear sample size justifications and inadequate statistical control for confounding variables may bias findings, though sample sizes were generally acceptable.

The wide variety of instruments used to assess mental health and SWB^{107,108} complicates comparisons across studies. Furthermore, inconsistencies in defining QoL and psychological factors, merging multiple factors into a single measure, and overlapping constructs (e.g. positive affect and wellbeing item bank) further hinder comparability. Some concepts, such as acceptance, are variably defined (e.g. as an appraisal or coping strategy), and for constructs like coping, a plethora of terminology and definitions exists. Many psychological factors (e.g. locus of control, blame and coping) consist of multiple sub-dimensions, which are often assessed using different instruments, subscales, or definitions. Additionally, some studies intertwined psychological factors and outcome measures. For example, the Reactions to Impairments and Disability Inventory (RIDl) subscales *acknowledgment* and *adjustment* were used to assess adaptation.^{24,41} However, acknowledgment is defined as efforts to find new meaning and engage in social activities, which could also be considered an illness cognition or appraisal. Such ambiguities illustrate the challenges of consistent classification across studies. We resolved these issues through consensus discussions to ensure comparability as much as possible. Despite these challenges, we have made every effort to categorize and present the findings as accurately and consistently as possible. However, these methodological limitations in the included studies affect research quality and limit the synthesis of findings.

Limitations of this systematic review

This review has several limitations. First, the literature search was restricted to English-language articles and four databases, which may have omitted relevant studies. Second, only studies reporting bivariate associations or longitudinal relationships were included in the main results. While longitudinal studies often reported alternative indicators such as standardized β -coefficients from multivariable analyses, these were not used in the main results to maintain comparability with bivariate findings; they are, however, presented in the tables. This approach allowed for consistent synthesis, and longitudinal findings largely corroborated cross-sectional results. Third, synthesizing the data was challenging due to the

diversity of psychological factors, instruments and study designs. To maintain clarity, related constructs were categorized (e.g. depression, anxiety, and PTSS; life satisfaction and psychological well-being) while keeping mental health and SWB separate, reflecting their conceptual distinction.¹⁰⁹ Subscales were separated in **Appendix B** where possible, and inconsistencies were examined across instruments and populations. Despite these efforts, some nuances remain, limiting the comparability of findings across studies and precluding meta-analysis. Fourth, mediation effects were not examined, though psychological factors and outcomes likely interact. Nevertheless, the identified bivariate associations underscore the relevance of these relationships. Fifth, time since injury varied across studies, with about one-third focusing on inpatients and the rest on community-dwelling individuals with SCI/D. While the impact of time since injury was not formally analyzed, the associations were assumed to be relevant both short- and long-term. Sixth, the classification of affect and posttraumatic growth as determinants rather than outcomes is debatable, as these constructs may also be considered components of mental health or SWB.

Further research

Future research should address the methodological issues outlined in this review. Adhering to reporting guidelines can improve study design and transparency. We recommend conducting longitudinal studies with validated, widely accepted tools, such as the International Spinal Cord Injury Data Sets,¹¹⁰ to clarify temporal relationships. Additionally, further research should explore under-examined factors, such as personality and existential spirituality, to better understand their role in QoL. Although these factors are relatively stable and not directly modifiable, they may inform screening, risk stratification, and the tailoring of interventions. Finally, studies should ensure precise terminology and clear conceptual distinctions, avoiding overlap between determinants and outcomes.

Clinical implications

This review underscores the importance to address psychological factors in SCI/D rehabilitation to optimize individuals' mental health and SWB. Rehabilitation professionals, whether explicitly or implicitly, draw on principles of rehabilitation psychology, emphasizing development of positive self-concept and fostering personal mastery.¹¹¹ Our findings reinforce this by demonstrating consistent associations between psychological resources—such as sense of coherence, self-

efficacy, resilience—and better outcomes. Conversely, maladaptive attributions of blame and other negative psychological factors may hinder psychological adjustment.

Targeted interventions to enhance these psychological resources or mitigate risk factors are essential. Cognitive-Behavioral Therapy (CBT) remains an important one, focusing on modifying maladaptive beliefs and promoting adaptive coping strategies.¹¹² Acceptance and Commitment Therapy (ACT) promotes psychological flexibility and acceptance of SCI-related challenges,^{113,114} while mindfulness-based and self-management interventions enhance resilience, emotional regulation, psychological flexibility, or self-efficacy.^{23,115} Additionally, therapies such as Eye Movement Desensitization and Reprocessing (EMDR) may address threatening appraisals and self-blame associated with depression.¹¹⁶ Furthermore, peer support or role models can play a crucial role in fostering positive psychological factors and mitigating negative ones, contributing to improved QoL.¹¹⁷ For example, it is demonstrated that it leads to greater gains in self-efficacy over time.¹¹⁸

To maximize the effectiveness of these interventions, psychological screening upon admission is crucial for tailoring care to individual needs. Integrating psychological support throughout the rehabilitation process ensures continuity of care. A multidisciplinary approach (marked by collaboration, effective communication, and shared knowledge) is key to delivering comprehensive, individualized psychological care.^{119,120}

Conclusion

This review underscores the growing evidence for evidence linking psychological factors to mental health and SWB in individuals with SCI/D. Compared to the 2012 review, this update highlights consistent associations between factors such as attribution of blame, personality traits, and resilience with improved mental health and QoL. In addition, strong and sustained associations were found for locus of control, sense of coherence, positive affect, hope, purpose in life, and self-worth.

Despite these advancements, evidence for certain factors, such as spirituality, coping styles and post-traumatic growth, remains limited and inconsistent,

indicating a need for further investigation. Future research should prioritize longitudinal designs, clear definitions of psychological constructs, and robust methodologies to better clarify these associations and inform clinical practice. Strengthening psychological care within multidisciplinary rehabilitation can enhance beneficial psychological resources, address maladaptive factors, and ultimately improve mental health and SWB outcomes in individuals living with SCI.

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Appendices

Appendix A. Search strings

See http://www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_4.pdf

Appendix B. Detailed overview results

See http://www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_4.pdf

Appendix C. Quality assessment of included studies

See http://www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_4.pdf



CHAPTER 5

Life satisfaction following spinal cord injury and psychological factors – a prospective longitudinal cohort study

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Objectives: To examine (1) the course of life satisfaction in individuals with SCI from admission to inpatient rehabilitation until 4 years after discharge and (2) the associations between psychological factors and this course of life satisfaction.

Design: Prospective longitudinal cohort study.

Setting: Rehabilitation center and community.

Participants: This study includes 266 individuals with recent-onset SCI.

Interventions: Not applicable.

Main outcome measures: Life satisfaction was assessed using the 2-item Life Satisfaction Scale (2LS, range 2–13) at 9 time points. Patient characteristics, psychological resources (general self-efficacy, disability management self-efficacy, resilience, neuroticism, meaning in life), coping and cognitive appraisals were assessed at admission. Multilevel regression analyses were performed.

Results: Mean age of the participants was 55.8 years (SD 15.2), 47% had paraplegia, 50% had traumatic SCI and 77% had incomplete SCI. Median duration of inpatient rehabilitation was 11 weeks. Life satisfaction gradually increased from 5.3 (SD 2.3) at admission up to 7.2 (SD 2.1) 4 years after discharge, with significant increases in the first four weeks ($\Delta=.8$ (SD=.6)), and between 1 and 4 years after discharge ($\Delta=.4$ (SD=.7)). In the final regression model, younger age, Dutch nationality, higher education level, higher disability-management self-efficacy and lower threatening appraisals were independent predictors of a more positive course of life satisfaction.

Conclusion: Life satisfaction of individuals with SCI increased significantly over time. Results from this study suggest that long-term life satisfaction could be positively influenced by modifying low self-efficacy and high threatening appraisals during inpatient rehabilitation.

Introduction

Spinal cord injury (SCI) is associated with loss of mobility and sensibility, bladder and bowel dysfunction, pain and pressure ulcers, reduced participation in society and lower life satisfaction.^{1,2} Life satisfaction has long been considered an important outcome of rehabilitation and life satisfaction among individuals with SCI has been extensively studied. However, most of these studies had cross-sectional designs or applied only few measurement time points during and after inpatient rehabilitation.³⁻⁶ Therefore knowledge on the progression of life satisfaction during and after inpatient rehabilitation is still imprecise. During inpatient rehabilitation life satisfaction increases,³⁻⁵ beyond this period the literature is inconsistent. Most studies have found that life satisfaction continues to improve.^{1,7,8} However, an older study found that after the first year of injury life satisfaction remained largely stable over the next 4 years.⁹ Although individuals' life satisfaction improves, it remains substantially lower than the life satisfaction of the general population.²

Recent research has tended to focus on protective psychological factors that contribute to restore and promote life satisfaction. Systematic reviews have shown that higher levels of self-efficacy, self-esteem, sense of coherence and positive affect, and lower levels of post-traumatic cognitions and negative affect are consistently associated with higher levels of life satisfaction.^{10,11} From these findings one could assume that fostering protective psychological factors may lead to a restoration of life satisfaction. However, due to the limitations outlined above, there is limited evidence on how these factors influence the course of life satisfaction during and after inpatient rehabilitation.^{10,11} Knowing more about factors which are most predictive of the course of life satisfaction could help healthcare professionals in their treatment to promote the recovery of life satisfaction.¹²

Summarizing, little is known about the course of life satisfaction during and after inpatient rehabilitation and how psychological factors influence this course. Therefore, the aim of this study is to describe the course of life satisfaction in individuals with SCI from admission to initial inpatient rehabilitation until 4 years after discharge and to investigate which psychological factors predict this course, in order to guide further refinement of patient care during and after inpatient rehabilitation. We hypothesized that the course of life satisfaction would extend up to 4 years after discharge, with self-efficacy being an important predictor.

Methods

Study design

This study was part of the SELF-SCI study, a multicenter prospective longitudinal cohort study with 8 measurement time points from the start of first inpatient rehabilitation to 1 year post-discharge.¹³ Patient inclusion took place between January 2016 and December 2017 and an extra follow-up measurement 3–5 years post-discharge took place in 2021.

Participants

Individuals with SCI who had been admitted to one of the eight specialized SCI rehabilitation centers in The Netherlands for their initial inpatient rehabilitation between January 2016 and December 2017, were considered for inclusion. The inclusion criteria were: 1) admission to first inpatient rehabilitation after onset of traumatic or non-traumatic SCI for at least 4 weeks; 2) at least 18 years of age; 3) being able to complete self-report questionnaires. Exclusion criteria were: 1) limited life expectancy (e.g. in case of metastasis-related SCI); 2) severe psychiatric or major cognitive impairment, active psychosis or severe traumatic brain injury; 3) insufficient knowledge of the Dutch language to understand and complete the questionnaires. Decisions on in/exclusion were based on the clinical judgment by the rehabilitation physician and checked by the research assistant who collected the data. If the participant was not able to complete the questionnaire because of hand function problems, help was offered by a research assistant during admission.

Procedure

All eligible participants were informed about the study by a rehabilitation team member in the first three days of admission to inpatient rehabilitation. After informed consent was given, the research assistant provided the participant with the baseline questionnaire (T1), which included measures of psychological factors and life satisfaction. The 2-item Life Satisfaction questionnaire (2LS) was further administered after 4 (T2), 8 (T3) and 12 weeks (T4), if the participant was still admitted for another 2 weeks at that time. In the last week of inpatient rehabilitation (T5), and at 3 months (T6), 6 months (T7), 1 year (T8) and 3 to 5 years after discharge (T9). During inpatient rehabilitation, participants completed paper/pencil versions of the questionnaires. After discharge, the participants could choose whether they wanted to complete the questionnaire on paper or

online. Further, the research assistant collected data on SCI-characteristics from the medical record.

Measures

Life satisfaction was assessed using the 2LS.¹⁴ The first item asks to rate their life satisfaction at this moment, on a scale ranging from 1 (very unsatisfying) to 6 (very satisfying). The second item asks to compare their life satisfaction now with their life satisfaction before the SCI, ranging from 1 (much worse) to 7 (much better). The total 2LS score is the sum of the 2 item scores. The 2LS showed good validity and acceptable internal consistency in a previous SCI study.¹⁴ In the current dataset Spearman Brown coefficients for the 2LS ranged from .62 to .78 across the 9 time points. This reliability measure is specifically developed for short questionnaires like the 2LS.¹⁵

Demographic and SCI related characteristics

Variables collected included age, sex, presence of a partner (yes/no), education level (bachelor degree or higher, yes/no), whether participants received premorbid psychological help (yes/no), Dutch nationality (yes/no), length of inpatient rehabilitation (in weeks), time since injury at admission, traumatic or non-traumatic etiology, paraplegia or tetraplegia, and completeness of injury (ASIA Injury severity Score).¹⁶

Psychological factors

Psychological factors were only measured at T1, included and grouped into 'psychological resources' and 'coping and appraisals', according to the Spinal Cord Injury Adjustment Model in which coping and appraisals mediate the relationship between psychological resources and life satisfaction.¹⁷ Psychological resources comprised general self-efficacy, disability management self-efficacy, resilience, neuroticism, and purpose in life. Coping and appraisals comprised passive and proactive coping, as well as threat, challenge and loss appraisals. Definitions of all included psychological factors are shown in **Table 5.1**. This table additionally provides detailed information on the measurement instruments applied, including the number of items, score range, and corresponding Cronbach's alpha coefficients.

Table 5.1. Definitions and measurements of psychological factors

Psychological factors	Definition	Instrument	Items	Scale	Score range*	Cronbach's $\alpha^{\dagger}$
General self-efficacy	The self-beliefs of a person to cope with a variety of difficult commands in general. ¹⁸	Alcos-12 ¹⁸	12	5-point	12-60	.81
Disability management self-efficacy	The confidence that individuals have in their ability to manage the challenges related to their chronic condition. ¹⁹	UW-SES-6 ¹⁹	6	5-point	6-30	.87
Resilience	The personal qualities that enable one to thrive in the face of adversity. ²⁰	CD-RISC-10 ²⁰	10	5-point	0-40 ²¹	.91
Neuroticism (personality)	The tendency to experience frequent and intense negative emotions in response to various sources of stress. ²²	EPQRS-N ²²	12	Dichotomous	0-12	.84
Purpose in life	The mental sense of a goal or aim in the process of living or in existence itself. ⁴¹	PIL-SF ²³	4	7-point NRS	4-16	.84
Appraisals	The cognitive evaluation of the nature and significance of a phenomenon or event. ⁴¹	ALE-threat ²⁴ ALE-challenge ²⁴ ALE-loss ²⁴	6 6 4	6-point 6-point 6-point	0-30 0-30 0-20	.89 .81 .84
Passive coping	A stress-management strategy in which a person absolves themselves of responsibility for managing a stressor and instead relinquishes control over its resolution to external resources. ⁴¹	UCL- passive reacting ²⁵	7	4-point	7-28	.76
Proactive coping	People's attempts to anticipate the occurrence of potential negative consequences of illness before undertaking an activity to deal with these consequences as effectively as possible. ²⁶	UPCC-sf ²⁶	7	4-point	7-28	.82

* Higher scores indicate a greater degree of the respective psychological factor.

[†] Cronbach's α values reported were calculated based on the data collected in this study.

Analyses

All collected data were analyzed using IBM SPSS program for Windows (version 27)^a. To enhance the reliability of the data, a second person independently verified the manually entered data. The database included 284 participants. Participants who completed the first assessment and at least two follow-up measures of the 2LS were included in the current study, resulting in 266 participants. A non-response analysis was performed if the response rate at that time point was lower than 70 percent, using Chi-square and independent t-tests.²⁷ At T9, 37 participants could not be re-invited because one center declined to participate at that timepoint.

Descriptive statistics were used to summarize participant characteristics. We used multilevel modelling to examine the average trajectory of life satisfaction during the study period. These models are suitable for analyzing longitudinal data with repeated measures with different intervals, allowing us to model the variation in life satisfaction changes across individuals. We adjusted for potential differences between participants, by permitting random slopes in regression coefficients.²⁸ First, we analyzed the course of life satisfaction across measurement time points with the participant as the subject and time after onset of SCI as a fixed determinant. In addition to the summed score, we explored individual items separately to examine whether the course was more strongly reflected in current life satisfaction or in retrospective comparisons with pre-injury levels. Second, to analyze predictors of the course of life satisfaction, we included time after onset of SCI as a random coefficient, allowing the effect of time to vary between participants and thereby accounting for variation in the temporal distribution of our observations. All predictors were first analyzed individually to determine the univariable relationships, after which multilevel modeling was performed to determine the adjusted relationships. To obtain standardized beta coefficients and allow for meaningful comparison across independent variables, all predictors were transformed into z-scores.

To ensure the validity of the model, the normality of residuals was assessed using Q-Q plots and Shapiro-Wilk tests. Although the normality assumption was violated ($p < .001$), the residuals displayed a light leptokurtosis, indicating the presence of both left and right tails. Despite mild violations of the normality assumptions, the model was retained due to the robustness of multilevel models particularly because the sample size is sufficient. The homoscedasticity assumption was evaluated through residual plots against the predicted values. Multicollinearity

was examined through Variance Inflation Factor (VIF) analyses, which indicated no multicollinearity among the predictor variables, confirming that the variables did not exhibit problematic overlap. Finally, a Log-Likelihood Ratio Test was performed to determine the best fitting model for the data. The Restricted Maximum Likelihood (REML) estimation method, in combination with an autoregressive (AR1) covariance structure, provided the best fit. No formal correction for multiple comparisons was applied because some predictor variables were mildly correlated, but not to an extent that would affect the analyses, and the focus of the results was on comparing standardized predictors (z-scores) rather than solely on p-values. Readers are advised to interpret p-values with caution.

Based on the Spinal Cord Injury Adjustment Model, our model comprises three steps.²⁹ The first step encompasses all patient characteristics, the second step supplements the psychological resources, and the third step supplements the coping and appraisal factors.

Results

Descriptives on participant characteristics and psychological factors at baseline (T1) are detailed in **Table 5.2**. Mean age of the participants was 55.8 years (SD 15.2), most participants were male (68.4%), and had an incomplete SCI (77.4%). Approximately half of the participants had traumatic and half had paraplegia. The median time between SCI onset and first assessment was 4 (IQR 3–6) weeks. The last assessment was executed on average 4.3 (SD .7) years after discharge.

Out of the 7 time-points we evaluated, the 70 percent response rate threshold was achieved at all time points except T9. Details of the non-response analyses are shown in **Table 5.2**. At T9, we observed that non-responders were more likely to be male and single, had a lower level of education, and had lower levels of challenge appraisals and pro-active coping compared to the responders.

The trajectory of life satisfaction is displayed in **Figure 5.1** and **Table 5.3**. Details are provided in the **Appendix**. **Figure 5.1** and **Table 5.3** show the results of the multilevel models to analyze the course of life satisfaction during the study period. The average total 2LS score increased from 5.3 (SD 2.3) at admission to 7.2 (SD 2.1) four years after discharge. Life satisfaction showed the largest increase in the first month after admission, with a change score of .8 (SD .6) (between T1

and T2). During the rest of inpatient rehabilitation (between T2 and T5) and the first year after discharge (between T5 and T8), life satisfaction remained relatively stable. Life satisfaction showed a further significant increase between one and 4 years post-discharge (between T8 and T9) with a change score of .4 (SD .7). This increase of life satisfaction was mainly seen in the responses to the 'life satisfaction now' question, this score increased with 1.3 points, which is clearly larger compared to the .6-point increase in the comparison-question score.

Table 5.2. Participant characteristics and non-response analyses

	T1 (N=266)	T9, N=131	p-value
Characteristics, measured at T1			
Sex, male (n, (%))	182 (68.4)	81 (62.6)	.03*
Age, years, (mean (SD))	55.8 (15.2)	54.9 (14.6)	.38
Immigrant background (n, (%))	17 (6.5)	10 (7.6)	.67
Missing	4 (1.5)		
Partner, yes (n, (%))	188 (70.7)	102 (77.9)	.01*
Missing	3 (1.1)	1 (0.8)	
Paid job, yes (n, (%))	170 (63.9)	88 (67.2)	.21
Missing	2 (0.8)	2 (1.5)	
Bachelor degree, yes (n, (%))	73 (27.8)	47 (36.6)	.03*
Missing	5 (1.9)	2 (1.5)	
Premorbid psychological problems (n, (%))	61 (22.9)	31 (23.7)	.91
Missing	17 (6.4)	6 (4.6)	
Traumatic lesion (n, (%))	134 (50.4)	66 (50.4)	.99
Paraplegia (n, (%))	123 (46.8)	68 (51.9)	.07
AIS (n, (%))			.78
A	31 (11.7)	16 (12.2)	
B	27 (10.2)	11 (8.4)	
C	49 (18.4)	26 (19.8)	
D	157 (59.0)	78 (59.5)	
Missing	2 (0.8)		
Weeks between onset and T1 (med, IQR)	4.0, 3.0-6.0	4.0, 3.0-6.0	.59
Weeks in inpatient rehabilitation (med, IQR)	11.0, 6.0-18.0	11.0, 6.0-16.0	.09
Total life satisfaction (med, IQR)	5.0, 4.0-7.0	5.0, 3.0-7.0	.49
Personal factors, measured at T1			
General self-efficacy (med, IQR)	51.0, 44.5-56.0	52.0, 45.0-56.0	.25
Disability management self-efficacy (med, IQR)	17.0, 14.0-21.0	18.0, 15.0-22.0	.32
Resilience (med, IQR)	29.0, 25.0-29.0	30.0, 25.0-34.0	.97
Neuroticism (med, IQR)	2.0, 0.0-5.0	2.0, 0.0-5.0	.79
Purpose in life (med, IQR)	24.0, 21.0-26.0	24.0, 21.0-26.0	.22
Coping and appraisals, measured at T1			
Threatening appraisals (med, IQR)	11.0, 4.0-17.0	9.0, 4.0-16.0	.42
Challenging appraisal (med, IQR)	11.0, 6.0-16.0	7.0, 3.0-12.0	.02*
Loss appraisal (med, IQR)	8.0, 4.0-13.0	7.0, 3.0-12.0	.31
Proactive coping (med, IQR)	21.0, 19.0-22.0	21.0, 20.0-23.0	.05*
Passive coping (med, IQR)	10.0, 8.0-12.0	10.0, 8.0-12.0	.29

* Statistically significant at $p < .05$.

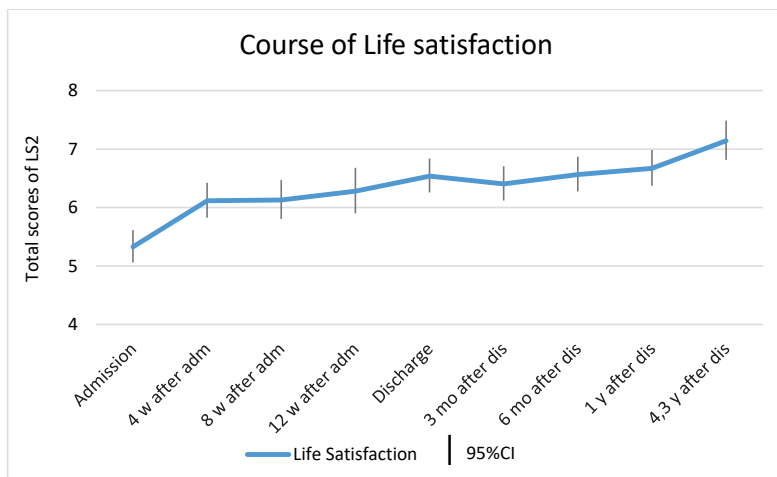


Figure 5.1. Course of life satisfaction, based on the multilevel models.

Table 5.3. Multilevel models for the course of life satisfaction

Variables	Beta	Δ score	SE	95% CI	p-value
Constant T1	5.3		.14	.54	
Time T2	6.1	.8	.15	.58	.00**
Time T3	6.1	.0	.16	.65	.94
Time T4	6.3	.2	.19	.78	.45
Time T5	6.5	.3	.14	.56	.17
Time T6	6.4	-.1	.14	.57	.32
Time T7	6.6	.2	.15	.57	.26
Time T8	6.7	.1	.15	.59	.33
Time T9	7.1	.4	.17	.65	.01*

Beta stands for a non-standardized regression coefficient in multilevel analysis. Participant is included as random intercept. No random slopes are included. Measurement moment before is used as reference time point. *Statistically significant at $p < .05$; **Statistically significant at $p < .001$.

The percentage of participants who indicated to be satisfied with their life as a whole 'now' (scores 4 or 5) increased from 22.3% at T1 to 58% at T9, whereas the percentage of participants who indicated to experience equal or higher life satisfaction compared to before (scores 3–6) only increased from 12.1% at T1 to 22.9% at T9. The correlations between life satisfaction at baseline and the various follow-up measurements were moderate to strong, again somewhat stronger for the 'now' question compared to the 'comparison' question, but the latter correlation only clearly lower at the final follow-up.

Table 5.4. Univariable and multivariable relationships between psychological factors and life satisfaction

Patient characteristics ¹	Univariable	Step 1		Step 2		Step 3	
	β^*	β^*	SE	β^*	SE	β^*	SE
Age	-.18**	-.20*	.07	-.20**	.06	-.19**	.06
Female (ref: Male)	-.01	-.03	.114	.11	.11	.11	.10
Non-Dutch nationality (ref: Dutch)	-.09	-.18	.22	-.42*	.20	-.46*	.19
No partner (Ref: Partner)	.04	.02	.12	.04	.11	.04	.11
Has paid job (ref: No paid job)	.20	.01	.13	-.05	.13	-.08	.12
Attend higher education or university (ref: No higher education)	-.22	-.32*	.12	-.33*	.11	-.26*	.11
No premorbid psychological help (ref: Premorbid psych. help)	.16	.24	.12	-.05	.12	-.00	.11
Tetraplegia (ref: paraplegia)	-.22*	-.08	.11	-.08	.10	-.07	.10
Complete injury (ref: Incomplete injury)	-.23	-.15	.15	-.19	.14	-.19	.13
Time of initial rehabilitation	-.20**	-.16*	.06	-.38	.46	-.34	.46
Predisposing psychological factors							
General Self Efficacy (GSES)	.09			-.14	.07	-.08	.05
Disability management self-efficacy (UW-SES)	.36**			.25**	.06	.19**	.06
Resilience (CD-RISK)	.22**			.04	.08	-.09	.08
Neuroticism (EPQ)	-.25**			-.25**	.07	-.12	.05
Purpose in life (PIL)	.23**			.04	.06	.02	.06
Coping and appraisals							
Appraisal life event (ALE) – Threat	-.46**					-.33**	.09
Appraisal life event (ALE) – Challenge	.20**					.06	.05
Appraisal life event (ALE) – Loss	-.44**					-.01	.09
Pro-active coping (UPCC)	.19**					.01	.6
Passive coping (UCL)	-.24**					.03	.7

β^* Standardized bèta coefficients. *Statistically significant at $p < .05$. **Statistically significant at $p < .001$. Random intercept: Time since SCI. ¹Reference category is shown between brackets.

Table 5.4 presents the univariable and multivariable relationships between patient characteristics, psychological factors and life satisfaction. The univariable analysis revealed that all psychological factors were significantly associated with the course of life satisfaction, either positively or negatively. In the first step of the multivariable analysis, younger age, a shorter duration of rehabilitation and higher level of education were significantly associated with a more positive course of life satisfaction. In the next steps, only age and level of education remained a significant independent predictor, while Dutch nationality became a significant positive predictor in steps 2 and 3. In the second step, including the psychological resources, higher DMSE and lower neuroticism were independent

predictors of a positive course of life satisfaction. The third step, including the appraisal and coping variables, showed that lower levels of threat appraisals were an independent positive predictor of life satisfaction. In this third model, DMSE remained a significant predictor, whereas neuroticism was no longer statistically significant. The standardized beta coefficients indicate that DMSE ($\beta^* = .19$) and threatening appraisal ($\beta^* = -.33$) were the strongest modifiable predictors of the course of life satisfaction. This suggests that these factors have the most substantial impact relative to other included psychological variables.

Discussion

The present study showed that average life satisfaction significantly increased during the first month of inpatient rehabilitation and again between 1 and 4 years after discharge. Psychological factors that were most strongly independently related to the course of life satisfaction were DMSE and threatening appraisal.

The demographics of our sample align with the broader SCI population: a similar proportion of male participants and comparable average age. While traumatic causes are more prevalent globally, their proportion is lower in developed countries, making our sample representative of these settings.³⁰ We found a significant increase in life satisfaction during the first month of inpatient rehabilitation. Previous studies showed an increase of life satisfaction between admission and 3 months of inpatient rehabilitation,³⁻⁶ but these studies did not have assessment points in-between. Our study showed that this increase seems to occur mainly during the first month of inpatient rehabilitation. This early increase in life satisfaction could reflect the psychological benefits of transitioning to rehabilitation, such as increased access to rehabilitation program and professionals, and peer support, which may provide individuals with a sense of direction and hope. Engaging in rehabilitation activities and setting recovery goals might enhance perceptions of control, which supports life satisfaction. However, after this first period, our data showed a gradual increase in life satisfaction up to one year after discharge, but without significant increases per period. These findings are supported by previous research, which demonstrated a similar course of life satisfaction during the period from discharge up to 6 to 15 months post-discharge.^{3,7,31,32} The significant increase in life satisfaction between 1 and 4 years post-discharge is also in line with previous research,^{1,7,8} although one previous study reported stable life satisfaction over this

time.⁹ This long-term increase may reflect a more extended adaptation process, in which individuals integrate their SCI into their identity and adjust to new life circumstances. Factors such as regaining independence, returning to work, school or social activities, and developing effective coping strategies could contribute to this later improvement in life satisfaction.³³ Part of this change may also result from a shift in how individuals evaluate their lives over time.³⁴

Our results further showed that DMSE and threatening appraisals were significant independent predictors for the course of life satisfaction. These findings correspond with results from previous studies, showing coefficients ranging from $r=.23$ to $.62$ and $\beta=0.05$ to 0.39 ^{2,35,36} and $r=-.41$ to $-.49$, respectively.^{37,38} Neuroticism was only significantly associated with life satisfaction in the first steps of the analysis, perhaps due the conceptual overlap between threat appraisals and neuroticism, i.e. people who score higher on neuroticism are more likely to perceive situations as threatening.³⁹ This finding aligns with the Spinal Cord Injury Adjustment Model, which suggests that coping and appraisals play a role in the relationship between psychological resources and life satisfaction.¹⁷ Interestingly, in contrast with this model, DMSE remained significant after coping and appraisals were added to the regression model, suggesting a direct association with life satisfaction. This is in line with a previous analysis of direct and indirect associations between psychological resources and life satisfaction and the hypothesized double-mediation by coping and appraisals.³⁸

Study limitations

The study's strength is that it utilizes a large sample. Secondly, this study included 9 assessments spread over more than 4 years. This provides detailed information about the course of life satisfaction, contributing considerably to the pre-existing body of scientific literature. This study also has several limitations. First, last assessment (T9) was added to the cohort as a separate study and participants had to be invited for the study again. This late addition resulted in more missing data and a wider spread of time since onset at T9. Second, the 2LS is not frequently used internationally, which limits our ability to compare our results with other studies. We used the 2LS because it is a brief and valid measure in this population,¹⁴ and it showed responsiveness in a previous longitudinal study,⁶ which made it easier to include it in a larger assessment. Third, results are not generalizable to all countries due to possible influences of environment and culture. Fourth,

psychological factors were measured only once at baseline. Therefore, it was not possible to analyze how changes in these factors were associated with the course of life satisfaction. However, the longitudinal nature of the study and the use of a multilevel models, in which time was included as a random coefficient, allows us to account for individual differences in the course of life satisfaction and to explore the predictive role of baseline psychological factors. Since these factors were measured once, these findings should be interpreted as reflecting the influence of initial psychological characteristics, rather than their potential change over time. Fifth, no formal correction for multiple comparisons was applied, which increases the risk of type I errors. Therefore, the findings should be confirmed in future studies.

Clinical implications

The results of the present study have implications for rehabilitation practitioners. Life satisfaction is an important rehabilitation outcome. Improved life satisfaction predicts higher levels of participation, greater independence in self-care, less rehabilitation needs and reduced impact of secondary health conditions.¹² Our study revealed that DMSE and threatening appraisal are psychological resources that could play a role in the restoration of life satisfaction following SCI. Early assessment of DMSE and threatening appraisals therefore could enable the delivery of early interventions targeted low self-efficacy and high levels of threat. Self-efficacy may be influenced by focusing on core elements of self-efficacy (e.g. enactive mastery experiences). Furthermore, unhelpful threatening appraisals can be reduced by Cognitive Behavior Therapy.⁴⁰ It is important to note that people with lower educational levels or from immigrant background showed lower life satisfaction than people with the opposite characteristics, which is consistent with previous research.⁹ Strikingly, this variable became only a significant independent predictor after inclusion of the psychological resources. This result and how to support this group needs to be explored further. In this context, future studies should include repeated assessments of psychological factors to examine how changes in self-efficacy and threat appraisals over time interact with life satisfaction trajectories.

Conclusion

Life satisfaction of individuals with SCI increases significantly in the first month of inpatient rehabilitation and between 1 and 4 years after discharge of inpatient rehabilitation. The course of life satisfaction is mostly linked to threatening appraisal and DMSE. These results highlight the importance of providing persons with SCI with early psychological support to foster life satisfaction and optimize DMSE and target threatening appraisal.

Supplier

^a SPSS program for Windows, version 27; IBM.

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Conflict of interest

The authors declare that they have no conflict of interest.

Data archiving

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

Statement of ethics

The research protocol was approved by the Medical Ethics Committee of the University Medical Centre Utrecht, reference number: 15-449/C. The Medical Ethics Committees of all participating rehabilitation centers approved this

protocol. We certify that all applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed during the course of this research.

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Appendix

Appendix A. Definitions of psychological factors

See http://www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_5.pdf“www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_5.pdf

Appendix B. Descriptives life satisfaction

See http://www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_5.pdf“www.kcrutrecht.nl/wp-content/uploads/2026/01/Appendices_Chapter_5.pdf



CHAPTER 6

General discussion

Introduction

The importance of understanding the diverse factors that influence quality of life (QoL) in individuals with spinal cord injury (SCI) is widely recognized. Given the complexity of these influences, particularly across different cultures and psychological dimensions, this thesis seeks to explore two research questions that aim to further our understanding of QoL in this population. 1) What is the meaning of quality of life for individuals with SCI across five different countries, and how is this reflected in the interpretation of the International Spinal Cord Injury Quality of Life Basic Data Set (SCI QoL-BDS), particularly regarding the social dimension? 2) How are psychological factors related to the QoL in people with SCI?

The main results were presented in the previous chapters. This final chapter begins with an overview of the main findings, followed by reflections and considerations about this thesis, and implications for clinical practice.

Main findings

Part 1 of this thesis focused on the meaning of QoL for individuals with SCI and the cross-cultural validation of the SCI QoL-BDS. Across five sites in four countries, individuals with SCI consistently used similar language to define QoL and the three SCI-QoL-BDS items. Thematic analysis revealed some site-specific nuances in how QoL was described. These nuances did not correspond to participants' demographic or injury characteristics. Overall, the SCI QoL-BDS demonstrated strong conceptual and item equivalence, highlighting its cross-cultural robustness (**Chapter 2**). Social life was frequently mentioned as important for QoL across the three items of the SCI QoL-BDS, particularly in responses regarding the definition of QoL and the psychological health item. This emphasis was primarily reflected in the International Classification of Functioning, Disability and Health (ICF) categories of family relationships, intimate relationships and recreation and leisure. Consequently, an item addressing individuals' social life was added to the SCI QoL-BDS to provide a more comprehensive measure (**Chapter 3**).

Part 2 of this thesis examined the relationship between psychological factors and QoL. In a systematic review, we confirmed the importance of psychological factors with respect to QoL and mood state of people with SCI. Recent studies have increasingly focused on the psychological factors appearing most relevant in

this review. Evidence consistently indicated associations between locus of control, attribution of blame, personality, sense of coherence, positive affect, hope, purpose in life, self-worth, resilience, emotion focused-coping, and appraisals and QoL (**Chapter 4**). The final study demonstrated that QoL increased after the onset of SCI, with significant improvements observed during the first four weeks of admission and again between one and four years after discharge. In the final regression model, among modifiable factors, disability-management self-efficacy, and threatening appraisals were significant predictors of the course of life satisfaction (**Chapter 5**).

Reflections and considerations

Quality of life in spinal cord injury (Part 1)

In the first part of this thesis, the SCI-QoL BDS was the focal point. The SCI QoL-BDS was developed to standardise the collection and reporting of QoL through a brief yet comprehensive instrument, enabling comparison and synthesis of QoL results worldwide.¹ During the development of the SCI-QoL BDS, consideration was given to adding a fourth item addressing social life. However, this was ultimately omitted, as social participation was covered separately in the International SCI Activities and Participation Data Set.² Consequently, the original SCI QoL-BDS consisted of three items, which is the version examined in this thesis. Subsequent, our cognitive interviews with participants from all sites indicated that the QoL-BDS would be incomplete without a question explicitly addressing satisfaction with social life.^{3,4} Therefore, we added a fourth question to this measure, resulting in a SCI QoL-BDS V2.0. The psychometric properties of this revised version are satisfactory.⁵⁻⁷ In the context of assessing cross-cultural validity, this thesis investigated conceptual equivalence. Internationally, the research group decided to retain the term 'social life' for this item, primarily to support international comparability. The SCI QoL-BDS V2.0 is, however, not yet widely used internationally. In the Netherlands, where this fourth item was already included during data collection, analysis of the Dutch data suggested that participants tended to distinguish between social and civic aspects of life.⁸ As a result, the broader phrasing 'social and civic life' ('sociaal en maatschappelijk leven') was considered more appropriate for the Dutch version, as it may better preserve the intended meaning of the item and support conceptual equivalence.

Internationally, version 2.0 is not yet widely used, which can make comparisons of total scores between the three- and four-item versions challenging, and given that publications persist, this issue is unlikely to disappear soon. Nevertheless, in our data the total scores of the three- and four-item versions were very strongly correlated, supporting their comparability. In general, item-level reporting is preferred over total scores, as it allows for more nuanced interpretation and facilitates comparison across different measurement versions and varying context.⁹ The four-item version demonstrated internal consistency comparable to that of the original three-item version.⁵ As emphasized in Chapter 4, it is essential to clearly describe which version of the instrument was used.¹⁰

An important consideration regarding the study procedure of the studies in Part 1 is the use of a qualitative design. This design yields context-specific findings that are partly shaped by the researchers.¹¹ To limit this influence, all data in the current study were coded independently by two researchers. In addition, international collaboration helped to broaden perspectives and reduce the potential impact of cultural biases. Although qualitative research inherently carries a risk of subjectivity and interpretation bias, it remains, in my opinion, essential for understanding QoL. It offers insight into how participants experience and give meaning to their QoL, insight that often goes beyond what standardised instruments can capture.¹² Part 1 was conducted within a larger project that also included quantitative analyses as part of the cross-cultural validation of the SCI QoL-BDS. Within this broader context, the qualitative component adds valuable complementary insights.⁵ Combining qualitative and quantitative methods is particularly important in cross-cultural validation: quantitative analyses test psychometric properties, whereas qualitative methods explore how items are interpreted and whether they are culturally relevant. Together, these approaches strengthen the content validity of the instrument and enhance its applicability across cultures.¹³

The study was conducted in the USA, Australia, Brazil and the Netherlands. Within each country, data were collected in specific regions (e.g., São Paulo in Brazil, Colorado and Michigan in the USA), which may not be fully representative of national context. Moreover, no low-income or lower-middle income countries from Africa, the Middle-East, or Asia were included. This is a limitation, given that individuals with SCI worldwide have reported that both national economic status and personal financial situation influence their levels of QoL.¹⁴ Nevertheless, there are encouraging indications that the SCI QoL-BDS may also perform adequately beyond the

countries included in this study. For instance, an initial psychometric evaluation of the original 3-item version in Thailand demonstrated acceptable measurement properties.⁷ Similarly, a qualitative study in Indonesia explored the meaning and components of QoL, most of which correspond with those reflected in the SCI QoL-BDS.¹⁵ One notable exception is the domain 'Relationship with God'. While this is framed in religious terms, it may more broadly reflect spiritual connectedness. Notably, spiritual or religious aspects are also absent in other widely used instruments, such as the WHOQOL-BREF, which has been validated in numerous of low- and lower-middle income countries. Cultural differences may influence the importance of this domain, with it playing a larger role in countries such as Indonesia compared with Western contexts. Taken together, these findings suggest that the SCI QoL-BDS can be cautiously recommended for use across diverse cultural and socioeconomic contexts to enhance comparability of research and clinical data. While further validation in low- and middle-income settings remains important, the minimal differences observed between countries in the present study (Chapter 2 and 3) indicate that the core components of QoL captured by this measure may be relevant beyond the settings in which it was developed. This brief measure enables the detection of differences ranging from macro-level comparisons across studied contexts to micro-level evaluations of intervention effects, though local cultural or spiritual factors may warrant consideration when interpreting results.

Psychological factors and QoL (Part 2)

In the second part of the thesis, the Spinal Cord Injury Adjustment Model (SCIAM) model provided a framework for understanding potential mechanisms underlying QoL. In Chapter 5, psychological factors were examined in a stepwise analysis, based on the SCIAM in which appraisals and coping may play an intermediary role in the relationship between other psychological factors and QoL.^{16–18} In this chapter, we used the Two Life Satisfaction questionnaire (2LS). This is also a valid, reliable, and concise tool specifically developed for individuals with SCI, with particular attention to detecting possible response shift effects.^{19,20} Selecting an appropriate measure of QoL should be based on several factors, including the type of measurement, personal and clinical characteristics, feasibility, and measurement properties.²¹ The choice for the 2LS enabled direct comparison with the study by Van Leeuwen et al., which assessed QoL during the first five years post-discharge from inpatient rehabilitation.²² This alignment enhances the interpretability of our findings. In this chapter, we observe a significant improve-

ment in QoL after the start of active rehabilitation, and again, between two and four years after discharge, visible in both scores of the 2LS and especially in the score reflecting current life satisfaction.¹⁸ The inclusion of two components, a score for current life satisfaction and a comparative score assessing satisfaction now versus before the SCI, appears to be a useful approach to capture adaptation or changes in internal standards. While retrospective comparisons may be prone to bias or idealization of life before SCI,²³ combining present and comparative perspectives provides a more nuanced picture of experienced QoL. In my view, this combination of questions captures adaptation more accurately than a single item on current QoL. The observed changes are, therefore, more likely to reflect healthy adjustment to new circumstances, rather than being the result of measurement bias.^{19,20,24}

Due to the multidimensional nature of QoL, as described in the introduction and reflected in the ICF model, it is not possible to capture all factors that may influence QoL. This limitation has influenced the second part of this thesis, as some relevant aspects, particularly social and environmental factors, may not have been fully captured. The observed increase in QoL during the first month after admission to rehabilitation could partly be attributed to the rehabilitation process itself. Actively engaging in recovery and regaining a sense of hope may have positively impacted QoL, although these factors were not measured in our study. What our findings do indicate is that QoL developed during and after rehabilitation with self-efficacy and threatening appraisals playing a significant role in this process. We are aware that other research indicates that factors such as the impact of secondary health conditions,²⁵ demographic and SCI-related factors, and social-related factors also influence the development QoL, with SCI-related factors playing a comparatively smaller role.^{26,27}

Another element worth considering is the potential influence of differences in rehabilitation trajectories across countries. Variation in length of stay, organization and continuity of care, and follow-up may shape QoL outcomes in ways not fully captured in the present study. This topic is currently being investigated in the international Length of Stay (LOS) project, in which the Kenniscentrum Revalidatie Utrecht (KCRU) is involved. The LOS project aims to contribute to a broader understanding of how structural and contextual aspects of rehabilitation impact QoL after SCI.²⁸

Psychological factors play a crucial role in enhancing QoL, preventing anxiety and depression, and promoting better participation after SCI.^{18,29–33} While physical health factors, such as mobility, pain management, and the absence of secondary conditions, form the basis for daily functioning, psychological resources like self-efficacy, appraisals, and resilience are essential for addressing the psychological and social challenges of living with SCI.^{29,34–36} These factors promote active engagement in rehabilitation and can enhance rehabilitation outcomes, contributing to a positive feedback loop between physical and psychological progress.^{31,37} A recent study using predictive models, including artificial neural networks, have demonstrated that psychological variables such as anxiety, depression, self-esteem, and emotional regulation significantly contribute to functional outcomes at discharge (SCIM scores).³³ A comprehensive diagnostic approach, combining medical assessment with an evaluation of psychological and emotional adjustment at admission, may help identify patients who need additional support, and to provide tailored and effective care.³⁸ Such an evaluation could focus on mood, acceptance of physical changes, understanding and managing the altered body, redefinition of self-concept, and coping strategies to adapt to the new situation. Addressing both physical and psychological needs is therefore key to promoting long-term participation and improved QoL.^{33,37,39,40} If possible, the persons' family should be included in this first process.⁴⁰

The findings of the second part of this thesis emphasize the significance of psychological factors, particularly self-efficacy and threatening appraisals, in the development of QoL over time. However, this process unfolds differently across individuals. Vulnerable groups, such as those with psychological comorbidities, a lower educational background, a migration background, or those showing low self-efficacy and high levels of threatening appraisals (Chapter 5), may face greater challenges due to cumulative psychological burdens and fewer personal resources.^{18,41,42} At the same time, it is important to recognize the heterogeneity within the SCI population. A subgroup of individuals appears to adapt relatively well and even demonstrates personal characteristics that are well-suited to providing peer support.^{41,43}

To further interpret these findings, it is important to consider how appraisals are conceptualized across studies. In the review presented in Chapter 4, appraisals and coping were included as independent determinants of QoL, similar to other psychological factors. However, it is important to note that the conceptual role

of appraisals may differ across studies. While they are sometimes measured as mediators, they are also used as outcome variables, especially in studies that evaluate psychological adjustment or distress.^{16,44,45} These differences may partly reflect the way in which appraisals are operationalized. For instance, when measured through items that capture general evaluations of life, health, or identity, appraisals may overlap conceptually with QoL itself. In such cases, the distinction between appraisal and QoL becomes less theoretical and more semantic, depending on the wording and focus of the questionnaire.⁴⁵

Clinical implications and recommendations

As Aristotles once said: “Intelligence consists not only in knowledge but also in the skill to apply that knowledge in practice”. This is precisely the challenge healthcare professionals face daily. Implementing new insights into clinical practice is not without challenges, as it requires adaptation to existing routines, resources, and organizational contexts.⁴⁶ Drawing on the findings from the chapters, I will outline some key clinical implications concerning: (1) integrating the SCI QoL-BDS version 2.0 (hereafter referred to as SCI QoL-BDS) into clinical practice, and (2) the multidisciplinary approach to fostering QoL in individuals with SCI.

Integrating the SCI QoL-BDS into clinical practice

QoL is an important rehabilitation outcome for individual well-being, fewer secondary health problems, and greater life expectancy.^{25,47} The application of the SCI QoL-BDS can probably help translate this priority into day-to-day practice by flagging early dissatisfaction in key domains—*life as a whole*, *physical health*, *psychological health*, and *social life*. Detecting low scores in any of these areas may indicate reduced QoL and can help identify individuals who might need further psychological or social support, with additional attention to potentially preventing secondary complications and promoting long-term participation.

In the Netherlands, the four-item version of the SCI QoL-BDS is administered at admission as part of the standard psychological screening. Coupled with measures of anxiety, depression, coping and appraisals, resilience, and self-efficacy it helps psychologists prioritize interventions based on the results and guides other disciplines in setting appropriate goals.⁴⁸ For example, Sam, as described in the introduction, may score high on depression on the HADS-depression scale, while

reporting low satisfaction with his social life on the SCI QoL-BDS. These experiences may partly reflect changes in his roles as a father, husband and employee. Understanding these factors is important for integrating targeted psychological care to support the achievement of his rehabilitation goals.

In conclusion, effective interventions begin with accurate and comprehensive screening at the start of rehabilitation.³⁸ Therefore, embedding the four-item version of the SCI QoL-BDS in the psychological screening ensures that social risk is also identified alongside the other important domains. After that, low scores in specific domains should trigger clear treatment pathways,^{38,48} such as Cognitive Behavioral Therapy for threatening appraisals, or peer mentoring in cases of low self-efficacy. Because the SCI QoL-BDS uses plain-language domains, all team members can develop or adjust their plans without having to wait for formal psychological reports. Repeating the SCI QoL-BDS assessment at discharge provides a simple, shared instrument that all disciplines can interpret and use to monitor QoL improvements and take appropriate action. This shared approach supports both the effective evaluation of interventions and the comparison of outcomes across rehabilitation centers or countries, as well as more efficient use of healthcare resources, a key consideration given limited budgets and workforce capacity.

The Multidisciplinary Approach to Fostering QoL in Individuals with SCI

Multidisciplinary rehabilitation is associated with improved outcomes across various domains, including activity, participation, body functioning, secondary health issues, and rehabilitation stay.⁴⁹ When each discipline aligns its expertise around key psychological and social determinants of QoL, such as threatening appraisals and self-efficacy, the rehabilitation process becomes more holistic and effective, addressing both physical and psychosocial dimensions.^{49,50} Although the rehabilitation psychologist typically leads on mental-health issues, every team member influences psychological and social well-being and QoL.^{49,51,52} Physicians have the overall responsibility for guiding the multidisciplinary rehabilitation trajectory, while nurses maintain continuous contact and are often the first to notice changes in mood or social dynamics and to reinforce coping strategies throughout the day.^{53,54} Occupational therapists support reintegration, and physiotherapists help restore physical independence, which can both strengthen self-confidence.⁵¹ Together, the team fosters trust, social support, and motivation,

which are crucial elements for self-efficacy, reducing threatening appraisals, and enhancing the ability to manage the challenges of SCI.^{55,56} In practice, this includes sensitive to signs of distress, providing emotional and social support, and using effective communication skills to address persons' psychological needs.⁴⁰ Such skills can be strengthened through targeted training; for example, Van Diemen and colleagues developed a course titled "*Samen bouwen aan vertrouwen*", for healthcare professionals in rehabilitation. The aim of this training is to explicitly integrate the enhancement of individuals' confidence in coping with the consequences of their SCI into multidisciplinary rehabilitation treatment.⁵⁷ By jointly addressing the psychological, social, and physical domains, the team contributes to a more comprehensive and sustainable recovery.⁵⁸

In the Netherlands, Onderwater et al. explored the needs of individuals with SCI and rehabilitation professionals regarding psychosocial rehabilitation.^{39,59} Their work contributed to the development of a national toolkit aimed at improving care in this domain. Today, psychological care is integrated into rehabilitation programs: psychological screening is a standard component at the start of rehabilitation for every individual with SCI, as recommended in the rehabilitation guideline, enabling the early identification of psychological needs.^{38,48} These insights are not only relevant for psychologists but also support the multidisciplinary team in delivering consistent, integrated care.^{49,50} Key practices include regular multidisciplinary meetings, where psychologists meet with nurses or other team members to discuss strategies for psychosocial support, and the use of the "emotional wellbeing toolkit", a practical resource that supports the team in providing psychological rehabilitation, with educational materials, guidelines, and tips. This is now part of basic nurse training in De Hoogstraat, with plans to expand it to other team members. Psychological stability, especially mental self-reliance, is also part of the discharge criteria, emphasizing its importance in overall rehabilitation outcomes.

Beyond the use of this toolkit, psychological interventions are firmly integrated into multidisciplinary care. Interventions such as cognitive-behavioral therapy (CBT), coping with pain, self-management training, mindfulness, Acceptance and Commitment Therapy (ACT) and Eye Movement Desensitization and Reprocessing (EMDR) have been shown to be effective, for example, in reducing negative cognitions, pain relief, enhancing self-efficacy and purpose in life.^{49,60-63} In some centers, such interventions are jointly delivered by professionals from different

backgrounds, such as a nurse and psychologist co-leading a mindfulness group. Innovations in delivery, including group-based formats, online modules, and digital tools such as virtual reality, offer promising ways to improve accessibility and cost-effectiveness, and have shown promising results for maintaining and improving psychological health.^{63–65} Peer support has also become a structural part of multidisciplinary teams, offering education, group support, and individual mentoring. People with lived experience contribute to enhanced self-efficacy, social participation and QoL.⁶⁶ Finally, pilot initiatives like the Rehabilitation is Learning (RIL) project demonstrate how multidisciplinary teams can support psychological growth and promote independence. In this pilot at De Hoogstraat, individuals with SCI participate in group sessions addressing daily life challenges, while professionals collaborate to enhance their goals of participation and self-management.⁶⁷

Although not the primary focus of this thesis, nurses play a crucial role in addressing psychological factors which are important for improving QoL.⁵³ Through their continuous presence at the bedside, they bridge physical care and psychological support by integrating psychological strategies, facilitating family communication, and translating therapeutic insights into daily life, as illustrated in Sam's case in the Introduction.^{54,68} Through daily interactions with persons with SCI and their social networks, nurses gain unique insight into contextual and personal factors, enabling them to identify psychosocial challenges and serve as a vital link between individuals and other professionals involved.^{68–70} In addition to their psychological support, nurses are responsible, for example, for managing secondary health conditions, coaching self-care activities, and promoting functional recovery.^{54,71} These clinical and personal responsibilities complement the therapies provided by the wider rehabilitation team.^{53,69,70} Tools such as the Emotional Wellbeing Toolkit can be integrated into daily care to foster self-management and coping with secondary conditions, emotional stress, and adaptation to mobility aids, enhancing both physical recovery and psychological adaptation.^{53,72}

Despite this broad contribution, much of nurses' work remains invisible. Shift patterns and bedside duties limit attendance at multidisciplinary meetings, and the full scope of their therapeutic contribution is still not always recognized.^{55,68,69} To strengthen and sustain their role, rehabilitation nursing practice must develop in line with broader professional developments.⁵⁴

Nurses often rely on intuition (an expression of tacit knowledge) when providing psychosocial care, to recognize emotional cues or respond empathetically.⁷³ While valuable in practice, there is limited evidence directly linking intuitive approaches to specific psychological interventions for e.g. enhancing self-efficacy or reducing threatening appraisals. Tacit knowledge can, however, be surfaced and refined through structured, experience-guided reflection. Current documents, including the *Opleidingsprofiel Bachelor Nursing 2030* urges nurses to combine evidence-based knowledge, critical reflection, and interprofessional collaboration.⁷⁴ Having access to the outcomes of psychological screening and integrating these into care delivery is part of that. The Dutch rehabilitation-nursing profile (*expertisegebied revalidatieverpleegkunde*) likewise stresses integration of physical, psychological, and social domains to support self-management,⁷⁵ yet the explicit nursing role in strengthening self-efficacy and reducing threatening appraisals remains underexplored.

Supporting nurses through reflective training on their own practice, tailored to their role and level of education, can help them recognize and consciously apply their intuitive insights and experiential knowledge. This approach enhances the alignment, coherence, and effectiveness of care, particularly in addressing persons' psychological needs.^{76,77} In this way, the reflective development of nurses not only strengthens their contribution to psychological care but also reinforces their position as essential partners in multidisciplinary SCI rehabilitation.^{54,69}

Directions for further research

Directions for future studies were described in each chapter. In summary, the global use of a well-translated SCI QoL-BDS is essential for enabling comparisons of research and clinical data worldwide. Specifically for the Dutch version, I recommend expanding the four-item version to include "*sociaal en maatschappelijk leven*" [social and civic life], as it better captures the multidimensional aspects of QoL. However, conceptual equivalence for this item is not yet established across cultures. It would therefore, be valuable for future research to explore how the concept of social life is understood in different cultural contexts. Although this tool is not routinely used at discharge, individuals can complete it themselves with minimal additional time required, making it an efficient way to collect valuable data on the trajectory of QoL, thereby further contributing to long-term care planning.

Furthermore, longitudinal studies with larger participant groups are needed to gain more insight into the course of QoL after SCI, particularly with precise terminology and conceptual clarity regarding both QoL and psychological factors. In this context, the influence of the rehabilitation environment on the experience of QoL is not fully understood. Finally, research should focus on identifying the most effective treatments for fostering self-efficacy and reducing threatening appraisals, ultimately influencing QoL. While meta-analyses in broader patient populations show that such interventions can improve psychological outcomes and processes related to self-efficacy and threatening appraisals, evidence directly comparing different approaches in SCI is scarce.^{78–80} This underlines the need for consistent outcome measures and comparative research to determine which treatments are most effective.

Given the underexplored nature of the nursing contribution to psychological outcomes in SCI rehabilitation, future research should examine how nurses can effectively support self-efficacy and reduce threatening appraisals in daily practice. Mixed-method designs may be useful in uncovering both the mechanisms and contextual factors that enable or hinder this role.

Conclusion

In conclusion, this thesis demonstrates the central role of social and psychological factors, particularly self-efficacy and threatening appraisals, on the QoL of people with SCI. Returning to Sam's case from the introduction, it is evident that supporting psychological well-being and social participation is crucial for personalized rehabilitation. Interventions that address these factors can help people like Sam manage daily challenges, strengthen adaptive coping, and enhance their QoL. The results underscore the pivotal role of rehabilitation team in identifying psychosocial needs, integrating psychological insights into care, and fostering self-management, thereby contributing to effective, evidence-based rehabilitation practices.

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SUMMARY

Spinal cord injury (SCI) is a neurological condition causing partial or complete loss of motor, sensory, and autonomic functions, affecting daily and social life. Individuals with SCI must adapt to a new way of living. While many achieve a positive quality of life (QoL), some develop psychological conditions such as depressive or anxious symptoms. The International Classification of Functioning, Disability and Health (ICF) provides a framework for understanding these differences between persons by linking impairments, activities, and participation with personal and environmental factors that influence individual outcomes.

QoL reflects an individual's overall perception of life, including physical health, mental well-being, and social support. The SCI QoL-Basic Dataset (SCI QoL-BDS) is a brief questionnaire consisting and was developed to standardize measurement and facilitate international comparison and data sharing. QoL is influenced by demographic, injury-related, and psychological factors (such as self-efficacy and purpose in life), which can be targeted during rehabilitation to support adaptation to the individual's new situation.

The goal of rehabilitation is to create an environment that supports optimal recovery by addressing health conditions, body functions, activities, participation, and personal and environmental factors to improve QoL. All members of the rehabilitation team contribute to psychological support, making collaboration essential for enhancing QoL. Interventions that promote independence, self-care, and social participation indirectly improve QoL, as many rehabilitation activities, even those not explicitly aimed at QoL, foster a person's sense of mastery and autonomy, which are key components of overall well-being.

Chapter 1 provides an overview of the content of this thesis, covering the consequences of SCI, its impact on QoL, the use of the SCI QoL-BDS to measure QoL, and the role of psychological factors in managing the consequences of SCI.

Part 1: Measuring what matters: QoL in SCI

Chapter 2 reports on an international mixed-methods study conducted across five sites in four countries (the United States, Australia, Brazil, and the Netherlands). Using cognitive interviews with 51 people with SCI, the study examined whether the concept of QoL—and the three items of the SCI QoL-BDS—are understood in a comparable way across cultures. Despite some contextual nuances, participants across all sites described QoL using similar language and responded to

the SCI QoL-BDS items in consistent ways. The high degree of overlap in how individuals defined QoL and interpreted the items indicates strong conceptual and item equivalence.

Chapter 3 deepens the understanding of the social domain of QoL by reanalyzing a subset of the interview data using the ICF classification. This approach examined which aspects of social life are most important to QoL from the perspective of 39 individuals living at least one year post-SCI. Text fragments were linked to ICF categories related to community, social, and civic life (ICF chapters d6–d9). The analysis showed that social life is a central component of QoL. Participants frequently referred to family relationships, intimate partnerships, and participation in recreation and leisure as essential to living well after SCI. Social themes also appeared when discussing physical and psychological health, illustrating how social aspects are intertwined with all domains of life. Other relevant topics included formal social roles, financial independence, and the ability to engage meaningfully with one's community. These results confirmed that social life plays a central role in how individuals evaluate their QoL and supported the addition of a fourth item on satisfaction with social and civic life to the SCI QoL-BDS, which originally included three items on satisfaction with life as a whole, physical health, and psychological health.

Part 1 demonstrates that the SCI QoL-BDS is both cross-culturally valid and conceptually enriched by the explicit inclusion of social life. This strengthens its value for international research, data comparison, and clinical assessment, ensuring that QoL is measured in a way that reflects what truly matters to individuals living with SCI.

Part 2: The mind's role: Psychological factors in QoL

Chapter 4 presents an update of a previous systematic review on the relationship between psychological factors and QoL in people with SCI. A total of 66 studies published between 2010 and 2023 were identified that examined the association between psychological factors and QoL after SCI. Since the previous review in 2010, evidence has become stronger for consistent associations with personality characteristics, resilience and who individuals hold responsible for the occurrence of the SCI (*attribution of blame*) with both QoL and mental health. Clear associations were also found for perceived control over one's situation (*locus of control*), sense of coherence, positive emotions (*positive affect*), hope, purpose

in life, self-worth, emotion-focused coping, and how people think about their situation (*cognitive appraisals*). Evidence remained limited for negative emotions (*negative affect*), spirituality, other coping styles, and post-traumatic growth. The review highlights the need for more longitudinal research, clearer terminology, and better reporting standards.

Chapter 5 describes a longitudinal cohort study of 266 individuals with a recent spinal cord injury, who were followed over time from admission to the rehabilitation center up to four years after discharge. At admission, a selection of psychological factors were assessed, while QoL was measured at nine time points during inpatient rehabilitation and up to four years post-discharge. Life satisfaction steadily increased over time, with the largest improvements occurring during the first four weeks of rehabilitation and between one and four years after discharge. In longitudinal multilevel models, younger age, Dutch nationality, higher education level, higher confidence in managing one's SCI (*disability-management self-efficacy*), and perceive the SCI as less threatening (*threatening appraisals*) predicted a more positive course of life satisfaction. Strengthening self-efficacy and reducing threatening appraisals during inpatient rehabilitation may support better adjustment and enhance long-term life satisfaction.

Part 2 shows that psychological resources, self-efficacy and threatening appraisals play a meaningful role in QoL outcomes after SCI. They underline the importance of addressing self-efficacy and threatening appraisals early in rehabilitation to support long-term QoL.

In **Chapter 6**, we described and discussed the main findings of this thesis. We elaborated on the fourth item added to the SCI QoL-BDS, examining its use both internationally and nationally, as well as the internal consistency of the measure. We reflected on the qualitative design of the study, the generalizability of findings, and the absence of 'spiritual connectedness' in the results of Part 1. Regarding the second part of the thesis, we discussed the choice of measurements and the potential influence of the rehabilitation process on the increase in QoL during the first month. We also examined the interplay between physical and psychological processes, emphasizing that addressing both is key for successful rehabilitation.

A key focus of this chapter is the clinical implications for the multidisciplinary team, particularly nurses. Adding the fourth SCI QoL-BDS item to standard screening helps identify psychosocial needs early, allowing interventions to begin at the

start of rehabilitation. The team fosters trust, support, and motivation, which enhance self-efficacy, reduce threatening appraisals, and help individuals manage challenges after SCI. Nurses play a central role through daily interactions with individuals and their social networks, gaining insight into personal and contextual factors. This enables them to identify psychosocial challenges and act as a vital link within the team.

Finally, further research should continue to examine the cross-cultural equivalence of the fourth item added to the SCI QoL-BDS. Longitudinal studies are needed to better understand QoL trajectories, the influence of rehabilitation, and interventions that enhance self-efficacy and reduce threatening appraisals. The role of nurses in supporting these psychological factors also warrants further exploration.

NEDERLANDSE SAMENVATTING

Een dwarslaesie is een neurologische aandoening die leidt tot gedeeltelijk of volledig verlies van motorische, sensorische en autonome functies, waardoor het dagelijks en sociale leven wordt beïnvloed. Mensen moeten zich aanpassen aan een nieuwe manier van leven, en hoewel veel mensen een positieve kwaliteit van leven (KvL) bereiken, ontwikkelen sommigen psychologische klachten zoals depressieve of angstige klachten. De Internationale Classificatie van Functioneren, Beperkingen en Gezondheid (ICF) biedt een kader om deze verschillen tussen mensen te begrijpen door beperkingen, activiteiten en participatie te koppelen aan persoonlijke en omgevingsfactoren die de uitkomsten beïnvloeden.

KvL weerspiegelt iemands algehele beleving en tevredenheid over het leven, inclusief fysieke gezondheid, mentaal welzijn en sociale ondersteuning. De Spinal Cord Injury Quality of Life-Basic Dataset (SCI QoL-BDS) is een korte vragenlijst, ontwikkeld om het meten van KvL te standaardiseren en internationale vergelijking van data te vergemakkelijken. Demografische, dwarslaesiegerelateerde en psychologische factoren (zoals veerkracht en zingeving) beïnvloeden iemands KvL en kunnen tijdens de revalidatie worden gestimuleerd om aanpassing aan de nieuwe situatie te ondersteunen.

Het doel van revalidatie is het creëren van een omgeving die optimaal herstel ondersteunt, door aandacht te besteden aan de gezondheidstoestand, lichaamsfuncties, activiteiten, participatie en persoonlijke en omgevingsfactoren. Binnen het revalidatieteam heeft ieder een eigen expertise, waarbij ieder indirect meewerkt aan het verbeteren van KvL. Interventies die zelfstandigheid, zelfzorg en sociale participatie bevorderen, versterken het gevoel van autonomie en ondersteunen zo indirect de KvL.

Hoofdstuk 1 biedt een overzicht van de context van dit proefschrift, inclusief de gevolgen van de dwarslaesie, de impact op de KvL, het gebruik van het meetinstrument SCI QoL-BDS om KvL te meten, en de rol van psychologische factoren bij het omgaan met de gevolgen van de dwarslaesie.

Deel 1: Meten wat telt: kwaliteit van leven na een dwarslaesie

Hoofdstuk 2 beschrijft een internationale mixed-methods studie uitgevoerd op vijf locaties in vier landen (Verenigde Staten, Australië, Brazilië en Nederland). Aan de cognitieve interviews namen 51 personen met een dwarslaesie deel, waarin werd onderzocht of het concept van KvL en de drie vragen van de SCI

QoL-BDS (leven als geheel, fysieke gezondheid, psychologische gezondheid) in verschillende culturen op dezelfde manier werden begrepen. Ondanks enkele contextuele verschillen beschreven de deelnemers KvL grotendeels hetzelfde. Deze grote overeenstemming in de definitie van KvL en de interpretatie van de items van de SCI QoL-BDS wijst op een sterke conceptuele en item-equivalentie.

Hoofdstuk 3 verdiept het begrip van het sociale domein van KvL door een deel van de interviewgegevens uit Hoofdstuk 2 opnieuw te analyseren met de ICF-classificatie. We onderzochten welke aspecten van het sociale leven het belangrijkste zijn voor KvL en koppelden tekstfragmenten aan ICF-categorieën over gemeenschaps-, sociaal en maatschappelijk leven (ICF hoofdstukken d6–d9). Sociaal leven bleek een centrale component van KvL, waarbij familiebanden, intieme relaties en deelname aan recreatie en vrije tijd vaak als essentieel werden genoemd. Ook bij vragen over fysieke en psychologische gezondheid kwamen sociale thema's terug, wat de verwevenheid van sociale aspecten met alle andere aspecten van het leven laat zien. Andere belangrijke onderwerpen waren formele sociale rollen, financiële onafhankelijkheid en zinvolle deelname aan de gemeenschap. Deze resultaten bevestigden het belang van het sociale leven voor de evaluatie van KvL en ondersteunden de uitbreiding van de SCI QoL-BDS van de 3-item versie, met vragen over het leven als geheel, fysieke gezondheid en psychologisch welzijn, naar een 4-item versie waarin tevredenheid met het sociale en maatschappelijke leven is toegevoegd.

Deel 1 van deze thesis laat zien dat de SCI QoL-BDS cross-cultureel valide is en conceptueel verrijkt wordt door het toevoegen van een item over het sociaal leven, waardoor beter wordt weergegeven wat belangrijk is voor KvL. Dit versterkt de bruikbaarheid voor internationaal onderzoek en de klinische praktijk.

Deel 2: Het psychologisch perspectief: psychologische factoren in KvL

Hoofdstuk 4 beschrijft een update van een eerdere systematische review over de relatie tussen psychologische factoren en KvL bij mensen met een dwarslaesie. In totaal zijn 66 studies gevonden, gepubliceerd tussen 2010 en 2023, die de samenhang tussen psychologische factoren en KvL na een dwarslaesie hebben onderzocht. Sinds de eerdere review in 2010 is het bewijs sterker geworden voor consistente associaties voor persoonlijkheidskenmerken, veerkracht en wie je verantwoordelijk houdt voor het ontstaan van de dwarslaesie (*attribution of blame*). Ook werden duidelijke associaties gevonden voor het ervaren van

controle over je situatie (*locus of control*), het gevoel van verbondenheid (*sense of coherence*), positieve emoties, hoop, zingeving, zelfwaardering, emotiegerichte coping en cognitieve beoordelingen over je situatie (*appraisals*). Voor negatieve emoties, spiritualiteit, andere copingstijlen en posttraumatische groei blijft het bewijs beperkt. De review benadrukt de noodzaak van meer longitudinaal onderzoek, heldere terminologie en betere rapportage van onderzoek.

Hoofdstuk 5 beschrijft een longitudinale cohortstudie van 266 personen met een recente dwarslaesie, die gevolgd zijn in de tijd vanaf opname in het revalidatiecentrum tot vier jaar na ontslag. Bij opname in het revalidatiecentrum werden diverse psychologische factoren gemeten, terwijl KvL op meerdere momenten tijdens de opname en na ontslag werd gemeten. De resultaten laten zien dat de KvL geleidelijk toenam, met de grootste verbeteringen in de eerste vier weken van de revalidatie en tussen één en vier jaar na ontslag. Met longitudinale multilevelanalyse zijn de belangrijkste voorspellers voor het verloop van KvL onderzocht: jongere leeftijd, Nederlandse nationaliteit, hoger opleidingsniveau, meer vertrouwen hebben bij het omgaan met de gevolgen van de dwarslaesie (*disability-management self-efficacy*) en minder bedreiging ervaren door de dwarslaesie (*threatening appraisals*), waren geassocieerd met een positiever verloop van KvL. Het versterken van het vertrouwen bij het omgaan met de gevolgen van de dwarslaesie en het verminderen van de ervaren bedreiging door de dwarslaesie tijdens opname in de revalidatie kan de aanpassing aan de dwarslaesie ondersteunen en de kwaliteit van leven op lange termijn bevorderen.

Deel 2 laat zien dat psychologische factoren, het vertrouwen bij het omgaan met de gevolgen van de dwarslaesie en het verminderen van de ervaren bedreiging door de dwarslaesie, een belangrijke rol spelen in de KvL na een dwarslaesie. Vroege signalering en aandacht voor deze factoren tijdens de revalidatie kunnen helpen bij betere aanpassing en het bevorderen van kwaliteit van leven op de lange termijn.

In **Hoofdstuk 6** hebben we de belangrijkste bevindingen van dit proefschrift beschreven. We zijn dieper ingegaan op het vierde item dat aan de SCI QoL-BDS werd toegevoegd, waarbij zowel het internationale als nationale gebruik en de interne consistentie van de vragenlijst werden onderzocht. Daarnaast reflecteerden we op het kwalitatieve ontwerp van de studie, de generaliseerbaarheid van de bevindingen en het ontbreken van 'spirituele verbondenheid' in de

resultaten van Deel 1. Voor het tweede deel van het proefschrift bespraken we de keuze van de meetinstrumenten en de mogelijke invloed van het revalidatieproces op de toename van de KvL in de eerste maand. Ook bespraken we de interactie tussen fysieke en psychologische processen, waarbij we benadrukten dat aandacht voor beide cruciaal is voor succesvolle revalidatie.

Een belangrijk aandachtspunt in dit hoofdstuk zijn de klinische implicaties voor het multidisciplinaire team. Het toevoegen van het vierde item van de SCI QoL-BDS aan de psychologische screening bij de start van de revalidatie helpt psychosociale behoeften vroegtijdig te signaleren, zodat interventies vanaf het begin kunnen worden ingezet. Ieder teamlid speelt hierin een rol door vertrouwen te bevorderen en iemand te motiveren, wat de zelf-effectiviteit versterkt, bedreigende cognities vermindert en mensen helpt omgaan met de uitdagingen van een dwarslaesie. Verpleegkundigen spelen een belangrijke rol door hun dagelijkse interacties met personen en hun sociale netwerk, wat vaak inzicht geeft in iemands persoonlijke en contextuele factoren. Hierdoor kunnen zij psychosociale uitdagingen signaleren en fungeren als een belangrijke schakel binnen het team.

Er is behoefte aan verder onderzoek naar de cross-culturele equivalentie van de toegevoegde vierde vraag over sociaal en maatschappelijk leven in de SCI QoL-BDS. Daarnaast zijn longitudinale studies nodig om de trajecten van KvL beter te begrijpen, de invloed van revalidatie te onderzoeken en interventies te evalueren die het vertrouwen in het omgaan met de gevolgen van de dwarslaesie vergroten en bedreigende cognities verminderen. Ook de rol van verpleegkundigen bij het ondersteunen van deze psychologische factoren verdient nadere verkenning.

DANKWOORD
ABOUT THE AUTHOR
LIST OF PUBLICATIONS

Dankwoord

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promotietraject, maar in het vinden van vreugde in God zelf. Daarbij mogen we genieten van de gaven die Hij geeft, zoals betekenisvol werk, goede relaties en wijsheid. Die vreugde in God hield mij gefocust op wat werkelijk waardevol is en maakte dat ik het onderzoek meestal met plezier en dankbaarheid kon doorlopen.

About the author

Aline Hakbijn-van der Wind was born on July 14, 1989, in Montfoort. After completing her VMBO diploma, she pursued nursing studies at Hoornbeeck College in Amersfoort. During her final internship, she developed an interest in the rehabilitation of individuals with spinal cord injury. In 2009, she commenced her clinical career as a nurse on the spinal cord injury/orthopedics ward at Revalidatiecentrum De Hoogstraat. While initially considering a broader professional trajectory, she chose to remain on this ward, as both the patients and the team had captured her heart.

In 2015, she enrolled in the accelerated Bachelor of Nursing program, where she was introduced to clinical research through the Topclass program. She subsequently completed a Master's degree in Nursing Science and obtained an adjunct position at the Utrecht Centre for Rehabilitation Medicine (KCRU), where her research focused on quality of life in individuals with spinal cord injury. In 2022, this project evolved into a PhD trajectory. Currently, Aline remains professionally active both as a researcher at KCRU and as a clinical nurse on the spinal cord injury ward.

Aline is married to Job, and together they have two children: Ruben (2020) and Marith (2023).

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