Aus der Schweizer Paraplegiker Forschung, Nottwil Direktor: Prof. Dr. med. Gerold Stucki

Understanding the associations of social skills and social support with mental health, participation and quality of life in persons with spinal cord injury

> Dissertation zum Erwerb des Doktorgrades der Humanbiologie an der Medizinischen Fakultät der Ludwig-Maximilians-Universität zu München

> > vorgelegt von Rachel Müller aus Colmar, Frankreich 2013

Mit Genehmigung der Medizinischen Fakultät der Universität München

Berichterstatter:	Prof. Dr. rer. biol. hum. Alarcos Cieza, MPH
Mitberichterstatter:	Prof. Dr. Stefan Zausinger
	Priv. Doz. Dr. Oliver Pogarell
Mitbetreuung durch den promovierten Mitarbeiter:	Dr. rer. biol hum. Szilvia Geyh, MPH
Dekan:	Prof. Dr. med. Dr. h.c. Maximilian Reiser, FACR, FRCR
Tag der mündlichen Prüfung:	8.2.2013

Acknowledgements

I would like to thank Dr. Szilvia Geyh for the learning experiences throughout all the years. Special thanks go to Professor Alarcos Cieza for her support in giving feedback and advice for the development of this work. I also thank Claudio Peter for being very supportive while sitting in the same boat. I am very grateful for the opportunity to write this thesis at the Swiss Paraplegic Research (SPF). In this sense, I would like to thank Professor Gerold Stucki and Mirjam Brach for enabling me to conduct the studies included in this thesis.

My special thanks go to the patient who participated in the case report. To accompany him was a meaningful and impressive experience. But I would also like to thank his physiotherapist, occupational therapist, his nurse and social worker who provided helpful and comprehensive information to conduct this case report.

I would like to thank Eva Nick for her contribution in the data collection and management of the psychometric study. I specially would like to thank the study participants and the cooperating study centers Swiss Paraplegic Centre in Nottwil (Schweizer Paraplegiker-Zentrum in Nottwil), Paraplegic Centre of the Uniklinik Balgrist in Zurich (Paraplegikerzentrum Zürich der Uniklinik Balgrist) and the Swiss Paraplegic Centre in Basel (Schweizerisches Paraplegikerzentrum in Basel (REHAB Basel)).

Many thanks go to the study participants of the Swiss Spinal Cord Injury Study (SwiSCI), especially the ones who participated in the Health Behavior and Personal Factors Module (HB-PF Module). I like to thank the people working in the SwiSCI study center who helped with the collection of the data. Especially, I like to thank Carolina Ballert and Claudia Zanini who helped translating the questionnaires.

Last but most important, I would like to thank my own social support system. Thanks to my friends, but especially Romana for being my best friend and an important part in my sports coping strategy, Fabienne for sharing all her happiness with me and Nicole for being my backup at the SPF. Thank you Albert for being with me.

I owe all my thanks to my family, my mother and my father for their tremendous support, my brother David for being my soul mate, my sister Michelle for all her love, advice, fun and energy and my brother Philippe for his generosity, open-mindedness and calm.

Contents

I. Introduction	1
I.1. Spinal cord injury and its consequences	1
I.1.1. Depression and the challenges of measuring it in SCI	2
I.1.2. Participation in SCI	3
I.1.3. Quality of life in SCI	5
I.2. Factors associated with depression, participation and QoL in SCI	6
I.2.1. Social support	7
I.2.2. Social skills	9
I.2.3. Social skills, social support and their relation to depression, parti	cipation and QoL
in persons with SCI	10
I.3. Summary of the introduction	11
II. Objectives and aims of the present thesis	12
III. Psychometric study: Rasch analysis of the Hospital Anxiety and I	Depression
	•
Scale in SCI	13
Scale in SCI	13
Scale in SCI III.1. Specific aims III.2. Methods	13 13 13
Scale in SCI III.1. Specific aims III.2. Methods III.3. Results	13 13 13 13
Scale in SCI III.1. Specific aims III.2. Methods III.3. Results III.4. Discussion	13 13 13 13 18
Scale in SCI III.1. Specific aims. III.2. Methods III.3. Results III.4. Discussion. IV. Systematic literature review: The role of social support and social	13 13 13 13
Scale in SCI III.1. Specific aims. III.2. Methods III.3. Results. III.4. Discussion. IV. Systematic literature review: The role of social support and social persons with SCI.	
Scale in SCI III.1. Specific aims III.2. Methods III.3. Results III.4. Discussion IV. Systematic literature review: The role of social support and social persons with SCI IV.1. Specific aims	
Scale in SCI III.1. Specific aims. III.2. Methods III.3. Results. III.4. Discussion. IV. Systematic literature review: The role of social support and social persons with SCI. IV.1. Specific aims IV.2. Methods.	
Scale in SCI III.1. Specific aims III.2. Methods III.3. Results III.4. Discussion IV. Systematic literature review: The role of social support and social persons with SCI IV.1. Specific aims IV.2. Methods IV.3. Results	

V. Case study: Social support and functional independence in a person with SC	I -
the role of social skills	62
V.1. Specific aims	62
V.2. Methods	62
V.3. Results	63
V.4. Discussion	66
VI. Empirical study: Social skills: A resource for more social support and better	
mental health, participation and quality of life in persons with SCI?	75
VI.1. Specific aims	75
VI.2. Methods	75
VI.3. Results	82
VI.4. Discussion	84
VII. General discussion	94
VII.1. Clinical implications of this thesis	96
VII.2. Conclusions	98
VIII. Summary	99
IX. Zusammenfassung	107
X. References	116
XI. Appendix	138
Appendix 1: Illustration of the concept of social skills	138
Appendix 2: The Hospital Anxiety and Depression Scale (German Version)	140
Appendix 3: Eligibility criteria for the systematic literature review	141
Appendix 4: Social Skills Inventory (SSI) Framework, scale definitions and sample	
items ¹⁴⁸	145
Appendix 5: The Short Form Social Support Questionnaire (SSQ6)	146

I. Introduction

I. Introduction

I.1. Spinal cord injury and its consequences

Spinal cord injury (SCI) is a devastating life event resulting in physical disability and numerous secondary medical problems. Per year, 25 to 83 people per million inhabitants sustain an SCI in North America.¹ In Europe, the incidence rates range between 12.1 and 36 per million inhabitants a year.²⁻⁶ Although improvements in primary and critical care have led to an increased immediate survival, life-expectancies of persons with SCI are still lower than in the general population.⁷

SCI is an insult to the spinal cord resulting in a change, either temporary or permanent, in its normal motor, sensory, or autonomic function.⁸ Injuries to the spinal cord can be classified as either traumatic in cause (e.g., motor vehicle accidents, falls, violent incidences, sports-related) or non-traumatic (e.g., tumors, spinal stenosis, vascular).⁹ Tetraplegia is defined as an injury to the spinal cord in the cervical region, with associated loss of muscle strength in all four extremities. Injury in the spinal cord in the thoracic, lumbar, or sacral segments, including the cauda equina and conus medullaris is classified as paraplegia. A complete SCI is defined as an absence of sensory and motor functions in the lowest sacral segments. Preservation of sensory or motor function below the level of injury, including the lowest sacral segments is classified as incomplete SCI.¹⁰

Besides the loss of motor and sensory functions below the level of a spinal cord lesion, bladder, bowel and sexual dysfunctions are additional disabling impairments.¹¹ Persons with SCI may experience spasticity,¹² and chronic pain is highly prevalent (48% to 94%).^{13, 14} Secondary health conditions, such as pressure sores, urinary tract infections, pulmonary complications, or osteoporosis are frequently reported in persons with SCI.¹⁵⁻²⁰

Managing the consequences of SCI requires continuous psychological adjustment which has its impact on mental health. The risk of depressive and anxiety disorders,

posttraumatic stress disorders (PTSD), substance abuse and suicidal attempts is increased in persons with SCI compared to the general population.²¹⁻²³ Psychological morbidity in patients with SCI is associated with increased durations of hospital stay, less functional improvement in rehabilitation,²⁴ difficulties in adjustment²⁵ and increased mortality.²⁶

Successfully managing the consequences and adjustment to SCI is indicated by good mental health, high participation in social life and high quality of life (QoL). This thesis focuses on depression, participation and QoL of persons living with SCI and about how specific factors, namely social skills and social support, influence them.

I.1.1. Depression and the challenges of measuring it in SCI

Depression is the most common psychological disorder associated with SCI²⁷ and represents a central mental health outcome.^{28, 29} About one third of persons with SCI develop depressive disorders.^{28, 30} High levels of depression are observed in the acute phase following the injury and during first rehabilitation.²⁹ An estimated 30% of individuals still experience depression at two years after injury.³¹

Depressive mood is to be differentiated from a full-blown depressive syndrome, which is indicated by affective, cognitive and neuro-vegetative symptoms of sufficient frequency and severity to negatively impact functioning.³² Depression disorders are typically diagnosed using structured interviews, e.g. based on the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV)³². But also self-report instruments, such as the Center for Epidemiologic Studies Depression Scale (CES-D)³³, the Beck Depression Inventory (BDI-II)³⁴, the Patient Health Questionnaire depression module (PHQ-9)³⁵ or the Hospital Anxiety and Depression Scale (HADS)³⁶ are frequently used in clinical as well as research settings.

The HADS focuses on affective and cognitive rather than somatic aspects and is specifically developed to be used among patients with somatic complaints, in contrast to the psychiatric perspective of other assessment instruments. It can therefore be applied in health conditions, accompanied by problems similar to the symptoms of depression, such as loss of appetite, fatigue, or sleep disturbance, which are usually found among newly injured individuals with SCI. The HADS was found to be reliable and valid in assessing the symptom severity and caseness of anxiety disorder and depression in somatic, psychiatric, primary care and general populations.^{37, 38} It is frequently used in SCI³⁹⁻⁴² and demonstrated good internal consistency, with promising construct validity.⁴³ However, the psychometric evaluation of the HADS so far has not yet focused on the question, if the HADS scores are suitable to "map" the whole range of anxiety and depression in a population with SCI, or if there are problems with floor and ceiling effects, whether the response categories are functioning properly and whether there is item bias among subgroups of respondents. This thesis addresses the question if the HADS is a valid and reliable instrument to be applied in persons with SCI to measure their level of anxiety and depression.

I.1.2. Participation in SCI

Persons with SCI encounter various activity limitations and participation restrictions. Participation is defined as involvement in a life situation and participation restrictions are problems an individual may experience while involved in life situations.⁴⁴ The typical spectrum of activity limitations and participation restrictions relate to mobility such as transfers and locomotion,⁴⁵⁻⁴⁸ self-care activities such as bathing, dressing, and toileting,^{49, ⁵⁰ difficulties in regaining work, maintaining social relationships, participating in leisure activities and being active members of the community.^{51, 52}}

Rehabilitation treatment is aimed at improvement of functional independence and, ultimately, social participation.⁵³ However, measuring participation is challenging since there are many factors that contribute to a person's level of participation. Some measures assess objective participation (i.e. outsider perspective such as return to work). The Craig Handicap Assessment & Reporting Technique (CHART),⁵⁴ as an example, is useful for research purposes to describe from a societal perspective, how individuals with SCI differ from other health conditions and the general population. However, objective measures do not include the individual's perspective and subjective information about how the person performs the tasks as well as what tasks are important to them is not assessed.⁵⁵ Four measures of participation used in SCI capture both objective and subjective participation. The Assessment of Life Habits Questionnaire (LIFE-H)⁵⁶ rates accomplishment and satisfaction with daily activities and social roles, however, its responsiveness has not been established.^{57, 58} The Participation Survey / Mobility (PARTS/M) provides measurement of performance, perceived limitations and satisfaction, but only covers the mobility domain.⁵⁹ The Participation Measure for Post-Acute Care (PM-PAC) includes questions on performance and satisfaction, but satisfaction is only asked regarding interpersonal relationships.⁶⁰ The Participation Objective Participation Subjective (POPS) provides scores on frequency of participation and satisfaction (i.e. desire to change current level of participation).⁶¹ Finally, the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation)⁶² consists of three separate scales: Frequency, Restrictions and Satisfaction of participation. The Frequency scale includes questions about vocational activities (e.g. number of hours at paid work), leisure and social activities (e.g. going out). The Restriction scale measures experienced participation restrictions in vocational, leisure and social activities as a result of the person's health or disability and the Satisfaction scale consists of questions about satisfaction with vocational, leisure and social relationships. The USER-Participation was found to be a valid and reliable measure for

objective and subjective participation in persons with a disability⁶²⁻⁶⁴ and is therefore used in this thesis to measure participation in persons with SCI.

I.1.3. Quality of life in SCI

SCI impacts QoL. The concept of QoL in rehabilitation research primarily came along with the emphasis on patient-centeredness, as the patient was considered to be the one who can best report on what is important in his or her life.⁶⁵ Measuring QoL of individuals with certain health conditions should provide information about health states beyond diagnosis, about the impact of a disease or disability, its treatment on different domains of daily life, and about the health experience from the insider perspective of the affected persons themselves.⁶⁶

QoL is a multidimensional concept and therefore difficult to define. WHO defines QoL as individuals perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.⁶⁷ Three main conceptualizations of QoL are well-accepted in the literature: (1) the subjective approach, whose focus is set on the person's emotional or cognitive assessment of the congruence between life expectations and achievements (i.e. life satisfaction or subjective well-being), (2) the objective approach, based on a person's characteristics that can also be objectively measured by an external appraiser or outsider (i.e. health-related QoL)^{68, 69} and (3) a subordinate construct of QoL that includes both health-related QoL and well-being.⁷⁰

Examples of most frequently used subjective measures of QoL are the Satisfaction with Life Scale (SWLS)⁷¹ and the Life Satisfaction Questionnaire (LISAT-9).⁷² The SWLS assesses very broad global life satisfaction by addressing the cognitive evaluation of one's own life in terms of ideal life, wish for change, and current and past satisfaction. In

I. Introduction

contrast, the LISAT-9 measures domain-specific life satisfaction in general life, self-care, vocational, financial, leisure situation, sexual life, partner relationship, family life and social contacts. However, it lacks of psychometric information relative to the field of SCI.⁷³

The objective approach, including health-related QoL, focuses mostly on physical and mental health, social and role achievements, and thus is more oriented toward functional performance than is subjective QoL.⁷⁴ An example of a health-related QoL measure is the World Health Organization's short health related quality of life measure, the WHOQOL-BREF.^{75, 76} It conceptually fits the WHO definition of QoL by covering overall QoL, satisfaction with health, daily activities, relationships, and living conditions. Five items of the WHOQOL-BREF were found to be valid in measuring QoL in samples with persons with SCI.⁷⁷ Therefore, in this thesis the 5 items of the WHOQOL-BREF are used to measure QoL in persons with SCI.

I.2. Factors associated with depression, participation and QoL in SCI

Several factors are found to place individuals with SCI at risk for the development of depression, having more restrictions in participation and lower levels of QoL.

Low levels of education and unemployment, ^{78, 79} the presence of pain,^{80, 81} low selfefficacy, inadequate coping abilities ^{78, 82} or having fewer pleasant rewarding activities⁷⁸ are predictors of greater depression severity after SCI.

Participation seems to be independent of level or completeness of the injury, however, the functional status, time since discharge from rehabilitation, neuroticism, self-efficacy and self-esteem explain a substantial amount of variance in participation. ^{83, 84} In addition, environmental factors, i.e. barriers or a lack of facilitators in daily life, can lead to participation restrictions in persons with SCI.⁸⁵⁻⁹⁵ For instance, many disabled persons

I. Introduction

encounter barriers in their mobility due to lack of adapted equipment, transportation or obstacles in the built environment.⁹⁶

QoL has been found to be diminished following SCI compared to the general population.^{97, 98} In specific, considerable decreases in QoL in the immediate phase after the diagnosis of SCI have been found.⁹⁹ However, several studies reported a stable course of QoL in relation with time since injury, indicating that QoL improved during inpatient rehabilitation and remained stable during the first years after discharge.¹⁰⁰⁻¹⁰³ Physical factors associated with QoL are level of pain, secondary impairments and functional independence.^{102, 104} Mental health, positive and negative affect, post-traumatic cognitions, self-efficacy, locus of control, sense of coherence, self-worth, hope, purpose in life are psychological determinants of QoL.^{102, 105} Additionally, social factors, such as support, marital status, and level of participation contribute to QoL in persons with SCI.^{102, 105}, 105

However, there are also factors that could positively influence depression, participation and QoL, such as resources and strengths of a person. Social support and social skills are examples of such resources and strengths.

I.2.1. Social support

Social support is known to positively influence physical and mental health,^{107, 108} social integration,¹⁰⁹ QoL,^{110, 111} and even mortality.^{112, 113} in the general population.

Social support is defined as an exchange of resources between individuals intended to enhance the well-being of the recipient.¹¹⁴ It acts as a buffer to protect people against negative effects of stressors.¹¹⁰ This thesis does not include social support that is paid (e.g. from health professionals or social worker).

The beneficial effect of social support can be explained by different underlying mechanisms (i.e. evolutionary, behavioral, physiological and psychological). Living in social groups has enabled humans to avoid the ill effects of physical limitations.¹¹⁵ Through collective activities such as gathering, hunting and defense human beings have survived and thrived.¹¹⁶ Social support is health-promoting as it facilitates healthier behaviors such as exercise, eating right, or not smoking; as well as greater adherence to medical regimens.¹¹⁷⁻¹¹⁹ From a physiological perspective, social support positively impacts cardiovascular, neuroendocrine, immune and inflammation functions.¹⁰⁷ In addition, social support conveys the information of being loved, cared for, esteemed, valued and bestows a sense of belonging which leads to higher self-efficacy, self-esteem, lower distress and higher well-being.^{120, 121}

Different perspectives of social support can be considered. From a functional perspective, social support can be instrumental (e.g. tangible assistance), emotional (e.g. exchange with a close friend), or informational (e.g. advice from a peer). Social support can be described from a quantitative (e.g. network size) or qualitative (e.g. satisfaction with support) perspective. ¹²²⁻¹²⁵ Also the source of social support (i.e. partner, family, friends, peers) can be taken into account, as well as the distinction between perceived (i.e. perception that support would be available if needed), received support (i.e. exchange of support resources)^{126, 127} and providing and receiving social support.¹²⁸

In SCI, sociodemographic and lesion-related characteristics seems to be unrelated to the amount of perceived social support.¹²⁹ However, types of social support from different sources seem to have different impacts on mental health, participation and QoL. For example, quality of social support is associated with lower depression,¹³⁰ the availability of peer support is linked to higher levels of participation¹²⁹ and emotional support from the family was related to greater QoL.¹³¹ However, a comprehensive understanding of the

relationship between social support and depression, participation and QoL is missing in the field of SCI.

I.2.2. Social skills

Social skills, according to evolutionary theory, are prerequisites for survival and adaptation.¹³² Depression,¹³³⁻¹³⁶ social phobia,¹³⁷ substance or alcohol abuse,¹³⁸ low adherence in rehabilitation,¹³⁹ social isolation¹⁴⁰ and low QoL¹⁴¹ correlate with social skills deficits.

A blurry cloud exists around the conceptualization of social skills. A possible illustration of the different conceptualisations of social skills is provided in appendix 1. Social skills can be defined as being simple behavioural or cognitive "tools" or "topography"¹⁴² of social interactions (e.g. interpersonal skills, communication skills or social cognition¹⁴³). The more evaluative judgement of social skills refers to social competence, social intelligence¹⁴⁴ or emotional intelligence¹⁴⁵ (i.e. ability to identify, assess and manage emotions of one self and others). All the existing definitions of social skills have one thing in common, namely the satisfaction of personal needs and achievement of goals without "harming" any other person. Social skills are therefore the ability to interact with other people in a way that is both appropriate and effective.¹⁴⁶

Social skills comprise aspects of verbal and non-verbal communication and they include, for example, styles of social problem-solving (e.g. rational, impulsive, or avoidant), assertiveness, goal-direction, or self-monitoring.¹⁴⁷ In addition, emotional as well as relationship aspects of social skills can be described. This includes skills in encoding (i.e. expressivity) and decoding (i.e. sensitivity) of information in social situations and the regulation of emotion and control of social situations in a non-verbal (i.e. emotional) and verbal (i.e. social) way.¹⁴⁸

Social skills are important for people with disabilities. They help to overcome discomfort and stigmatization, to be assertive in social situations, to ask for help, to solve social problems, to elicit feedback, and to develop and foster social relationships.^{149, 150} In SCI, social skills seem to be related to education and the level of injury.¹⁵¹⁻¹⁵⁴ Social skills, such as social problem-solving and assertiveness are associated with depression. Person with SCI and high levels of self-monitoring show higher levels of participation¹⁵⁵ and verbal communication is related to QoL.¹⁵⁶ However, a complete overview on how social skills impact the receipt of social support, depression, participation and QoL in persons with SCI is lacking.

I.2.3. Social skills, social support and their relation to depression, participation and QoL in persons with SCI

Research findings in the general population indicate that social support and social skills are related to depression, participation and QoL. However, there is no clear understanding of the potential relevance of social support and social skills and their interrelation in persons living with SCI. It is also unclear, how social support and social skills and social skills influence depression, participation and QoL in SCI. Understanding social skills and social support and their impact on depression, participation and QoL could provide information about what to target in interventions to counteract the negative consequences of SCI and enhance mental health, the level of participation and QoL of persons living with SCI.

Therefore, to clarify these issues mentioned above, the thesis includes: the performance of a systematic literature review to learn about the importance of social support and social skills in SCI and to generate hypothesis about the pathways between social support, social skills, depression, participation and QoL; a case study to

complement the literature review to generate hypothesis about the pathways between social support, social skills, depression, participation and QoL; an empirical study to test the hypothesis generated based on the literature review and the case study.

I.3. Summary of the introduction

This thesis is about understanding how social skills and social support influence depression, participation and QoL in persons with SCI.

While there are valid and reliable measurement instruments to assess participation and QoL in persons with SCI, there is still one open question regarding assessment of depression, namely if the HADS is applicable to persons with SCI.

There are different factors that may influence depression, participation and QoL. Research in general population shed light on the relevance of social support and social skills. However it is unclear how relevant they are in SCI and how they influence depression, participation and QoL.

II. Objectives and aims of the present thesis

The objective of this thesis is to understand how social skills and social support interrelate and how they are associated with depression, participation and QoL in persons living with SCI.

The following specific aims are addressed:

- a) To evaluate the psychometric properties of the Hospital Anxiety and Depression Scale (HADS) applied in a SCI population using Rasch analysis.
- b) To examine the current knowledge from the scientific literature of how social support and social skills are relevant in SCI and to obtain first hints and generate hypotheses about the association of these factors with depression, participation and QoL of persons living with SCI.
- c) To complement the literature review (b) regarding the generation of hypotheses about the influencing pathways of social skills and social support on participation by using data of a case study.
- d) To test the following hypotheses generated in b) and c) using empirical data:
 - 1) Higher levels of social skills relate to higher levels of social support.
 - Higher levels of the social skills dimensions expressivity, sensitivity and control are related to higher levels of social support.
 - The relationship between social skills and depression, participation and QoL is mediated by social support.
 - Social support shows a direct positive effect on depression, participation and QoL.

This thesis is divided in four parts, each of which addresses one of the specific aims.

III. *Psychometric study*: Rasch analysis of the Hospital Anxiety and Depression Scale in SCI

III.1. Specific aims

The aim of the first study is to answer the question, if the Hospital Anxiety and Depression Scale (HADS) can be applied in persons with SCI to measure their level of anxiety and depression. Using Rasch analysis the questions are answered a) if the anxiety, and the depression subscales measure a unidimensional construct, and if the combination of the two subscales form a HADS total score to measure psychological distress, b) if the measurements are reliable, c) if the response options differentiate adequately between levels of anxiety and depression, d) if the HADS scores can represent the full spectrum of symptom severity in anxiety and depression in SCI, and e) are comparable across age groups, gender, level of lesion, education and relationship status.

III.2. Methods

Study Design, Participants and Procedure

The Rasch analysis of the HADS was conducted using data from a cross-sectional multi-center study including persons with SCI living in the community, recruited through three major SCI rehabilitation centers in Switzerland (Paraplegic Centre, University Clinic Balgrist, Zurich; Swiss Paraplegic Centre, REHAB Basel; Swiss Paraplegic Centre (SPZ), Nottwil)¹⁵⁷. The design and materials of the study were approved by the ethical committees of the cantons Lucerne, Basle, and Zurich.

Persons were eligible for participation if they have sustained a spinal cord lesion according to the ASIA Impairment Scale¹⁰ due to injury, iatrogenic or comiogenic causes

(e.g. surgical procedures, radiation, or medical complication), or due to acute nonprogressive diseases (e.g. infection, bleeding, ischemic event), irrespective of level and completeness of injury. Included were German-speaking persons, 18 years and older, who have been living in the community for at least 6 to 30 months at the beginning of the data collections. The person had to provide a signed informed consent form. Persons were excluded if they had a progressive neurological disorder, a neoplasm of the spine, or a concurrent neurological condition that affected mental functions, e.g. traumatic brain injury, cerebral ischemia or intracerebral haemorrhage.

The data were collected by a self-report questionnaire sent to the eligible participants by postal mail. For the current analyses, sociodemographic information including age, gender, level of injury, education, relationship status, and the responses to the HADS were used.

Hospital Anxiety and Depression Scale

The HADS³⁶ is a self-report questionnaire comprising 14 items which can be summed to provide a total score (HADS-T) as well as two subscales with 7 items each, assessing anxiety (HADS-A) and depression (HADS-D). Patients are asked to rate how they felt during the past week. Responses are given on a 0 to 3 Likert scale. Higher scores indicate more distress. Scores between 8 and 10 are considered as mild cases, 11-15 moderate cases, and 16 or above severe cases.³⁶ In the present study the German Version of the HADS was used,^{158, 159} which is provided in appendix 2.

Rasch analyses

The psychometric properties of a questionnaire can be examined using techniques of classical test theory, but currently also Rasch analysis has been increasingly used in rehabilitation research.¹⁶⁰⁻¹⁶² Rasch analysis can transform ordinal scale observations into

interval scale measurement, which is the prerequisite for additivity of scores, and for meaningful change measurement in relation to interventions.¹⁶³ Rasch analyses provides refined information on validity, for example examining unidimensionality of the measured construct and the fit of the items of the questionnaire by using a reference that is external to the data. This reference is the Rasch model itself, which in its mathematical formulation holds the requirements for fundamental measurement.^{164, 165} Rasch analysis also enables the evaluation of response scale validity within a probabilistic framework. By yielding sample- and test- independent estimates of person and item parameters placed on the same continuum, Rasch analysis makes possible a direct appraisal of test targeting, and provides an index of reliability that is independent of sample distribution.¹⁶⁶

Data analyses

Descriptive statistics are reported about the recruitment of participants, sociodemographic and lesion-related variables. Continuous variables were checked for normal distribution (Kolmogorov-Smirnoff-test, alpha=0.01). Mean and standard deviation for normally distributed data, otherwise median and interquartile range are shown.

Rasch analyses were carried out using the RUMM software.¹⁶⁷ The partial credit Rasch model¹⁶⁸ was applied as for all items in the HADS different response choices are presented to the respondent, instead of items where the rating scales are all the same (i.e. rating scale model). Applying this type of Rasch analysis, three parameters are estimated: The person parameters (for the participants), the item parameters, and the parameters of the thresholds of the response scale (e.g. three threshold parameters for a 4-point Likert-scale). These parameters describe the position of the persons, items and thresholds on the continuum of the measured latent variable (e.g. low to high depression).

First, the dimensionality of each subscale and the total scale was examined. Unidimensionality describes the idea that items should contribute to the measurement of

only one attribute at a time and should not be confounded by other attributes or dimensions.¹⁶⁵ This ensures the interpretability of the summary scores of the instrument. Unidimensionality can be checked for by comparing the observed responses in a set of items to the expected values predicted by the unidimensional Rasch model.¹⁶⁶ The fit of each item is indicated by standardized residuals (z values) and Chi2 test results. Z values exceeding +/-2.5 indicate misfit to the Rasch model. Item misfit was resolved by stepwise removal of the most misfitting items. The remaining fitting items were checked again for overall fit statistics and response scale disorder. To further examine dimensionality, principal components analyses (PCA) of the residuals not explained by the Rasch-model were performed. The residuals should show a random pattern to indicate unidimensionality.¹⁶⁹ Eigenvalues below 1.9 in the PCA results are indicative of random residual variation, eigenvalues above 1.9 indicate some structure in the residuals.¹⁷⁰ In addition, the Rasch person parameters of each patient were estimated separately for the items with positive versus negative loadings on the first PCA factor, and then compared using independent t-tests. Where less than 5% of the t-tests (a = 0.05) are significant would be indicative of a unidimensional scale.^{171, 172}

The structure of the response scale was studied based on the ordering of the threshold parameters. The category probability curve is used to illustrate the ordering, i.e. the relation between the probability to choose a given category as a function of the person's level of anxiety or depression. The threshold parameters should take increasing values, as they represent the successive transition points along the response scale from low to high anxiety or depression. Reversed thresholds show that the scores do not differentiate as intended.¹⁷³ This is the case if respondents would have difficulties in differentiating, for example, between "quite often" and "very often" as it is used in the 4-point Likert style response scale in the HADS.

Reliability is indicated by the person reliability index (PRI), which is the Rasch-based correspondent to Cronbach's alpha.^{168, 174} The PRI is constructed using the person parameter estimates and the standard errors of measurement to calculate the ratio of true person ability variance to the observed variance.^{166, 175} It addresses the question how reliably the HADS does distinguish among the test-takers. PRI ranges between 0 and 1, where the value of 1 indicates perfect comparability of persons scores on the level of anxiety and depression.

To ascertain how well the HADS is targeted (i.e. suitable to indicate various levels of anxiety and depression) in the population being assessed, the respective distribution of the person and item parameters along the latent variable continuum was examined. The distance between the mean person location and the mean item location (zero by definition) indicates targeting. On a well-targeted scale, the mean person location value indicates that the sample, as a whole, is located at a higher level of the latent variable than the average for the scale and vice versa. Poorly targeted measures often result in floor and ceiling effects. The percentage of persons with measures above the level of the highest and below the level of the lowest thresholds are calculated for the total scale and both subscales to evaluate ceiling and floor effects.¹⁶⁵

To investigate whether the items have different meanings for different groups, differential item functioning (DIF) analyses were conducted.¹⁷⁶ DIF occurs when items do not operate in the same way for different groups (e.g. tetraplegic and paraplegic, men and women) who otherwise have the same value on the latent variable. This means that the items do not work in the same way when answered either by a para- or tetraplegic person, and a man or a woman and their results would not be comparable. To address DIF, analysis of variance (ANOVA) of the residuals is conducted for each item comparing scores across each level of the person factor and across different levels of the latent

variable (referred to as class intervals). The literature shows high female to male ratio in the prevalence of depression¹⁷⁷ and anxiety,¹⁷⁸ different loadings on the depression and anxiety factor in psychometric analysis of the HADS by level of injury,⁴³ higher levels of depression in people living alone¹⁷⁹ and an association between lower level of education and higher risk for depression and anxiety.¹⁸⁰ Studies conflict on the prevalence of depression and anxiety in relation to age, some data suggest there is a reduction in older age group,¹⁸¹ others show a positive linear age dependency.¹⁸² Therefore, in this study, we examined the person factors age (older vs. younger than the median=52 years), gender (female vs. male), relationship status (single vs. in a relationship), level of lesion (paraplegic vs. tetraplegic) and education (more vs. less than median=13 years of education) to account for their potential effect. The criteria of 25% of the whole sample was set to address sample size in DIF analysis. Uniform DIF is indicated by a significant main effect for the person factor, while the presence of non-uniform DIF is indicated by a significant interaction effect (person factor x class interval). A respective Bonferroni corrected type I error level (p=0.01) was applied correcting for the multiple significance tests conducted.¹⁸³

III.3. Results

In the three rehabilitation centers, the records of 557 persons with SCI were screened for eligibility, 394 eligible persons were invited to participate in the study (Figure 1) and 100 responded to the HADS (response rate: 25.4%). Two persons did not fill in the questionnaire completely, leading to a deletion of two cases. Comparing the study participants (n=102) with the eligible non-responders (n=294) shows that among the non-responders were significantly more women, and that time since onset and time since discharge were 4 months longer for the non-responders than for the study participants

(Table 1). Sociodemographic and injury related characteristics of the study sample show that 25.5% were female, 61.8% were paraplegic, mean age was 56.5 years and 63.7% indicated having a relationship. No differences between responder and non-responder were found in these variables. In the anxiety subscale 25% and in the depression subscale 31% scored higher than the cut off 8, representing mild to severe cases (Table 2).

Anxiety subscale

Table 3 shows the Rasch-based statistics for the anxiety subscale. According to Chi^2 , p- and z-value of the items, the anxiety subscale overall and the 7 items each fitted the model. PCA eigenvalue is just at 1.9 and the series of t-tests performed on the person estimates from two subsets of items identified from PCA of the residuals revealed acceptable 5% statistically significance. The PRI of the anxiety subscale showed an value of 0.72. The response scale structure was examined by checking the sequence of the estimated threshold parameters for each item. For the anxiety subscale the response scales showed no disordering according to their thresholds. The average mean person location in the person-item distribution of -1.41 (SD=1.27) suggests that the sample on average ranged below the HADS-A average. With 11% of the persons located below the lowest threshold, a small floor-effect is apparent. The possibility of group differences according to age, gender, level of lesion, education and relationship status was explored by testing for DIF with a Bonferroni-adjusted p-value of 0.01 (total scale: 0.01/14=0.00071 subscales: 0.01/7=0.00143). None of the items of the anxiety subscale showed probability values exceeding the adjusted value. No uniform or non-uniform DIF was apparent. However, it is noteworthy that item Anx7 ("I can sit at ease and feel relaxed") in the anxiety subscale almost reached the probability level for uniform DIF (p=0.00147) in education.

Depression subscale

For the depression subscale the Rasch-based statistics are reported in table 4. The depression subscale fitted the Rasch model, no misfitting items were found, PCA eigenvalue lie below 1.9 (PCA eigenvalue = 1.63), and the independent t-tests calculated from PCA showed 5% of cases which had statistically significant t-values. An adequate reliability index of 0.82 was found. The response scales of the depression subscales structure showed no disordering according to their thresholds. According to the personitem distribution of the depression subscale, the mean person location of -1.49 (SD=1.86) indicates that participants, on average, reported lower levels of depression than the average of the depression scale items. A small floor-effect is found with 4% of the sample located below the lowest threshold. No uniform or non-uniform DIF was evident, indicating that the item location parameters can be considered as invariant and unbiased with respect to the five dichotomous person factors.

HADS total score

The combination of the 14 items showed misfit to the Rasch model indicated by the significant overall Chi² test (Table 5). PCA eigenvalue lie above 1.9 (PCA eigenvalue = 2.49) showing some underlying structure in the residuals not explained by the Rasch model. According to the independent t-tests, 19.19% of the person estimates were significantly different. At the item level, item Dep10 ("I have lost interest in my appearance") demonstrated misfit to the model according to a probability level below p < 0.01 (p=0.004). An acceptable reliability index for the combination of the 14 items was found (r=0.86). The category probability curves showed disordered thresholds for item Dep12 ("I look forward with enjoyment to things"). A mean person location value of -1.35 (SD=1.36) was found and 5% of the sample were located below the lowest threshold,

indicating a minimal floor-effect. None of the items of the total scale showed probability values exceeding the adjusted value, indicating no uniform or non-uniform DIF.

Removing Item Dep10 resulted in misfit of item Anx11 ("I feel restless as I have to be on the move") (p=0.002). Both items Dep10 and Anx11 were removed from the data, which leaded to misfit of item Anx13 ("I get sudden feelings of panic") (p=0.002). Therefore, item Dep10, Anx11 and Anx13 were removed. The remaining items demonstrated fit to the model (Chi^2 =30.464; df=22; p=0.107) and a PRI index of 0.86. However, PCA of the residuals showed an eigenvalue above 1.9 (PCA eigenvalue = 2.11) and the independent t-tests showed that 10.10% of the person estimates were significantly different.

III.4. Discussion

This study examined the measurement properties of the HADS in an SCI sample. The results confirmed that the HADS is a valid instrument to measure anxiety and depression in persons with SCI. The items of the anxiety and depression subscales each contribute to one single underlying construct. The reliability coefficient of the depression subscale is acceptable, the one of the anxiety subscale marginal. For both subscales, no ceiling but small floor effects were found, the response scales worked as expected, and the items are comparable across different subgroups of persons with SCI.

The current findings support the assumption of unidimensionality for the two HADS subscales separately. All items in the anxiety and depression subscale have been proven to assess the same latent variable and no misfitting items were found. Rasch analyses in persons with stroke,¹⁸⁴ cancer,¹⁸⁵ and coronary heart disease¹⁸⁶ supported the unidimensionality of the constructs. However, the unidimensionality of the depression subscale was rejected in a study in Parkinson disease,¹⁸⁷ and motor neuron disease.¹⁸⁸

This illustrates that the same scales cannot be applied indiscriminately across different disease populations.

The reliability indices of the HADS are comparable to Cronbach's alpha values in other psychometric studies of the HADS (r=0.72).³⁷ The precision of measurement with the HADS is therefore adequate for self-report, screening and group comparison,¹⁸⁹ but for individual decision-making purposes higher levels of reliability are recommended.

The response scales of the anxiety and depression subscales showed no disordering. These results maintain that the response scales are working as expected, i.e. the categories of the response scale are mutually exclusive, univocal, exhaustive¹⁹⁰ and the scores do differentiate as intended. In principle, disordered thresholds might appear because of too wide or narrow response options.¹⁷³ In a Rasch framework, the problem of disordered thresholds could be solved by collapsing adjacent response categories. Reducing categories could simplify and improve the instrument,¹⁹¹ but can lead in turn to loss of information from the single items.¹⁷³ In contrast, a high number of response categories could decrease reliability and feasibility.¹⁹² One study focusing on the depression subscale suggests that a two category scoring scheme ('Yes' or 'No'), in comparison to the original four category version, had better item fit statistics.¹⁸⁴

The current analysis showed that the two subscales are well targeted to be used in an SCI population. Only minimal floor effects and no ceiling effects are found in the two subscales, which is also found in studies with persons with cancer and Parkinson disease.^{185, 187} The anxiety and depression subscales might not be sufficient to identify and separate persons with low levels of anxiety or depression. Rasch analyses can help to identify gaps along the latent variable where items could be added to improve measurement ability and differentiation. In this case, additional items might be required to cover low levels of anxiety and depression. However, it can be questioned if the HADS

should be the measure of choice if non-pathological aspects of well-being are to be assessed.

No DIF was found in these analyses which supports construct validity of the two subscales. The HADS is meant to detect differences in scores due to level of anxiety and depression and not due to differences in age, gender, level of lesion, education and relationship status. The measurement needs to work the same way for different subgroups. The current findings show, that the items were working in the same way when answered either by a man or a woman, older or younger, para- or tetraplegic, with longer or shorter education and living in a relationship or not. However, the item Anx7 ("I can sit at ease and feel relaxed") almost reached the level of uniform DIF, indicating that persons with higher levels of education tend to answer this item differently than people with lower education. In the literature, item Anx7 was consistently found to load relatively low on the anxiety factor and relatively high on the depression factor.^{37, 193, 194} It could have a potentially different meaning within the SCI population. Because of difficulties with mobility and posture, this item might result in awareness of losses in physical domains, resulting in a loading onto the depression factor rather than, or in addition to, anxiety.⁴³

Finally, Rasch analysis of the 14 HADS items combined demonstrated a lack of fit to the model expectations. Stepwise deletion of the misfitting items based on Chi2-tests did not produce an overall score that fulfilled the statistical criteria for unidimensionality. Therefore, our results conflict with the assumption of an overall distress score. Multidimensionality was evident and although anxiety and depression are related concepts, these results suggest they should remain separate constructs in the assessment. This finding is congruent with results based on Rasch analysis for example in musculoskeletal disease,¹⁹⁵ stroke,¹⁸⁴ coronary bypass patients¹⁸⁶ and caregivers of cancer survivors.¹⁹⁶ Analyses based on classical test theory approaches have shown contradictory findings concerning the factor structure and dimensionality of the HADS. According to a review of 19 studies reporting factor analysis, 11 (total N = 14,588) showed a two-factor structure, 5 studies (total N = 3459) a three-factor structure and 2 studies (total N = 235) a four-factor structure.³⁷ However, some studies found for the combination of the two subscale to form a total score a higher-order single factor structure corresponding to psychological distress with a common variance shared by both of the subscales.^{197, 198}

For the current study, a number of limitations need to be mentioned. First, the low response rate of the potential participants can be considered as a major limitation of the study and the representativity and the generalizability of the sample can be questioned. However, responders and non-responders could be compared using the documentation of the eligibility criteria. Thereby, age, level and completeness of injury did not differ, but non-responders were more frequently women and time since injury was longer.

Second, the sample consists of persons with an average age of 56 years. In general populations, for both dimensions of the HADS a nearly linear age dependency was found which was more pronounced for depression (r = 0.36) than for anxiety (r = 0.14).¹⁸² Rasch analysis of the HADS in a sample with lower average age might have revealed different results. However, the age distribution of persons with SCI living in Switzerland is unknown and the representativity of this sample with regard to age cannot be estimated.

Third, there are other variables, for example pain, in which DIF could be detected. In this case a person with high levels of pain could answer, for example, item Dep2 "I still enjoy the things I used to enjoy" according to the painful experiences and not due to dysphoria which could hold the person back to enjoy things. We decided to select as much of the sociodemographic variables for the DIF analysis as possible. However, only these sociodemographics and injury-related characteristics were assessed.

Finally, only persons who have been living in the community for at least 6 to 30 months were included in the study. Mean time since injury of the sample was 43.60

months. In the acute phase after the injury and during first rehabilitation high levels of anxiety and depression are found, but tend to decrease with time since injury.²⁸ Conducting Rasch analysis of the HADS with data from the first 6 months after injury might have shown different results.

Conclusions

An effective screening for psychological distress is important in SCI rehabilitation as well as research in rehabilitation psychology. Remittent dysphoria needs to be differentiated from cases of major depression, enabling health professionals to adjust individual interventions. The HADS is sensitive to assess symptom severity and caseness of anxiety and depression disorder in somatic, psychiatric, primary care and general populations.^{37, 38} While the HADS anxiety and depression subscales show sufficiently robust basic psychometric properties also in SCI, little is known about their sensitivity to change in this population. However, in SCI research there is an increasing need for longitudinal observational and intervention studies. Therefore, further research should focus on the sensitivity to change of anxiety and depression measures in the population of SCI, which could be a representative contribution to disability research in general.





	Participants	Non- responder	Comparison					
			Test	Test value	df	p		
Sociodemographic characteristics						<u> </u>		
Years of age			T-test	1.928	223.04	0.06		
mean (SD)	56.5 (16.7)	52.6 (21.1)						
Gender			Chi ² -test	4.438	1	0.04*		
% male	74.5	62.3						
Years of education								
median (IQR)	13 (3)							
% missing	6.9							
Marital status								
% never married	18.6							
% married or cohabiting	63.7							
% separated, divorced, widowed	15.7							
% missing	2.0							
Occupational situation								
% paid work, self-employed	45.1							
% unemployed	8.8							
% retired	33.3							
% other (student, house-maker, etc.)	10.8							
% missing	2.0							
Spinal cord injury characteristics								
% sports injury	19.6							
% traffic accident	18.6							
% work accident	12.7							
% fall	21.6							
% other traumatic	9.8							
% non-traumatic	13.7							
% other	2.0							
% missing	2.0							
Level of injury			Chi ² -test	0.026	1	0.87		
% paraplegia	61.8	62.6						
% tetraplegia	38.2	37.4						
Completeness of injury			Chi ² -test	0.002	1	0.96		
% complete	26.5	26.7						
% incomplete	73.5	73.3						
Time since onset								
mean (SD) in months	43.6 (13.5)	48.0 (14.1)	T-Test	-2.824	184.35	0.01*		
% missing	0.0	1.0						
Time since discharge from first rehabilitation								
mean (SD)/ median (IQR) ^a in months	38.4 (13.9)	42.5 (22.8) ^a	MWUT	12410.00		0.02*		
% missing	1.0	0.0						

Table 1 Sociodemographic and spinal cord injury related characteristics of the study participants (n=102) in comparison with the non-responders (n=292).

a: Median and interquartile range are reported due to a significant Kolmogorov-Smirnov test (alpha<.01); MWUT: Mann-Whitney U-test; * p<0.05

Table 2: HADS scores.

		n	%	р	m ^a	sd ^b
HADS	Total score	100			11.46	7.59
	Anxiety	100			5.83	4.17
	Anxiety ≥ 8 (mild case)	25	25			
	Anxiety ≥ 11(moderate to severe case)	10	10			
	Depression	100			5.87	3.62
	Depression ≥ 8	31	31			
	Depression ≥ 11		21			
	Missing data	2				

p: probability of Kolmogorov-Smirnov-Tests for normal distribution; a: mean; b: standard deviation * Kolmogorov-Smirnov, alpha<.01

Items		δ	SE	Z	Chi ²	df	р	PCA eigen- value	t-test %	4 step scale	r
Overall					16.934	14	0.260	1.90	5.00		0.72
Anx1:	I feel tense or "wound up"	-0.477	0.163	0.169	5.025	2	0.081			ord	
Anx3:	I get a sort of frightened feeling as if something awful is about to happen	-0.053	0.151	-0.651	0.943	2	0.624			ord	
Anx5:	Worrying thoughts go through my	0.257	0.161	-0.974	3.108	2	0.211			ord	
Anx7:	I can sit at ease and feel relaxed	-0.310	0.152	1.318	1.621	2	0.445			ord	
Anx9:	I get a sort of frightened feeling like "butterflies in the stomach	0.537	0.174	-0.538	2.123	2	0.346			ord	
Anx11:	I feel restless as I have to be on the move	-0.174	0.148	1.190	2.774	2	0.250			ord	
Anx13:	I get sudden feelings of panic	0.220	0.156	-0.088	1.341	2	0.511			ord	

Table 3: Anxiety subscale: Rasch-based fit statistics, ordering of the response scale and reliability.

Index:

a: Exceeds the critical value of z > +/-2.5

b: Below probability level of p < 0.01

c: Exceeds the decision level for chance distribution of residuals with eigenvalue >1.9

d: Exceeds the 5% boundary for the number of significant independent t-tests based on the PCA results

δ: Item location

z: Fit residuals

PCA: Principal component analysis

t-test %: Percentage of significant independent t-tests

r: Person reliability index

Items		δ	SE	Z	Chi ²	df	р	PCA eigen- value	t-test %	4 step scale	r
Overall					24.411	14	0.041	1.63	5.00		0.82
Dep2:	I still enjoy the things I used to enjoy	0.156	0.180	-1.259	3.926	2	0.140			ord	
Dep4:	I can laugh and see the funny side of things	0.747	0.185	-1.136	2.544	2	0.281			ord	
Dep6:	I feel cheerful	0.560	0.178	-0.763	5.233	2	0.073			ord	
Dep8:	I feel as if I am slowed down	-1.907	0.172	0.066	2.148	2	0.342			ord	
Dep10:	I have lost interest in my appearance	0.586	0.174	0.735	4.678	2	0.096			ord	
Dep12:	I look forward with enjoyment to things	-1.249	0.162	-0.464	0.003	2	0.998			ord	
Dep14:	I can enjoy a good book or radio or TV program	1.107	0.190	1.056	5.878	2	0.053			ord	

Table 4: Depression subscale: Rasch-based fit statistics, ordering of the response scale and reliability.

Index:

a: Exceeds the critical value of z > +/-2.5

b: Below probabilityy level of p < 0.01

c: Exceeds the decision level for chance distribution of residuals with eigenvalue >1.9

d: Exceeds the 5% boundary for the number of significant independent t-tests based on the PCA results

 δ : Item location

z: Fit residuals

PCA: Principal component analysis

t-test %: Percentage of significant independent t-tests

r: Person reliability index
Items		δ	SE	Z	Chi ²	df	р	PCA eigen- value	t-test %	4 step scale	r
Overall					54.931	28	0.002 ^b	2.49 ^c	19.19 ^d		0.86
Anx1:	I feel tense or "wound up"	-0.312	0.166	-0.573	0.464	2	0.793			ord	
Dep2:	I still enjoy the things I used to enjoy	-0.027	0.163	-1.077	4.561	2	0.102			ord	
Anx3:	I get a sort of frightened feeling as if something awful is about to happen	0.067	0.150	0.390	3.803	2	0.149			ord	
Dep4:	I can laugh and see the funny side of things	0.557	0.169	-1.762	4.066	2	0.131			ord	
Anx5:	Worrying thoughts to through my mind	0.376	0.162	-0.262	0.908	2	0.635			ord	
Dep6:	I feel cheerful	0.366	0.161	-1.409	6.118	2	0.047			ord	
Anx7:	I can sit at ease and feel relaxed	-0.111	0.157	-0.257	0.399	2	0.819			ord	
Dep8:	I feel as if I am slowed down	-1.775	0.153	-0.762	3.711	2	0.156			ord	
Anx9:	I get a sort of frightened feeling like "butterflies" in the stomach	0.654	0.173	0.387	1.031	2	0.597			ord	
Dep10:	I have lost interest in my appearance	0.328	0.157	1.032	11.019	2	0.004 ^b			ord	
Anx11:	I feel restless as I have to be on the move	-0.038	0.148	2.226	6.708	2	0.035			ord	
Dep12:	I look forward with enjoyment to things	-1.197	0.141	-1.188	2.111	2	0.348			disord	
Anx13:	I get sudden feelings of panic	0.346	0.155	0.812	4.046	2	0.132			ord	
Dep14:	I can enjoy a good book or radio or TV program	0.765	0.174	2.109	5.987	2	0.050			ord	

Table 5: Total scale: Rasch-based fit statistics, ordering of the response scale and reliability.

Index:

a: Exceeds the critical value of z > +/-2.5

b: Below probability level of p < 0.01

c: Exceeds the decision level for chance distribution of residuals with eigenvalue >1.9 d: Exceeds the 5% boundary for the number of significant independent t-tests based on the PCA results

δ: Item location

z: Fit residuals

PCA: Principal component analysis

t-test %: Percentage of significant independent t-tests

r: Person reliability index

IV. Systematic literature review: The role of social support and social skills in persons with SCI

IV.1. Specific aims

The aim of the second study is to examine the current knowledge from the scientific literature of how social support and social skills are relevant in SCI and to obtain first hints and generate hypotheses about the association of these factors with depression, participation and QoL of persons living with SCI. The specific aims are to answer the questions (1) which aspects of social support and social skills are addressed in SCI research, (2) which methods are used to assess social support and social skills (3) to summarize the evidence about social skills and social support in SCI.

IV.2. Methods

A systematic literature review was conducted to identify scientific publications which refer to social support and social skills in persons with SCI. The procedures followed five steps: electronic literature search, paper selection, data extraction, quality assessment of the studies and narrative synthesis.

Searches were conducted in Pubmed, Embase, PsycINFO, ERIC (Educational Resources Information Centre), CINAHL (Cumulative Index to Nursing and Allied Health Literature) and the SSCI (Social Sciences Citation Index). The search terms 'social support', 'social skills' and synonyms combined with 'spinal cord injury' were used. Publications were selected that generate data which target, assess and intervene in social support and/or social skills. Studies referring to different dimensions of social support, that is, type (such as emotional, instrumental, informational), source (such as family, friends,

peers) and qualifier (such as satisfaction, appreciation with social support) were selected. Support that is paid, such as professional support, was excluded. The theoretical framework of Liberman¹⁴⁷ was used to capture the multidimensional types of social skills (that is, topographical, functional, information processing). The topographical dimension emphasizes on verbal and non-verbal behavior (such as communication skills, eye contact). The functional view defines social skills in terms of the outcome of social interactions (such as assertiveness, self-monitoring). Information-processing skills refer to the individual's ability to attend to, receive, process cues, generate and decide on a response and implement it (for example, social problem solving, decision making). Randomized controlled or clinical trials, cross-sectional or longitudinal studies, published in English between 1990 and 2010 with a sample of persons with SCI, who are at least 13 years of age were selected. In addition, studies with a sample size smaller than 30, qualitative and psychometric studies, reviews, meta-analyses and studies in which SCI was not the main target population were excluded. The eligibility criteria for in- and exclusion of publications are listed in appendix 3.

Data extraction included documentation of the main objective, study design, country, size and description of the sample. In addition, the variables assessed, measurement instruments and the results of the study were extracted.

For quality assessment of the studies, evidence grading according to STROBE (Strengthening the Reporting of Observational Studies in Epidemiology)¹⁹⁹ and PEDro (Physiotherapy Evidence Database)²⁰⁰ were implemented. STROBE represents a quality assessment tool for observational studies, which consists 22 items to evaluate the background, study design, data collection and data analysis of the study. PEDro includes 11 criteria, such as randomization, concealed allocation, blinding, etc., relevant for randomized controlled trials. The criteria fulfilled by STROBE and PEDro were counted.

Finally, results about social support and social skills were grouped according to topic domains, which represent the variables in relation to which social support and social skills have been studied. The narrative synthesis²⁰¹ considered the number of studies pertaining to a topic domain, the statistical significance and consistency of the results, the analyses methods and the methodological quality of the study, including design, sample size, application of standardized measures or potential sources of bias.

For quality assurance, paper selection, data extraction (for one-third of the publications) and quality assessment of the studies were conducted in parallel by two independent reviewers. To resolve disagreements between the two reviewers, the original paper was consulted and rating mistakes, if any, were corrected. In case of controversial issues, a discussion was led by a third person, in which the two reviewers stated their pros and cons for the decision regarding paper selection, data extraction or quality assessment. On the basis of these statements, the third person made an informed decision. All review steps were conducted using an MS Access database (Access 2007, Microsoft Corporation, Redmond, WA, USA.).

IV.3. Results

The electronic searches in the six databases resulted in 795 hits. Fifty-eight papers on social support, 11 on social skills and one study including both constructs were eligible for analyses (Figure 2). Study characteristics, demographical and lesion-related data of the study populations are summarized in Table 6. The majority of the papers were cross-sectional studies (n=44). Most studies were conducted in the United States (n=32). Sample sizes ranged between 33 and 1312. Two third of the participants were male. Para-and tetraplegia, complete and incomplete lesion were approximately equally distributed.

Reviewer agreement on paper selection was 81%. On the data extraction of variables and measurement instruments, agreement was 82%, agreement on results was 81%, and agreement for STROBE quality assessment was 94%.

Table 7 shows the various aspects of social support addressed in SCI research. Studies focused on emotional (n=9), instrumental (n=9), and informational (n=9) aspects of social support provided by the family (n=8), friends (n=8), intimate partners (n=8), peers (n=1), and the community (n=1). Quality, i.e. satisfaction with social support (n=9), as well as quantity of social support, e.g. numbers of friends (n=9), were captured. Table 8 shows the four different social skills examined in persons with SCI: Social problem-solving ability (n=7), assertiveness (n=3), self-monitoring (n=1), and communication skills (n=1).

Fourteen standardized self-report instruments assessing social support were used in 58 studies (Table 9). The most commonly used instrument in SCI was the Interpersonal Support Evaluation List (ISEL)²⁰², measuring availability of different types of social support. Five standardized self-report instruments were used to assess social skills (Table 10). As social problem-solving is the most frequently examined social skill in SCI, the Social Problem-solving Inventory – Revised,²⁰³ assessing problem orientation and problem-solving skills, was most commonly used.

Regarding study quality, percentage scores on the STROBE ranged from 50.0% to 86.4%. Figure 3 shows the histogram of the results, demonstrating a normal distribution located in the upper half of possible percentage scores (Mean=68%; Range=50-86%; SD=8.76). The quality assessment according to PEDro was used in one study (N=40), which scored 7 out of 11(ref.²⁰⁴). Considering the methodological characteristics of the studies, the strengths of evidence is frequently diluted, because most of the results referred to bivariate correlations, which cannot specify direction or causal mechanisms of relationships. In addition, due to the lack of representativeness of the samples, the results of the identified studies cannot be generalized.

SOCIAL SKILLS AND SOCIAL SUPPORT

Only one cross-sectional study (N=156) addressed the relationship of social support to social skills.²⁰⁵ Correlations between assertiveness and different types of social support were non-significant (r=0.13 - -0.38). However, including the interaction between support in a multivariate assertiveness and social analysis (together with sociodemographic and injury related variables) revealed an association with depression and psychosocial disability. It indicates that assertive people were found to be more depressed and psychosocially disabled under conditions of high informational support. The model of the relationship between assertiveness and social support accounted for 38% of the variance in depression scores.

SOCIAL SUPPORT

Findings about social support were grouped into 8 topical domains (Table 11, Figure 4).

Mental health

The most consistent relationship identified in this review is that between social support and mental health. This is due to the large number of studies that report significant associations between them. In 16 studies (N=33-256), social support was associated with lower depression,^{82, 130, 205-217} helplessness,²¹⁸ pessimissm,¹³⁰ negative thoughts about the world and about oneself,^{219, 220} alexithymia,²²⁰ suicidal ideation.^{130, 221} In one study, social support accounted for 26.5% of the variance in hopelessness.¹³⁰ In 4 studies (N=37-165) social support correlated with anxiety and moderated the relation between stress and anxiety.^{82, 204, 207, 210} Social support was related to less psychosocial disability (N=156-290)^{205, 222, 223} and lower severity of post-traumatic stress disorder (PTSD) (N=50-168) in one longitudinal study.^{219, 224-226} Alcohol and drug use ideation was associated with lower

quality of social support⁸² and pre-injury drinker reported lower levels of social support, and perceived higher family than friend support.²²⁷

Life satisfaction, subjective well-being and quality of life

The evidence of the relation between social support and life satisfaction, QoL and well-being is consistent, showing similar results in different studies. Twelve studies (N=62-256) showed that social support was associated with life satisfaction, subjective well-being and QoL.^{129, 206, 208, 210, 214, 216, 223, 228-232} However, lower satisfaction with social life was associated with higher instrumental and informational support, higher emotion-oriented support from friends and lower from family.²²⁹ The availability of peer support positively affected satisfaction with life.¹²⁹

Mortality, morbidity, secondary conditions and health care utilization

The evidence regarding social support and the association with mortality is mainly supported by a longitudinal study (N=1312) on survival analysis. The mortality risk decreased by 14% with every standard deviation unit increase in reciprocal social support.²³³ With respect to morbidity, 11 studies show correlations between social support and better health (N=125-475),^{206, 216, 228, 229, 231, 232, 234} lower frequency of health problems,²²³ disability-related problems²²³ and secondary conditions,²³⁵ such as urinary tract infections^{216, 236} and pressure ulcers.^{236, 237} Three studies showed inconsistent results in the relation between social support and numbers of days in hospital, hospital admissions, and doctor visits, depending on the kind and source of social support.^{129, 215, 236} Emotional support was positively linked to health care use²³⁵ indicating the more social support, the more health care use.

Pain

In 4 cross-sectional studies (N=96-182), correlations between social support and lower degree of pain and catastrophizing were found.^{234, 236, 238, 239} However, the direction of the relationship cannot be determined. Informational and instrumental support were positively related with pain, and negatively related with emotional support.²³⁶

Beliefs, coping, and adjustment

Fairly strong evidence maintains the relation between social support, beliefs, coping and adjustment. Social support was related to self-efficacy,^{231, 235, 240} and hope,²⁴¹ but inconsistently to self-esteem (N=77-270).^{241, 242} Social support was associated to coping in 7 studies (N=37-255).^{82, 218, 224, 226, 242-244} In one longitudinal study the perception of social support predicted coping.²⁴⁴ Social support was negatively associated with emotional coping,^{226, 242} positively with fighting spirit and sense of humour.^{82, 218} Informational support was related to more problem-oriented coping²⁴² and an internal coping style was connected to higher levels of support compared to external coping.²⁴³

Social support was correlated with better adjustment to disability in 5 studies (N=70-255)^{208, 218, 220, 236, 245} and mediated the relation between leisure engagement and adjustment.²⁴⁵ Support from friends was associated with acceptance of disability and emotional support with personal growth.^{218, 220}

Functioning, activity and participation

The evidence of the relation between social support and functioning is consistent. Ten cross-sectional studies examined aspects of functioning and integration in relation to social support (N=37-290). Persons who have more social support,^{214, 245} more reciprocal relationships,²⁴⁶ more support from peers,¹²⁹ and fewer relationships in which other persons provided more help²⁴⁶ were more likely to be mobile, productive and interested in leisure activities. Satisfaction with social support was associated with functional independence.^{82, 247} Social and emotional support was linked to better psychological and social functioning. ^{206, 229} Together with self-efficacy and perceived health, social support was linked to and accounted for 25% of the variance in psychological well-being.^{223, 230} However, these studies address very different aspects of functioning, activity and participation.

Sociodemographic and injury related characteristics

The existing evidence indicates, not always in a consistent way, that social support is not related with sociodemographic and lesion-related variables. Results of the relation with gender,^{129, 219, 220, 229} education,^{129, 218, 223, 225, 229, 231} race^{205, 231, 235} or employment status^{129, 231, 248} were not significant. The relations to marital status and age were inconsistent, depending on the source and type of support.^{129, 205, 215, 218, 223, 229, 235, 241, 247} Social support was not related to age at injury^{129, 210, 218, 220, 228, 231} and level or completeness of injury.^{205, 209, 215, 219, 220, 228, 231}

Overall perceived social support was higher in persons with SCI than controls without SCI.^{230, 249} Persons with SCI experienced more support than persons with stroke.²⁴⁷ In 3 longitudinal studies (N=40-120), overall social support did not change over time.^{207, 244, 250} However, when source and function of support is differentiated, friend and informational support decreased after injury.^{227, 244} The family was the most frequently mentioned (N=308) ²²³ and most important source (N=52-100) ^{251, 252} of social support.

Social support intervention

One intervention study was found, which compared a coping effectiveness training with supportive group therapy.²⁰⁴ After treatments, anxiety and depression were reduced. However, no differences between the two treatments were found.

SOCIAL SKILLS

Findings about social skills were grouped into 4 topic domains (Table 12, Figure 4).

Mental and physical health

The evidence regarding the relation between health outcomes and specific social skills is strong but not always consistent. Results from 5 studies (N= 51-199) showed a relation between social problem-solving skills and depression or psychosocial disability.^{151, 154, 253, 254} Higher assertiveness was associated with lower depression.¹⁵¹ However, assertive people were more depressed and psychosocially disabled under conditions of high informational support in a rehabilitation setting.²⁰⁵ Results about social problem-solving skills and the occurrence of pressure sores^{152, 154, 255} were inconsistent. One longitudinal study (N=188) showed that problem-solving skills were associated with the occurrence of pressure sores in the first 3 years.¹⁵² Higher positive problem orientation, a rational problem-solving style, lower impulsive, careless and avoidant style were associated with decreased occurrence of pressure sores.^{152, 255} Avoidance of problems was associated with urinary tract infections.²⁵⁵

Personal factors

Evidence for the relation between specific social skills and personal factors, such as locus of control or extroversion, is difficult to summarize, because each of the studies investigate different factors. Being assertive was one of the most difficult problems rated by persons with SCI (N=35).²⁵⁶ Social problem-solving skills (low negative problem orientation, impulsive, careless and avoidant problem-solving as well as high rational problem-solving) were related to acceptance of disability.^{151, 154, 254} Effective problem solving was associated with assertiveness, confidence and perceived control in problem-solving but not with a person's health locus of control.^{151, 253} Scoring high in positive

problem orientation and using a rational problem-solving style was related to high scores in extroversion, openness to experience, conscientiousness and resilience, low scores in neuroticism, career choice anxiety and generalized indecisiveness.^{154, 254} Overall, only five cross-sectional studies dealt with the relation between specific social skills and personal factors.

Activity, participation and life satisfaction

Three cross-sectional studies (N=51-206) examined activity, participation and life satisfaction and their relation to social skills.^{153, 155, 156} Positive problem orientation and rational problem-solving were associated with performing more wellness and accident prevention behaviour.¹⁵³ Individuals with SCI who were high in self-monitoring did not differ from those who were low in self-monitoring on free time boredom, but they participated more frequently in recreation activities and socializing, and perceived higher freedom in leisure.¹⁵⁵ Communication skills of 158 person correlated with life satisfaction but in regression analysis no significant contribution was found.¹⁵⁶

Sociodemographic and injury related characteristics

The evidence is inconsistent regarding the relation of social skills to sociodemographic and lesion-related variables. In 4 studies, social problem-solving skills did not correlate with gender and race.^{152-154, 253} Assertiveness and effective social problem-solving were related to higher levels of education and age.¹⁵¹⁻¹⁵⁴ Persons with paraplegia were found to be slightly more effective communicators and problem-solvers than persons with tetraplegia^{154, 156} and the higher the level of SCI the lower the tendency to act assertively.^{151, 205}

IV.4. Discussion

This literature review provides a systematic overview on the current state of research in SCI about the relationship of social support and social skills with health and well-being outcomes. The full range of aspects pertaining to social support (i.e. type, source, qualifier) and social skills dimensions (i.e. topographical, functional, information-processing skills) were addressed in SCI research. However, five times more studies on social support compared to social skills and only one study addressing both concepts in SCI were found. Most studies are of cross-sectional design. In the past 20 years, only few longitudinal and intervention studies were conducted and social support and social skills were mainly measured by self-report questionnaires.

The only study examining both social support and social skills in SCI indicated that the social skills of an individual are correlated to the outcome of social support exchange.²⁰⁵ Research in the general population^{257, 258} and in mental illness^{134, 259} shows that social skills are correlated to social support. However, the relationship between social skills and social support and the association of the two with health and quality of life remain unclear. Therefore, a key finding of this review is that there is a need for future research in SCI to confirm whether or not effective social skills can mobilize social support and how.

In general, the results confirm that social support and social skills are positively related to physical and mental health. Social support seemed to decrease the risk of mortality, facilitate coping and enhance QoL in persons with SCI. Sociodemographic and lesion-related variables were rarely associated with social support but can be related with social skills. However, findings about the relation of social support and social skills to participation are fragmented and whether or not a person with effective social skills does mobilize social support and has in turn better mental health and higher levels of participation and QoL remains to be explored.

The studies included in this review have fulfilled at least 50% of the STROBE quality criteria. However, most of the studies are of cross-sectional design and hence, do not clarify cause-effect mechanisms. For example, the results show that social support is associated with higher levels of well-being. However, the literature also indicates that well-being of a person with SCI predicts the availability of social support.²²³ In addition, moderating and mediating effects or change and time effects stay concealed with cross-sectional studies. Longitudinal research is needed in future. This could be facilitated for example by building registries or research platforms similar to those in the US Model Systems.²⁶⁰ Such platforms should include a comprehensive set of assessment domains addressing all dimensions of functioning and disability as well as contextual and personal factors, e.g. according to the International Classification of Functioning, Disability and Health (ICF).²⁶¹

The findings of this review in SCI are largely in line with current research. The relationship of social support with mortality,^{262, 263} physical and mental health,²⁶⁴⁻²⁷⁰ coping²⁷¹⁻²⁷³ and life satisfaction¹¹⁰ has been confirmed in the general population and in other diseases.²⁷⁴⁻²⁷⁶ Social support is also related to the available strengths and internal resources of persons with SCI.¹²¹ Social skills have been found to relate to physical and mental health in the general population²⁷⁷⁻²⁷⁹ and other diseases.^{133-135, 137, 138, 280}

There are only few studies addressing social skills in SCI. The concept of social skills is difficult to define. Social skills, social competence, social intelligence or social performance are often used interchangeably.¹³³ In addition, social skills do not seem to change in SCI. However, social skills are important in the development and maintenance of interpersonal relationships, in general and in SCI.¹⁵⁶ Social skills training has shown its effectiveness in general population,²⁸¹ with children and adolescents²⁸² in relation to mental^{135, 283} and physical health.²⁸⁴⁻²⁸⁶ In SCI, there are two publications but small sample sizes.^{150, 287} Intervention studies in social skills have also reported improvements in social

support ratings.²⁸⁸ Therefore, social skills training could be integrated in treatment plans²⁸⁹ and could also prepare persons with acquired SCI for difficult social situations.

Only specific social skills, such as social problem-solving or assertiveness were examined. General social skills as they are assessed, for example, by the Social Skills Inventory¹⁴⁸ are not addressed in SCI. Clinical interviews or behavioural observation (e.g. role play) are comprehensive assessments used in general practice to assess social skills.²⁹⁰ They are demanding in terms of administration and analysis. Few instruments exist that have been designed specifically for SCI, such as the Spinal Cord Injury Assertion Questionnaire (SCIQ).²⁹¹

Looking at issues of measurement, in SCI and in the general population, mostly the different types of social support are measured. However, instruments assessing also the quality and not only the quantity of social support should be considered in research, since quality^{82, 130, 207, 216, 217} not quantity^{130, 207, 219, 224} of social support is linked to mental health. Overall, a "gold standard" in assessing social support does not exist, nonetheless, investigators must determine what aspect of social support they consider as important to be evaluated in relation to their specific research question.²⁸⁸

Demographic characteristics of a person do not affect the amount of support perceived. However, there seems to be a difference in levels of importance of social support for older compared to younger people.²⁹² The relation between being married and social support was inconsistent. This may reflect the difference in assessment of quantitative and qualitative aspects of marital support and being married is only a source of social support if the marriage is a good one.^{293, 294} However, social support, in specific marriage, is also affected by SCI.²⁴⁷ Divorce rates in persons with SCI range between 8% to 48%.²⁹⁵ While SCI represents a major burden to the spouses,²⁹⁶ partners report also some positive changes, such as more open and honest communication.²⁹⁷ To strengthen

marriage as an important social support system, comprehensive support should be provided to caregivers, e.g. in terms of relationship counselling.

Social support was slightly related to the type of disability (SCI vs. stroke), but not to the level of injury. Assistance to persons with SCI, due to the physical impairment, is in large part support that is paid. This kind of support, however, was not included in this review.

Although social support was consistently found to be positively related to life satisfaction, subjective well-being and QoL, one study showed somewhat contradictory findings.²²⁹ While social support is thought of as a positive concept, social relationships may also serve as sources of stress.^{298, 299} The results show that higher instrumental and informational support and emotional support from friends are related to lower satisfaction with social life.²²⁹ This type of social support might lead to unsatisfactory social life, because it may act as a constant reminder of the presence and impact of the disability. It reflects a relative inequality of exchange between the provider and recipient and fosters the feeling of being "in dept".^{208, 300} In SCI, negative experience of support may lead to dysfunctional coping styles,²²⁶ exacerbate acceptance to disability,²³⁶ enhance risk of developing PTSD^{224, 226} and is related to numerous health conditions.²³⁶

Social skills, such as assertiveness, are helpful in general life situations, but can also have negative effects. In rehabilitation, assertive persons with SCI may encounter increased attempts from health professionals to control their behaviour, while receiving care and treatment.¹⁴⁹ As a result, assertive persons may experience more psychological distress.²⁰⁵

Limitations

The study is subject to several limitations: First, search terms were specific to social support and excluded broader terms such as social integration. Terms referring to

participation which is understood as involvement in a life situation,³⁰¹ were excluded. Articles about social relationships were only included if the relationship provides support in some way. For example, papers comprising the term *marital status* were only included, if the support by marriage, such as spousal support, was examined.

Second, the selection criteria concerning age, qualitative studies and sample size are disputable. Basic social skills are learned and more or less effective for good developmental outcome and adaptation around the age of thirteen.³⁰²⁻³⁰⁴ However, the development of social skills is not completed at a certain age. Qualitative studies provide detailed insight and the possibility to generate hypothesis³⁰⁵ and could be addressed in a separate review. The decision to solely include studies with N≥30 is based on reasons of generalizability and power of analyses.³⁰⁶

Third, using STROBE for quality grading can be problematic. STROBE has been applied to assess study quality in a wide variety of systematic literature reviews.³⁰⁷⁻³⁰⁹ However, STROBE addresses the reporting of studies rather than their quality.³¹⁰ A standardized interpretation manual for STROBE scoring does not exist. In addition, results from studies with higher scores in the quality assessment tool were not weighted differently than results from studies with lower quality.

Conclusions

The literature provides first hints about social support and social skills being important resources in persons with SCI, as they do relate to better physical and mental health and higher levels of QoL. Little is known about the relationship between social support, social skills and participation. The relationship between social skills and social support, and how this interrelation operates with depression, participation and QoL have not been fully understood in SCI. The following hypotheses should be tested by further studies: social skills relate to social support and social support has a positive effect on depression,

participation and QoL; the relationship between social skills and depression, participation and QoL is mediated by social support.

Figure 2: Flowchart of the systematic literature review.







Figure 4: Results overview of the systematic literature review.



	Social support (n=58)	%	Social skills (n=11)	%
Country	· -/		. /	
USA	32	55	10	91
Canada	7	12	-	-
UK	5	9	-	-
Netherlands	2	4	1	9
Denmark	2	4	-	-
France	2	4	-	-
	2	4	-	-
Sweden	∠ 1	4	-	-
Japan	1	1	-	-
South Korea	1	1	-	-
Taiwan	1	1	-	-
Study desian				
Observational cross-sectional	38	66	9	82
without control group				
Observational longitudinal without	11	19	1	9
control group				
Observational cross-sectional with	6	10	-	-
control group				
Observational other	2	4	1	9
Intervention RCT	1	1	-	-
Intervention CC1	-	-	-	-
control group	-	-	-	-
Sample size (mean / range)	166 (33-13	12)	125 (35	-206)
Age (weighted mean / range in years) Not specified (n)	42.5 (25-57 11	7)	37.7 (32 0	2-46)
Gender				
Male		76		78
Female		24		22
Not specified (n)	18		0	
Marital status				
Married (n)		44		36
Not specified (n)	27		9	
Age at injury (weighted mean / range in	30.9 (26-37	7)		-
Not specified (n)	40			11
Severity of injury				
Para		51		43
Tetra		42		40
Complete		53		48
Incomplete		47		51
l raumatic		93		90
Non-traumatic	215	12	20	8
not specified (ff)	213		20	
Time since injury (weighted mean / range in month)	148.6 (26-3	396)	79.6 (1. 137)	5-

Table 6. Characteristics of the 69 papers included about social support (n=58) and social skills (=11).

Not specified (n)	26	3
Setting		
Inpatient	5	4
Outpatient	9	1
Community based	10	-
Mixed	11	3
Not specified (n)	23	3

Abbreviations: CCT, controlled clinical trial; RCT, randomized controlled trial.

 Table 7: Social support variables and measurement instruments extracted from 58 papers.

Social support	In how many studies…	measured by ^a	Type of instrument
Social support (unspecified)	31	ISEL, PSD	Self-reports
Social support (total score)	6	SPS, PSS, SS-A, CSS, PSD	Self-reports
Functional perspective of social support			
Instrumental support	9	ISEL, SPS, RSSS	Self-reports
Emotional support	9	ISEL, SPS, RSSS, SSSI	Self-reports
Informational support	9	ISEL, SPS, RSSS	Self-reports
Social support sources			
Family	8	PSSS, SSSI	Self-reports
Friends	8	PSSS, SSSI, PSR, NF	Self-reports
Intimate partner	8	CSI	Self-report
Peers	1	PME	Self-report
Community	1	RSSS	Self-report
Quality - Satisfaction with social support	9	SSQ, ISEL, CSS	Self-reports
Quantity - Structural perspective of social support (i.e. network size, frequency of interaction)	9	SSQ, NFFF, CSS	Self-reports

Abbreviations: ISEL = Interpersonal Support Evaluation List / PSD = Procedures of Schulz and Decker (1985) / SPS = Social Provisions Scale / SS-A = Social Support Appraisals / CSS = Crisis Support Scale / SSQ = Social Support Questionnaire / NFFF= Number of friends, family member and frequency of seeing them / RSSS = Reciprocal social support scale / SSSI = Source of Social Support Inventory / CSI = Couple Support Inventory / PSSS = Perceived Social Support Scale / PSR = Provision of Social Relationship / NF = Number of friends / PME =Assessment of past experiences with a SCI mentor / UEF = Upset events with family (RSSS - subscale)

^amost frequently used questionnaires

Social skill	In how many studies…	measured by	Type of instrument
Social problem-solving ability		SPSI-R	Self-report
Positive problem orientation	5	SPSI-R, subscale	Self-report
Negative problem orientation	5	SPSI-R, subscale	Self-report
Rational problem-solving style	5	SPSI-R, subscale	Self-report
Impulsive/careless problem-solving style	5	SPSI-R, subscale	Self-report
Avoidant problem-solving style	6	SPSI-R, subscale	Self-report
Personal control in problem-solving	1	PSI	Self-report
Problem-solving confidence	1	PSI	Self-report
Assertiveness	3	SCIQ	Self-report
Communication skills	1	FAD	Self-report
Self-monitoring	1	SMS	Self-report

Table 8: Social skills variables and measurement instruments extracted from 11 papers.

Abbreviations: SPSI-R = Social Problem-solving Inventory - revised / PSI = Problem Solving Inventory (Form A), subscale / SCIQ = Spinal Cord Injury Assertion Questionnaire / FAD = Family Assessment Device (communication subscale) / SMS = Self-monitoring Scale

Instrument	In how	What does the instrument assess?
	many studies…	
Interpersonal Support Evaluation List (ISEL) ²⁰²	9	Availability of instrumental, emotional and informational support
Procedures of Schulz and Decker (1985) ³¹¹	6	Participants are asked to list persons who provide social support and indicate the frequency of examples of support (instrumental, emotional, cognitive) provided by these different persons
Perceived Social Support Scale (PSSS) ^{a 312}	5	Perceived social support from family and friends added together refer to total score on social support
Social Support Questionnaire (SSQ6) ¹²⁵	5	Social support quality in terms of satisfaction, and quantity of social support availability
Social Provisions Scale (SPS) ³¹³	4	Functional aspects of social support: attachment, social integration, guidance reassurance of worth, reliable alliance, opportunity for nurturance
Reciprocal Social Support Scale (RSS) ²³⁶	3	Support given and received. Frequency of advice, emotional, social and material support and negative aspects of social support from family, friends and community
Quantity ^b	4	e.g. network size, frequency of interaction
Crisis Support Scale (CSS) 314	2	Perceived and received social support after traumatic event: confiding in others, emotional and practical support, negative social support and satisfaction with social support
Social Ties Checklist (STC) 315	2	Number of social connections
Personal Resource Questionnaire (PRQ) ³¹⁶	2	Descriptive data about the person's resources, satisfaction with these resources and whether there is a confidant
Multidimensional Scale of Perceived Social Support (MSPSS) ³¹⁷	2	Perceived social support from family, friends, significant other and global perceived support
Couple Support Inventory (CSI) ³¹⁸	1	Existence, quality and quantity of emotional, instrumental/practical and informational support (schemata, availability, behaviours) as well as its motives, characteristics and outcomes
Source of Social Support Inventory (SSSI) ³¹⁹	1	Emotion- and problem oriented support from family network, informal network and professional network
Social Support Appraisals (SS-A) ³²⁰	1	Perception of appreciation, esteem from family, friends and others and integration into community
Provision of Social Relationship (PSR) ³²¹	1	Family and friend support
Availability of attachment and social integration (AVAT/AVSI) ³²²	1	Availability of attachment and social integration

 Table 9: Self-report standardized instruments measuring social support extracted from 58 papers.

^a PSSS Version by Hamilton, 2001: Measuring support received from family, friends, community and government ^b Patient-report

IV. Systematic literature review: The role of social support and social skills in persons with SCI

_		
Instrument	In how many studies	What does the instrument assess?
Social Problem-solving Inventory - Revised ²⁰³	5	Problem orientation (positive and negative) and problem- solving skills (rational problem-solving, impulsive/careless problem-solving, avoidant problem-solving)
Problem-Solving Inventory (PSI) ²⁷⁸	2	Self-appraised problem-solving ability. Thereby problem- solving confidence, approach-avoidance and personal control are assessed
Spinal Cord Assertion Questionnaire (SCIQ) ²⁹¹	2	Rating of 26 social situations specific to SCI on a 1 (all of the time) to a 5 (never) Likert scale the degree of which the person would likely respond assertively
Communication Subscale of the Family Assessment Device (FAD) ³²³	1	Clarity and directness used in verbal exchanges of information
Self-Monitoring Scale (SMS) ³²⁴	1	Level of social appropriateness, degree of using social comparison information, degree to which an individual controls and modifies one's presentation of self to others and the extent to which one's presentation of self is tailored to fit the social situation

 Table 10: Self-report standardized instruments measuring social skills extracted from 11 papers.

Associated aspect	Analysis		Ref.
Mental health			
			82, 130,
			205, 207,
Depression	Correlation	r = -0.210.63	208, 210,
			211, 213- 217
			130, 205, 206, 210
	Regression	β= -0.200.53	211
		F(2.64) = 6.02 p=0.00 (before vs. after intervention)	204
			218
Helplessness	Correlation	r = -0.290.47	2.0
	Regression	β= -0.470.61	218
Pessimism	Correlation	r = -0.450.57	130
Negative thoughts about the world	Correlation	r = -0.250.31	219, 220
Negative thoughts about the self	Correlation	r = -0.350.40	219, 220
Alexithymia	Correlation	r = -0.280.31	220
Suicidal ideation	Correlation	r = -0.580.66	130, 221
Hopelessness	Correlation	r= -0.440.58	130
	Regression	β = -0.45, -0.54; R ² = 0.26	130
Anxiety	Correlation	r = -0.360.53	82, 207, 210
		F(2,64) = 0.40, p. <0.00 (before via ofter intervention)	204
		r(2.04) = 9.49, $p < 0.00$ (before vs. after intervention)	205 222
Psychosocial disability	Correlation	r = -0.300.46	223
	Regression	β= -0.340.36; R ² =0.24 - 0.27	205, 222
			219, 224-
PTSD	Correlation	r = -0.240.48	226
	(M)ANOVA	F(1)= 4.3 (PTSD vs non-PTSD)	226
	Regression	X ² = 29.6, df = 8	226
Alcohol and drug use ideation	Correlation	r = -0.35	82
Alcohol consumption	(M)ANOVA	F(1.171) = 3.27, p=0.08 (drinker vs. non-drinker)	227
		F(3)=3.16, p=0.03 (family vs. friend support)	227

Table 11: Summary results on the associations of social support with aspects of health, functioning and quality of life. Only significant and consistent results are shown.

Life satisfactionCorrelationr = 0.21 - 0.75Regression $\beta = 0.52$ ANCOVA $F = 4.26; \eta 2 = 0.072^a$ Path analysisr = 0.25 - 0.48Subjective well-beingRegression $\beta = 0.22 - 0.30$

 $R^2 = 0.40$

Regression

Life satisfaction, subj. well-being, quality of life

•

208, 210, 214, 216,

228, 229 210

129

229

232 206

223, 230-

Associated aspect	Analysis		Ref.
Mortality, morbidity, secondary co	nditions, health care uti	lization	
Mortality	Survival analysis	SD=17.5(3.9)/SHR ^b =0.86	233
Health	Correlation	r = 0.29 - 0.34	216, 228, 229, 231, 232
	Regression	β = 0.14 - 0.29	206, 232, 234
Health/dis.rel. problems	Correlation	r = -0.16 - 0.27	223
Secondary conditions	Correlation	r = -0.16	235
	Path analysis	r= -0.15	235
Urinary tract infection (UTI)	Correlation	r = -0.21	236
	Difference	t(138)=2.01, p<0.05 (UTI vs. non-UTI)	216
Pressure sores	Correlation	r = -0.230.32	236
	Regression	OR = 0.98-0.99°	237
Health care use	Path analysis	r = 0.17	235
Pain			
	O a market i a re	r = -0.170.28 (emotional support)	234, 236
Pain	Correlation	r = 0.19 - 0.27 (informational/instrumental support)	- ,
	(M)ANOVA	F(6.6), p <0.01 (Dysfunctional vs. adaptive coper vs. interpersonally supported)	238
	(M)ANOVA	F(4.27), p<0.02 (consistent vs. inconsistent pain)	239
Catastrophizing	Correlation	r = -0.30	234
Beliefs, coping and adjustment			
Self-efficacy	Correlation	r = 0.26 - 0.43	231, 235, 240
Норе	Correlation	r = 0.89	241
	Regression	β = 0.47	241
Self-esteem	Correlation	r = 0.23-0.80	241, 242
Coping	Correlation	r = 0.22 - 0.47	82, 218, 226, 242
	(M)ANOVA	F = 29.52, 20.11, p<0.00	243
	Path analysis	r = 0.19 - 0.37	242, 244
Adjustment to disability	Correlation	r = 0.19 - 0.43	208, 218, 220, 236
	Path analysis	r = 0.65	245
Acceptance	Correlation	r = 0.27 - 0.34	218, 220
Personal growth	Correlation	r = 0.23 - 0.26	218
	Regression	β = 0.44	218
Functioning, activity and participat	tion		
Mobility	Correlation	r = 0.22	246
Productivity	Correlation	r = 0.24	246

IV. Systematic literature review: The role of social support and social skills in persons with SCI

Associated aspect	Analysis		Ref.
Leisure activity	Correlation	r = 0.25 - 0.33	214
	Path analysis	r = 0.21	245
Independence	Correlation	r = 0.19 - 0.36	82, 246
	Regression	$R^2 = 0.03 - 0.05$	247
Functioning	Regression	β = 0.12 - 0.22	206, 223, 230, 247
	Path analysis	r = 0.37 - 0.41	229
Participation	ANCOVA	F = 5.24; η2 = 0.09 ^a	129
Sociodemographic and injury related ch	aracteristics		
	Difference	t = 2.06 - 3.31, p<0.05 - p<0.00 (SCI vs. non-SCI)	230, 249
	Difference	t = 2.77, p<0.05 (SCI vs. stroke)	247
	(M)ANOVA	F(1) = 9.21, p=0.00 (family vs. friend support), NA ^d	227, 244
	Descriptive	65%, 94% (family as most important)	223, 251
Abbreviations: ANCOVA, analysis of co- traumatic stress disorder; SHR, standar Only significant and consistent results a ^a F-test for covariate for main and interact ^b Standardized hazard ratio.	variance; ANOVA, a dized hazard ratio. re shown. ction effect and Z2.	analysis of variance; NA, not available; OR, odds ratio; PTS	D, post-

Table 12: Summary results on the associations of social skills with aspects of health, functioning and quality of life. Only significant and consistent results are shown.

	Associated aspect	Analysis	Coefficient r	Ref.
Social skills	Mental health			
Assertiveness	Depression	Correlation	r = - 0.19	151
		Regression	$F_{inc}(1,15)=3.95, p < 0.05, R_{inc}^2=0.02$	205
Cooled anablem cohing	Dessession	Correlation	- 0.40 0.50	151, 154,
Social problem-solving	Depression	Correlation	r = -0.190.50	254
		Regression	F _{inc} (1,83)=21.18, p<0.00, R ² _{inc} =0.18	151
Assertiveness	Psychosocial disability	Regression	F _{inc} (1,15)=4.78, p < 0.05, R ² _{inc} = 0.03	205
Social problem-solving	Psychosocial disability	Correlation	r = -0.34	253
		Regression	β = -0.42	253
		Regression	$F_{inc}(1,83)$ =13.01, p<0.00, R^2_{inc} =0.12	151
	Physical health			
Social problem-solving	Pressure sores	Path analysis	r = -0.230.67	152, 154
		Regression	β = -0.23	152
		DFA ²	SDFC= 0.56, Wilks λ =0.79 ^a	255
	Urinary tract infection	DFA ²	SDFC =0.41, Wilks λ =0.34 ^a	255
	Personal factors			
Assertiveness		Descriptive	37% (most difficult problem)	256
Social problem-solving	Acceptance of disability	Correlation	r = 0.24 - 0.39	151, 154, 254
		Regression	β = 0.15, 0.17	154
Social problem-solving	Assertiveness	Correlation	r = 0.20 -0.25	151
	Confidence in problem- solving	Correlation	r = 0.84	151
	Control in problem-solving	Correlation	r = 0.76	151
	Extraversion	Correlation	r = 0.36; 0.33	254
	Openness to experience	Correlation	r = 0.29	254
	Conscientiousness	Correlation	r = 0.41, 0.44	254
	Resilience	Difference	d = 0.59, 0.81 ^b (resilient vs. non-resilient)	254
	Neuroticism	Correlation	r = -0.25, 0.31	254
	Generalized indecisiveness	Correlation	r = - 0.29	154
		Regression	β = 0.17	154
	Activity, participation and life	satisfaction		
Social problem solving	Accident prevention- and wellness behaviour	Correlation	r = 0.28 - 0.36	153

	Associated aspect	Analysis	Coefficient r	Ref.
Self-monitoring	Activity and socializing	(M)ANOVA	F(1.18)=9.65, p=0.00, (high vs. low in self-monitoring)	155
	Freedom in leisure	(M)ANOVA	F(1.18)=21.08, p=0.00 (high vs. low in self-monitoring)	155
Communication skills	Life satisfaction	Correlation	r = 0.20	156
	Sociodemographic and inju	iry related character	istics	
Assertiveness, Social problem-solving	Age	Correlation	r = 0.20;-0.17, -0.42 (NPO) [°]	151, 153, 154
	Education	Correlation	r = 0.20, 0.33	151, 153
Assertiveness, Social problem-solving, communication skills	Level of injury	Correlation	r = -0.15, -0.29	151, 152, 154, 205

Abbreviations: ANCOVA, analysis of covariance; ANOVA, analysis of variance; NA, not available; OR, odds ratio; PTSD, post-traumatic stress disorder; SHR, standardized hazard ratio. Only significant and consistent results are shown. ^aF-test for covariate for main and interaction effect and Z2. ^bStandardized hazard ratio.

V. *Case study*: Social support and functional independence in a person with SCI - the role of social skills

V.1. Specific aims

This case study complements the literature review regarding the generation of hypotheses about the influencing pathways of social skills and social support on participation by using data of a case study. The specific aims are to describe (1) the social skills and (2) the social support system of a patient with SCI, and (3) to illustrate how social skills and social support seem to interact and (4) influence functional independence.

V.2. Methods

This case report is part of a project highlighting selected topics in SCI for educational purposes in the field of rehabilitation management.¹⁷ The project was approved by ethical committee. The patient signed written informed consent.

The patient has been accompanied by the first author during four months on a daily basis in therapy sessions. The case report combined qualitative information from interviews and quantitative data gathered from structured clinical measurements. Two semi-structured interviews have been conducted with the patient and health professionals (i.e. physiotherapist, nurse, social worker) at the beginning and the end of the observation period and were transcribed verbatim. In addition, weekly unstructured open meetings with the patient took place to keep track of the rehabilitation process documented through detailed notes. Content analysis of the interviews was conducted. Text passages referring to social support were identified and categorized into type (i.e. emotional, instrumental, informational), source (i.e. family, friends, peers) and qualifier (i.e. quality of social support system). The theoretical framework of Liberman³²⁵ was used to capture the

multidimensional types of social skills (i.e. topographical, functional, information processing). The topographical dimension distinguishes verbal (i.e. expressing thoughts with words) and non-verbal behavior (e.g. mimic, gesture, eye contact). The functional view defines social skills in terms of the outcome of social interactions (e.g. assertiveness, goal-direction, asking for help, expressivity and sensitivity). Information-processing skills refer to the individual's ability to attend to, receive, process cues, generate and decide on a response and implement it (e.g. social problem-solving, decision making).

As a quantitative reference for functional independence, information from the Spinal Cord Independence Measure (SCIM)³²⁶ and medical records were used.

Documentation tools based on the International Classification of Functioning, Disability and Health (ICF)²⁶¹ were applied. ICF-Documentation tools are developed to facilitate a multidisciplinary, patient-oriented rehabilitation management.^{17, 327} In this case, the ICF Assessment Sheet was used for the systematic documentation of the collected information regarding functioning (i.e. body functions and structures, activity and participation, environmental and personal factors). It allows an overview of both, the patient's and health's professionals perspective.

V.3. Results

The patient is a 57 year old Swiss border guard, short before retirement. Together with his wife he lives in a mountain area, almost 2000m above sea level in a culturally protected house where the couple runs a small restaurant.

As a result of an emergent surgical intervention to treat an abdominal aortic aneurysm, the patient sustained a SCI resulting in sensomotor incomplete paraplegia sub L1, graded Asia Impairment Scale (AIS) C.²²

The ICF Assessment Sheet structures the aspects of functioning from both the patient's (upper part, using the patient's words) and health professional's perspective (lower part) (figure 5).

Table 13 shows the categorization system of social skills and social support and selected examples of text passages.

According to the observations and confirmed by health professionals the patient was perceived as overall socially skilled person. In the interview situation the patient showed high verbal communication skills (i.e. adequate use of words, enunciation, fluency, tone, pauses, loudness).

Being forced to sit in a wheelchair influenced his non-verbal communication. As a frontier guard he was used to represent an authorizing figure, which he also communicated with his gesture in an upright position. Now he felt like "I am not noticed anymore".

One of the patient's main goals was to be able to keep a standing position so that he can work in the restaurant. He chose this goal deliberately and put this decision into action by working hard at the physiotherapy and participating in cooking workshops to practice working in a kitchen. He seemed to know his rights and goals, was motivated and assertive in his behaviour by letting the people (i.e. health professionals, friends and family members) know what he concretely expects from them in an appropriate respectful way. For instance, he clearly communicated that he intends to be retrained in doing work in a restaurant rather than working at an office-job.

Asking for help and allowing others to help was a major problem for the patient who was being used to hold the position of the one who supports and helps others: "I always helped other people in every situation, but now I am the one who needs help, I am a burden for everyone, that's what concerns me the most." The patient's physiotherapist described the situation as following: "He's very afraid of not being able to do it on his own,

he's afraid of turning from the one who always helped people where he could, to the one who needs to ask for help."

In the relationship to his wife and other significant others expressivity and sensitivity played an important role in communication. The patient learned to express new and unknown feelings and also to be sensitive of the needs and feelings of his wife. "She (his wife) calls every day, she is tough but I know that she is truly loyal to me... there are so many new things for both of us... we need to talk a lot."

"I know that I'm sometimes impulsive when it comes to stressful situations....". The patient learned to manage the new circumstances in a more rational problem-solving style instead of being impulsive, careless or even avoidant in dealing with consequences of SCI. "I know that I need to see all these problems from a positive perspective, I have to take it step by step by clearly facing all difficulties that I will encounter in daily life and also with other people... That's not easy."

Social support played a central role and was considered as a strong environmental facilitator. The patient was visited by friends, colleagues from his work place and people from the valley. "My family gives me lots of love and affection.... They take me as I am." His family gave him strong backup and consolation providing emotional support and staying for some weeks near the clinic. His wife was running the restaurant by her own, and friends were taking care of machineries and outside work, both providing instrumental support. Laws about cultural protection of old buildings prohibited a reconstruction of the main house into a wheelchair-accessible home. By working out other solutions, the patient received comprehensive informational support from friends taking care of issues of constructional engineering and financing. The patient perceived his social support system as following: "My family was, still is and will always be very supportive and I am very thankful and happy for that. But I also get support from the people from the valley and all around. People whom I did not see for years now visit me, it really feels good...." In

addition, the patient had socialized with many of the other patients of the clinic. "Together with my roommates we build up a good team, we try to help and support each other, which gives me the feeling not being alone with my injury and not to fall into uselessness".

According to the treating health professionals' observations, the patient's assertiveness, goal-direction, expressivity and sensitivity in social relations (i.e. his social skills) were linked to different types (i.e. instrumental, informational and emotional) and different sources (i.e. health professionals, friends, wife) of received social support. For example the social worker stated that "his friends are taking care of outside work around the home, planning of the reconstruction of the barn and financing a wheelchair accessible home. I think it's his behaviour towards them that causes such an amount of received support". The patient summarizes: "I believe that all the things I have done for other people helping and how I treated and respected them comes now back to me."

Based on information from the medical records functioning at the body level (i.e. pain, decubitus ulcers, blood pressure, urinary and defecation function) improved during rehabilitation. Table 14 shows the SCIM scores from three different time points. An increase in the independence total scores can be found.

V.4. Discussion

This case report highlights aspects of social skills, social support, their potential interaction, provides hints for their relation to participation in the light of the scientific literature.

The patient presented a variety of appropriate and effective social skills.

The patient was perceived as goal-directed person. Working towards goals is an important aspect of subjective well-being,³²⁸ and leads to hope which is a vital issue in rehabilitation outcome.³²⁹ However, it is important to note, that such goals need to be
personally valuable, moderately challenging, construed in approach (rather than avoidance) and should share an instrumental relationship with each other.³³⁰ In this case, the patient set his goal to be able to work in a standing position in the kitchen of the restaurant. A highly challenging goal, as after several therapy session at the parallel bar the physiotherapist decided that he won't be able to remain in a standing position using his own physical force. However, in the end of the rehabilitation the patient received a stand-up wheelchair.

In addition, the patient was assertive in pursuing his goals. In rehabilitation assertive persons may encounter increased attempts from health professionals to control their behaviour, while receiving intensive care and treatment.¹⁴⁹ As a result, assertive persons may experience more psychological distress due to repressed self-assertion.²⁰⁵ Therefore, social skills, such as assertiveness, are helpful in general life situations, but can also represent a challenge in the rehabilitation setting.

The patient showed difficulties in asking for help. Experienced by other SCI patients, asking for help was rated as one main difficult issue³³¹ causing an aversive state of indebtedness and dependency,³³² and it also has been shown to raise anxiety in social situations.³³³

He also experienced new and unknown feelings and tried to communicate them in an appropriate and effective way. Expressivity, sensitivity and emotional control in social situations are components of social³³⁴ and emotional intelligence³³⁵ and are essential in fostering relationships.

During the rehabilitation process, the patient changed his social problem-solving style to a more effective, rational and mainly health-focused way to solve problems. In rehabilitation, social problem-solving is associated with adherence to medical regimens.³³⁶ In SCI, effective social problem-solving is related to better mental and physical health.^{253, 254, 337-341}

The patient received social support from numerous friends and acquaintances. Quantitative aspects of social support, e.g. network size, have been found to be associated with quality of life in general populations³⁴², and functional independence in SCI.^{82, 247} The patient stated being very thankful and satisfied with his social support system. Qualitative aspects of social support act as a buffer protecting from negative consequences of life stressors.³⁴³⁻³⁴⁶ Persons with SCI who report about satisfying social support systems are less likely to have negative³⁴⁷, hopeless and suicidal thoughts¹³⁰ and score lower in measures of posttraumatic stress disorder.^{347, 348}

Functional social support was provided by the patient's family and friends. In SCI, emotional support is linked to effective coping,²²⁶ higher self-efficacy,²³⁵ better adjustment to disability²³⁶ and greater satisfaction with social relationships.²²⁹ Informational and instrumental social support are related to lower occurrence of secondary conditions in SCI.^{223, 229}

During rehabilitation, the patient socialized with peers, which includes both providing and receiving social support. This reciprocity fosters well-being.²⁸⁸ Studies in general population show that not only receiving but also providing social support is highly beneficial for health and functioning.^{128, 288}

The patient's support network enhanced during rehabilitation. However, the social support system can be diminished following SCI.^{295, 349} Friend and informational support can decrease after injury^{244, 249} and divorce rates in persons with SCI range between 8% to 48%.²⁹⁵ Strengthening a patient's social support system through comprehensive counselling and guidance during rehabilitation is important to enhance a patient's level of functioning. A review on social support interventions showed that 83% of the support interventions in the field of e.g. cancer, overweight, substance abuse, surgery and birth preparation reported physiological and psychological benefits for the patients.²⁸⁸

It is suggested in this case that the patient received social support due to his effective social skills. Studies in the general population confirm that social skills positively correlate with perceived social support.^{141, 257, 350} Research about the interaction of social skills and social support in SCI is scarce. One study found that the relationship of social support to depression and psychosocial impairment was moderated by patient's assertion skills.²⁰⁵

In this case, improvements in functioning at the body level and an increase in independence total scores was found. Functional independence highly relates to and facilitates participation³⁵¹ and is an important outcome of successful rehabilitation.⁵³

It could be hypothesized that due to the patients effective social skills he was able to mobilize more social support during rehabilitation which in turn enhanced his functional independence and ultimately, participation. As an example, with the instrumental support of his family and friends, activated through his assertiveness and goal-direction, the rebuilding of the house and the surroundings became possible, which enhanced his functional independence, in specific his mobility. This in turn facilitates his participation in family and restaurant activities.

Conclusions

This case study generates the hypothesis that social skills relate to social support and that social support has a positive effect on participation. It is also hypothesized that the relationship between social skills and participation is mediated by social support. Further empirical studies are needed to test this hypothesis. Figure 5: ICF Assessment Sheet: illustrates the aspects of functioning from both the patient's (upper part, using the patient's words) and health professional's perspective (lower part, using ICF codes).

atients' perspective	I have pain down below the belly button, in the area of pelvis and the genitals, in my back, also during therapy, in the lower part of my legs and also my feet I can eat, but defecation and also urination does not function in a right way I know, that I have to watch my skin while sitting or lying in bed	Transferring myself to back goes well In a mountain area like difficult to move arour Washing myself needs To dress my upper par no problem, but somet assistance Smoking is sometime that helps	the bed and e I live it is nd s lots of time rt of the body is times I need s the only thing	Many people come and visit People don't notice me anymore Due to the reduced mobility I can't do many things I always helped other people but now I am a burden for everyone Getting around with the wheelchair (mobility) goes well, it would be easier with the Swiss trec, but in situation where it is steep someone has to push me I participate in a cooking workshop, because I would like to work in the restaurant together with my wife			
	Body functions/-structures	Activity		Participation			
onal perspective	Pain in back Pain in upper limb Pain in lower limb Pain in joints Blood vessel function Urinary function Defecation function Protective functions of the skin Repair functions of the skin Structure of areas of skin	Transferring oneself Moving around using e Washing oneself Caring for body parts Regulating urination Regulating defecation Dressing	equipment	Relating with strangers Formal relationships Informal social relationships Family relationship Remunerative employment			
ofes	Environmental Factors	Personal Factors					
Health pro	Medication Seat cushion in order to avoid pressure sore Outdoor mobility The house is not wheelchair accessible The restaurant is located on a mountain Very supportive wife and children Friends visit and are supportive Work colleagues and people from the valley a Supportive social worker Satisfied with support from health professiona	Social support re supportive Is (therapies)	57 year old, mal Living in the mo owns a restaura Former frontier Verbal and non- Goal direction Assertiveness Asking for help Social problem Sensitivity and e	old, male the mountains on 1800m above sea level, where the family estaurant rontier-guard, shortly before retirement nd non-verbal communication ection eness or help roblem-solving strategies ity and expressivity in social relations			

Table 13: Categorization system of social skills and social support and selected examples

	Description	Example(s)	Example(s) text passages (patient)	Example(s) text passages (health professionals)
Social skills				
Topographical	Non-verbal communication	Gesture, mimic, eye contact	"I feel like I'm not noticed anymore" "I am not that strong (physical) person anymore, who can assert his authority"	"The non-verbal communication changes after sustaining a SCI, now the person sits in a wheelchair" (physiotherapist)
Functional	Referring to outcome of social interaction	Assertiveness, goal-direction, asking for help, expressivity, sensitivity	"I'd like to work in the restaurant, that's what I want working in a office does not make sense at all" "I always helped other people in every situation, but now I am the one who needs help, I am a burden for everyone, that's what concerns me the most" "She (his wife) calls every day, she is tough but I know that she is truly loyal to me there are so many new things for both of us we need to talk a lot." "Sometimes I get angry at the whole world, and I wish that someone understands me"	"He is definitely an assertive person" (nurse) "He's very afraid of not being able to do it on his own, he's afraid of turning from the one who always helped people where he could, to the one who needs to ask for help" (physiotherapist) "Both the patient and his family are faced with a whole new area of feelings and these feelings need to be communicated (physiotherapist)
Information processing	Ability to attend to, receive, process cues, generate and decide on a response and implement it	Social problem- solving, decision-making	"I know that I'm sometimes impulsive when it comes to stressful situations" "I know that I need to see all these problems from a positive perspective, I have to take it step by step by clearly facing all difficulties that I will encounter in daily life and also with other people That's not easy "	"For us professionals it is certainly easier to work with a patient who is optimistic, is eager to make progress and things settled, and has decided on something, hopefully the right decision, but we also try to help in the decision-making process" (social worker)
Social support				
Туре	Emotional	Consolation or affection from a close person	"My family gives me lots of love and affection They take me as I am" "I get so many good wishes from the people in the valley where I live and from my work place, I feel that I am respected and belong to a strong group of peopleI'm one of them"	

	Description	Example(s)	Example(s) text passages (patient)	Example(s) text passages (health professionals)
	Instrumental	Help with work around the house	"My wife runs the restaurant, while I'm here in the clinic now in the wintertime she even does the snow removal by her own" "Friends of the family come up and checked the heating system, or did a control on the snow blower"	
	Informational Advice from a "I have a friend who friend now took over the p other friends the find reconstruction of the about the things I ne "One of my roomma beginning but know handles all the diffic		"I have a friend who's an architect, and he now took over the planning and together with other friends the financial issues of the reconstruction of the house, he informs me about the things I need to decide on" "One of my roommates was very quiet in the beginning but know we tells me how he handles all the difficulties in daily life"	
Source	Family	Wife, children, grandchildren, relatives	"My wife, my four children and even my grandchildren are a great support, I don't know what I would do without them"	"His family is a very important support system We can also help to strengthen this support system by providing essential medical information and counseling in all kinds of issues concerning SCI" (social worker)
	Friends	Friends from the valley and work place	"There are so many friends the whole valley is now concerned that the barn next to our house can be reconstructed to a wheelchair accessible building, they collect money" "People whom I did not see for years now visit me, it really feels good	"He's visited by lots of people, I mean a lot, four to ten people per day?" (physiotherapist)
	Peers	Roommates during rehabilitation	"Together with my roommates we build up a good team, we try to help and support each other, which gives me the feeling not being alone with my injury and not to fall into uselessness".	"They are roommates who can learn from each other" (nurse) "He is very open to other patients in the clinic, and I see him many times talking to them" (physiotherapist)
Qualifier	Quality of social support system	Satisfaction and appreciation with social support	"My family was, still is and will always be very supportive and I am very thankful and happy for that" "I think one should not take it for granted,	"I see that he very much appreciates the support he gets" (nurse)

	Description	Example(s)	Example(s) text passages (patient)	Example(s) text passages (health professionals)
			being supported like I am…I am grateful for that"	
Interaction between social skills and social support		Assertiveness can lead to more instrumental support, Sensitivity in social relations can activate more emotional support	"I believe that all the things I have done for other people helping and how I treated and respected them comes now back to me."	"Being assertive in his manner and knowing what he wants (to remain in a standing position to work in the kitchen) encouraged me to plan specific sessions at the parallel bars" (physiotherapist) "He set his personal goal to work in the kitchen of their restaurant I tried to support his decision by organizing round tables to inform all parties involved in the decision of his future remunerative employment" (social worker) "His friends are taking care of outside work around the home, planning of the reconstruction of the barn and financing a wheelchair accessible home. I think it's his behavior towards them that causes such an amount of received support" (social worker) "I see that he tries to communicate his feelings and in turn to also understand her (his wife's') perspective, I think they are a good team in supporting each other" (nurse)

 Table 14: Spinal Cord Independence Measure (SCIM) for three time points during rehabilitation.

		16.06.2008	01.10.2008	01.10.2008)
Selfcare						
	Feeding	3	3		3	
	Bathing (upper, lower part)	3,1	3,1		3,2	
	Dressing (upper, lower part)	3,0	4,1		4,4	
	Grooming (face)	3	3		3	
		6		6		6
Respiration	n and sphincter management					
	Respiration	10	10		10	
	Sphincter management-bladder	0	0		0	
	Sphincter mangament-bowel	0	8		8	
	Use of toilet	2	2		2	
		12		20		20
Mobility in	room and toilet					
	Motion in bed and sore prevention	2	6		6	
	Transfers: bed-wheelchair	0	2		2	
	Transfers: wheelchair-toilet-tub	0	2		2	
		2		10		10
Mobility in	doors and outdoors					
	Mobility indoors	0	2		2	
	Mobility for moderate distances	0	2		3	
	Mobility outdoors	0	2		3	
	Stair management	0	0		2	
	Transfers: wheelchair-car	0	1		1	
		0		7		11
TOTAL SC	ORE	20		43		47

VI. *Empirical study*: Social skills: A resource for more social support and better mental health, participation and quality of life in persons with SCI?

VI.1. Specific aims

The aim of the fourth study is to test the hypotheses generated according to findings of the systematic literature review and the case study using empirical data. The following hypotheses are tested:

- 1) Higher levels of social skills relate to higher levels of social support.
- Higher levels of the social skills dimensions expressivity, sensitivity and control are related to higher levels of social support.
- The relationship between social skills and depression, participation and QoL is mediated by social support.
- 4) Social support shows a direct positive effect on depression, participation and QoL.

VI.2. Methods

Design

A cross-sectional observational study is conducted. It is nested in the Swiss Spinal Cord Injury Cohort Study (SwiSCI). SwiSCI adheres to applicable national and international standards for research in humans and was approved by ethical committees. The overall goal of SwiSCI is to gain a better understanding of how to support functioning, health maintenance, and QoL of persons with SCI along the continuum of care, in the

community, and along their life span. The design of SwiSCI is reported in more details elsewhere.³⁵²

Participants

SwiSCI includes persons aged 16 years or older with a permanent residence in Switzerland with traumatic or non-traumatic SCI. Persons with the following conditions are excluded: a) congenital conditions leading to para- or tetraplegia including spina bifida, b) new SCI in the context of palliative (end-of-life) care, c) neurodegenerative disorders including multiple sclerosis (MS) and amyotrophic lateral sclerosis (ALS), d) Guillain-Barré syndrome.

Medical records of four specialized SCI rehabilitation centers in Switzerland and member lists of two SCI associations (i.e. Swiss Paraplegic Association (SPV), parahelp) and one accidence insurance (i.e. Swiss Accidence Insurance (SUVA)) were screened for eligible participants. Participants were recruited according to the predefined eligibility criteria and have signed an informed consent form.

Procedures

Study participants filled in self-report questionnaires sent by postal mail (online survey option available). As a first wave, information about SwiSCI, informed consent and enclosed first questionnaire about sociodemographic and lesion-related characteristics were sent to the eligible participants. Persons who sent the first questionnaire back and agreed to participate in SwiSCI were eligible for further participation (second wave). A random sample of 38% was drawn from the respondents to the second wave to receive additional questionnaires used in this study.

Instruments

Data collections for this study included, beside sociodemographic and lesion-related variables, assessments for social skills, social support, depression, participation and QoL. The following measurement instruments have been used:

Social skills. The short form of the Social Skills Inventory (SSI)²⁷⁹ was applied to measure social skills. This 30-item instrument assesses social and emotional expressivity, sensitivity, and control. Appendix 4 shows the SSI Framework, scale definitions and sample items.¹⁴⁸ The respondents indicate to what extent statements apply to them on a scale of "not at all like me", "a little like me", "like me", "very much like me", "exactly like me". The SSI has been used in a variety of applied settings.²⁷⁹ The short form has shown good content validity and acceptable internal consistency in the general population. In the present study, internal consistency of the social skills questionnaire was acceptable (Cronbach α = .80).

Social support. The Short Form Social Support Questionnaire (SSQ6)¹²⁵ measures two basic elements of perceived social support using 6 items: the number of social support providers (SSQN) and satisfaction with social support (SSQS). Appendix 5 shows the SSQ6. For the present study, the product of SSQN and SSQS was calculated. SSQ scores have high test-retestreliability, high internal consistency, and confirmed construct validity in the general population.¹²⁵ The SSQ is one of the most frequently used guestionnaires in SCI.³⁵³

Depression. The depression subscale of the Hospital Anxiety and Depression Scale (HADS-D)³⁵⁴ was used as a measure of depression. It contains 7 items and responses are given on a 0 to 3 Likert scale. The HADS-D was found to be reliable and valid in assessing the symptom severity and caseness of depression in somatic, psychiatric, primary care

and general populations.^{38, 355} It is also frequently used³⁹⁻⁴² and psychometrically evaluated in a SCI population.³⁵⁶

Participation. Participation was measured with the 11-item Restriction scale of the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-Participation).^{63, 357} The USER-Participation Restriction subscale aims to measure experienced participation restrictions in vocational, leisure and social activities as a result of the person's health or disability. The participants are asked to rate activities on a scale of "not applicable" (i.e. can be used in case the item is not relevant to the person or if experienced restrictions are not related to the person's health status or disability), "not possible", "with assistance", "with difficulty", "without difficulty". The USER-Participation showed satisfactory validity, test-retest reliability, and responsiveness in rehabilitation setting.^{63, 64, 358} Cronbach's α of the USER-Participation Restriction subscale in this study was good (.85).

Quality of life. The 5-item version of the World Health Organization Quality of Life Scale - BREF (WHOQOL) was used to assess quality of life.^{75, 77} The 5 items cover overall QoL, satisfaction with health, daily activities, relationships, and living conditions. Psychometric properties of the WHOQoL-BREF have been examined in 23 countries with samples of ill and healthy persons⁷⁶ and in people with SCI.⁷⁷

Preliminary analyses

Descriptive statistics are reported about the recruitment of participants, sociodemographic and lesion-related variables. Median and interquartile range are calculated.

Examination of data distribution and missing data pattern was necessary to determine further analyses in structural equation modeling (SEM).

Highly non-normal distributed data affects the accuracy of statistical tests in SEM.³⁵⁹ In addition to graphical inspection, univariate distributions are examined for skewness and kurtosis. For the skewness index, absolute values greater than 2.0 are considered extreme. Values over 7.0 for the kurtosis index suggest a problem.³⁶⁰

The information about data missingness is necessary to obtain, as it determines the method for handling missing data. Data can be missing completely at random (MCAR: the pattern of missing values does not depend on the data values), missing at random (MAR: the pattern of missing data is related to the observed data only) or not missing at random (NMAR: systematic loss of data).³⁶¹ MCAR and MAR are unproblematic and can be integrated into the subsequent estimation. In case of NMAR (for example, if participants were missing data on the social support construct because they have little support) the only way to obtain an unbiased estimate of parameters is to model missing pattern is conducted by performing Little's Missing Completely at Random Test (Little's MCAR Test).³⁶² For this test, the null hypothesis is that the data are MCAR, and the p value is significant at the 0.05 level. If the value is less than 0.05, the data are not MCAR, but MAR or NMAR. The question of MAR or NMAR was addressed by content-based discussion and detailed investigation of patterns of the missing data.

Structural equation modelling

Structural equation modeling (SEM) was performed to test the hypothesis that higher levels of social skills and their dimensions expressivity, sensitivity and control, relate to higher levels of social support, which in turn relate to lower depression and higher participation and QoL (figure 1, 2). The statistical program LISREL 8.8 (ref.³⁶³) was used.

SEM includes two statistical techniques: factor analysis and path analysis. In factor analysis, intercorrelations among measured variables are analyzed to confirm an unobserved latent construct (measurement model, e.g. for social skills). The path analysis depicts the relationship among the latent constructs (structural model, e.g. relation between social skills and social support). The combination of factor and path analysis is based on Jöreskog's (1973) outline of the structural equation model that consists of two parts: measurement models and structural models.³⁶⁴

To address missing data, full information maximum likelihood (FIML) estimation method was used.³⁶⁵ The FIML approach computes a casewise likelihood function using only those variables that are observed. The FIML algorithm does not impute missing values, however, this borrowing of information from the observed portion of the data is conceptually analogous to replacing missing data points with the conditional expectation of missing data, given the observed data. Under ignorable missing data conditions (MCAR and MAR), FIML estimates are unbiased and more efficient than other methods such as listwise deletion, pairwise deletion, and similar response pattern imputation.³⁶⁵ In addition, maximum likelihood estimation was used in all analyses, as the main variables were considered as continuous (i.e. sum scores were used). Maximum likelihood estimation is considered robust to moderate violations of the normality assumption.³⁶⁶

As a preparatory step, latent variables depression, participation and QoL were constructed by using item parcels. Item parcels were used instead of using the total sum score of a one-dimensional measure (e.g. the first and second six items instead of using the total score of 12 items). Thereby a latent variable is created instead of taking the observed variable consisting of the total score. By using latent variables, measurement errors are incorporated in the model, which can reduce bias of the parameter estimates.³⁶⁷ Another advantage of having parcels as indicators is that they generally have higher

reliability than single items or single summary scores³⁶⁸ which results in better model fits.³⁶⁹

The main analyses steps included testing the hypothesized models against the observed data, i.e. to determine whether the associations among indicators and latent variables in the hypothesized model adequately reflect the observed association calculated in the correlation matrix. To examine the relevance of social skills and their different dimensions (i.e. expressivity, sensitivity and control) in relation to social support, depression, participation and QoL, two models are specified: Model 1 incorporates social skills as one overall latent variable and estimates its relation to social support and the outcomes depression, participation and QoL; Model 2 includes the three dimensions (expressivity, sensitivity, control) of the social skills construct separately as observed variables, and estimates their relations to social support and the outcomes depression, participation and QoL.

Model fit was determined according to a non-significant Chi Square (set at p > 0.05), which indicates that the hypothesized model relationships between variables are not significantly different from those observed in the data. In addition, root-mean-square error of approximation (RMSEA), which takes sample size and model complexity into account, is used to assess model fit. An RMSEA value of < 0.06 was taken as indication of good model fit.^{370, 371} Standardizes path coefficients (β) were obtained. Values greater than .50 indicate a large effect, values around .30 a median effect and values around .10 a small effect.

The last step consists of model modification to better approximate the observed patterns of relationships between the variables. Model modification should be justifiable with regards to content³⁵⁹ and was mainly based in this study on the examination of

standardized residuals. Adjustments to the estimated model by, for example, setting additional paths or letting error covariances between indicators correlate, were performed.

VI.3. Results

Out of the 379 participants randomly drawn from the respondents to the second wave, 313 sent the questionnaires back (60.66% of the eligible participants). Two persons did not fill in the questionnaire completely, leading to a deletion of two cases (N=311). The characteristics of the study participants are described in table 15. Median scores of the six different subscales and three social skills dimensions expressivity, sensitivity and control, social support number and satisfaction as well as the outcomes depression, participation and QoL are provided in table 16. Correlations between these variables are shown in table 17. Low and non-significant correlations were found between social skills and sociodemographic and lesion-related characteristics. The number of social support providers correlated negatively with age.

Skewness and kurtosis values were found below the cut-offs and graphical inspection revealed normal distribution of the data. A total of 5.53% of the data were missing. In the Little's MCAR, the significant value was less than 0.05 (p=0.02) According to a content-based discussion and investigation of patterns of the missing data, it is assumed that the data are missing random, however NMAR cannot be ruled out.

SEM model fit

Model 1 depicts the relationship between social skills as a latent variable and social support as possible mediating variable to the outcomes depression, participation and QoL, with two item parcels for each outcome. Model 1 fits well, with a non-significant Chi Square 37.16, df=27, p=0.092 and a RMSEA of 0.035.

Model 2 includes the social skills domain expressivity, sensitivity and control and their relation to social support (possible mediator) and depression, participation and QoL. The second model fits very good, with a non-significant Chi Square 14.28, df=19, p=0.767 and a RMSEA of 0.00.

Relationship between social skills and social support

A standardized path coefficient .31 between social skills as a latent variable and social support is found in model 1. Social skills explained 10% of the variance in social support.

In model 2, the path between social skills dimension expressivity and social support was significant (β = .20). Non-significant path coefficients are found from the social skills dimension sensitivity (β = .05) and control (β = .09) to social support.

Relationship between social skills and depression, participation and QoL

Social skills as a latent variable was found to be directly related to depression (β = -.38) and QoL (β = .36) in model 1. Social skills explained 43% of the variance in depression and 17% of the variance in QoL. Social skills, social support, participation and QoL explained together 79% of the variance in depression, 73% of the variance in QoL is explained by social skills, social support, depression and participation and 26% of the variance in participation is explained by social skills, social skills, social skills, social support, depression and QoL. A non-significant path was found between social skills and participation.

In model 2, significant path coefficients between social skills dimension expressivity and depression (β = -.11) and QoL (β = .14) were revealed. Also the social skills dimension control showed a significant path to depression (β = -.21) and QoL (β = -.25). The social skills dimension sensitivity only indicates a significant negative path coefficient of -.14 to QoL, other paths are non-significant.

Social support as a mediator

The hypothesis of a mediating effect of social support between social skills and the outcomes depression and participation could not be supported. Path coefficients from social support to depression (Model 1: β = .01 / Model 2: β = -.03) and participation (Model 1: β = .04 / Model 2: β = -.03) were non-significant. Social support partially mediated the relationship between social skills and QoL (Model 1: β = .16) and the relationship between the social skills dimension expressivity and QoL (Model 2: β = .21). There is a significant partial mediating effect (p= .03) of social support between social skills and QoL.

VI.4. Discussion

Social skills are a resource for more social support and better mental health and QoL in persons with SCI, but not for overcoming participation restrictions.

This study supports the hypothesis that higher levels of social skills do relate to more social support in persons with SCI. Higher levels of the social skills dimension expressivity seems to hold the strongest relation to more social support. Social skills have a direct positive effect on mental health and QoL. In specific, being socially expressive and controlled is associated with lower levels of depression and higher levels of QoL. In contrast, being sensitive in social situations seems to have a negative effect on QoL. The hypothesis that social support mediates the relationship between social skills on one hand and participation and depression on the other could not be supported. Yet, social support partially mediated the relationship between social skills and QoL. No hypothesized direct positive effect of social support on depression and participation was found.

Social skills are an important resource in SCI.

Higher levels of social skills relate to more social support in the general population.^{141, 257, 350, 372} It can be assumed that in persons with SCI, being emotionally and socially expressive means being able to inform others about their emotional state (e.g. today I feel like a burden) and about their needs (e.g. now I need your tangible assistance). From a providers perspective, these information facilitates giving social support. However, these social skills seem to explain only a small amount of variance in social support. The question about the availability of social support could depend on a number of other factors: the support receiver's ability to construe social support as available and experience one's social network as supportive;³⁷³ the ability to form socially supportive relationships based on secure attachment formed in childhood;³⁷⁴ the principle of reciprocity and the support providers experiences of being needed by others and having a purpose in life;³⁷⁵ and the evolutionary theoretical perspective, that humans help others for the sake of survival. These factors were not measures in this study.

Higher levels of social skills were found to be related to lower levels of depression. This result is consistent with studies supporting the behavioral theories of depression, ^{136,} ³⁷⁶ which specify social skills deficits as a risk factor for subsequent depression³⁵⁰ and the possession of adequate social skills as a protective factor.³⁷⁷

Social skills were found to be directly related to QoL. Studies in the general population show that social skills are positively associated with indicators of psychological well-being (i.e. life satisfaction, environmental mastery, self-efficacy, hope, happiness and QoL).^{141, 378} It is assumed that a person who has skills in expressivity and control is able to achieve his or her interpersonal goals and to win the praise and admiration of others. These positive experiences could instill a sense of satisfaction with life and QoL.¹⁴¹

seems to have a negative effect on QoL in persons with SCI. It could be assumed that persons high in sensitivity are more likely to detect negative signals, e.g. in relation with negative attitudes, prejudice and discrimination against persons with disabilities.

A non-significant path was found between social skills and participation. Participation might be better explained by other factors then social skills. Studies in SCI show that functional status, functional status, time since discharge from rehabilitation, neuroticism, self-efficacy, self-esteem and environmental facilitators and barriers contribute to the level of participation. ⁸³⁻⁹⁵

In this study no or only small beneficial effects of social support were found.

Social support partially mediated the relationship between social skills and QoL, which is consistent with findings from the general population.^{141, 378} However, social support did not mediate the relation between social skills on one hand and participation and depression on the other. It needs to be considered, that social support could also act as a moderator (i.e. strengthening or weakening an interaction effect) instead of a mediator (i.e. clarifying the nature of an interaction effect). As an example, social support was found as a mediator between optimism and depression in cancer patients.³⁷⁹ But social support was also found being a moderator between psychological strengths (i.e. hope, optimism, self-efficacy, and resiliency) and subjective well-being.³⁸⁰

Surprisingly very low and non-significant paths were revealed between social support and the outcomes depression, participation and QoL. The stress-buffering theory of social support states that social support acts as a buffer to protect people against negative effects of stress.¹¹⁰ Evidence for the stress-buffering theory has been reviewed in the field of different health conditions³⁸¹ and persons with SCI.³⁵³ According to this theory, social support may represents a mediating or moderating factor that only becomes important when an individual experiences high levels of stress.³⁸² The relation of social support to

health and QoL seems to depend upon an individual's level of stress. Time since injury of the present sample is high with a mean of 20 years and the median depression score of 3 is very low and under the cut-off point 8 of mild cases.³⁶ Although stress has not been assessed in this study, the participants of this study might experience on average low levels of stress. In addition, other factors than social support determine depression, participation and QoL. As shown in this study social skills but also other factors such as functional independence, pain, coping strategies, self-efficacy and self-esteem or environmental barriers and facilitators determine depression, participation and QoL in persons with SCI.

Study limitations

Some limitations in this study need to be considered.

First, due to the randomization process within a list of responders that already agreed to participate in SwiSCI, this nested study can report a very high response rate. However, this procedure results in data of persons that are highly willing to report on their state. The part of these persons with SCI with low motivation and maybe concerned with more problem could not be reached. A respondent – non-respondent comparison would uncover sample based biases. However, information about non-responders of the whole SwiSCI study will be published elsewhere.³⁸³

Second, interpretation of these findings is constrained by the fact that all variables were measured by self-report. Self-reports may yield somewhat incomplete measures of certain constructs, especially social skills which can also be assessed through behavioral assessment, or social support by measuring support received rather than perceived.

Finally, SEM is a confirmatory method in which one-way arrows are specified, but it does not allow conclusions to be drawn about causality in studies with a cross-sectional design. Causality can be determined by conducting longitudinal studies.

Future research

The SEM approach of this study can be used to examine complex relationships. This study was a first attempt to examine the relationship between social skills, social support, depression, participation and QoL. However, further research is needed to test whether the relationships found in the present study can be confirmed and whether these models are also valid in other health conditions. In addition, this study only tested for a mediating effect as well as unidirectional paths from social skills to social support and to the outcomes depression, participation and QoL in a cross-sectional design. Further studies are needed to test a possible moderating effect of social support as well as the reciprocal relations between all directions. Longitudinal studies are needed to ascertain conclusions on causality.

Conclusions

Social skills are a resource for more social support and better mental health and QoL. In this study, social support seems not to play a key role in determining depression, participation and QoL. Instead, being socially and emotionally expressive and able to adequately control emotions and "fit" a social situation are important skills in persons with SCI, as they are associated with lower levels of depression and higher levels of QoL.

The findings of this study could inform clinical practice by providing information about what to target in interventions to enhance mental health and QoL of persons living with SCI.

Model 1: SEM model of the relationship between social skills, social support and depression, participation and QoL. Bold lines are significant paths.



Model 2: SEM model of the relationship between social skills dimensions (expressivity, sensitivity control) social support and depression, participation and QoL. Bold lines are significant paths.



 Table 15: Descriptive characteristics of study participants (N=311).

	Ν	%
Gender		
Male	223	71.7
Female	88	28.3
Missings	0	
Marital status		
Single (never married)	106	34.1
Married	152	48.9
Widowed	38	12.2
Divorced	12	3.9
Reg. Partnership	2	0.6
Missings	1	0.3
Age (mean / range in years)	53.54 (19-91)	
Missings	2	0.6
Education (mean / range in years)	13.9 (2-25)	
Missings	3	1.0
Time since injury (mean / range in months)	235 (8-748)	
Missings	12	3.9
Level of lesion		
Paraplegia	217	69.8
Tetraplegia	91	29.3
Missings	3	1.0
Completeness of lesion		
Complete	158	50.8
Incomplete	152	48.9
Missings	1	0.3
Cause of injury		
Traumatic	250	80.4
Non-traumatic	47	15.1
Other cause	13	4.2
Missings	1	0.3

Table 19. Descriptive onarabient and quality of me	Table 16: Descri	ptive characteristics	of Social Skills,	Social Suppor	t and the outcomes	depression,	participation a	and quality	of life.
---	------------------	-----------------------	-------------------	---------------	--------------------	-------------	-----------------	-------------	----------

Variable	Measure	Range	Median (IQR)	Missing n (%) ^a	
Social Skills (Total score)	SSI	30 - 150	93 (85- 102)	27 (8.7)	
Emotional Expressivity (SSIEE)	SSI	5 - 25	16 (14 - 18)	15 (4.8)	
Emotional Sensitivity (SSIES)	SSI	5 - 25	15 (13 - 18)	18 (5.8)	
Emotional Control (SSIEC)	SSI	5 - 25	17 (15 - 19)	12 (3.9)	
Social Expressivity (SSISE)	SSI	5 - 25	15 (12 - 18)	12 (3.9)	
Social Sensitivity (SSISS)	SSI	5 - 25	13 (11 - 16)	12 (3.9)	
Social Control (SSISC)	SSI	5 - 25	17 (15 - 19)	12 (3.9)	
Expressivity (SSIE)	SSI	10 - 50	31 (26 - 35)	17 (5.5)	
Sensitivity (SSIS)	SSI	10 - 50	29 (25 - 32)	20 (6.4)	
Control (SSIC)	SSI	10 - 50	34 (30 - 37)	15 (4.8)	
Social Support (Total) ^b	SSQ	0 - 1944	540 (325.8 – 828.0)	0	
Number of support persons (SSQN)	SSQ	0 - 54	16 (10 - 23) ^c	54 (17.4)	
Satisfaction with support (SSQS)	SSQ	6 - 36	35 (30 - 36)	49 (15.8)	
Depression	HADS	0 - 21	3 (1 - 6)	6 (1.9)	
Participation	USER-P	11 - 55	43 (37 - 49)	36 (11.6)	
Quality of life	WHOQOL	5 - 25	20 (17 - 21)	14 (4.5)	

Abbreviation: IQR: interquartile range

a: Values are n(%). Missing n total score, i.e. if there is one item missing, the total score could not be calculated and is therefore missing b: Total score of SSQ refers to the product of Social Support Number and Social Support Satisfaction

c: 3(2-4) support persons per participant and question

Table 17: Pearson correlation between sociodemographics, lesion-related characteristic, social skills (expressivity, sensitivity, control), social support, depression, participation and QoL.

		Gender Ag	ge E	Edu	MS	TSI	LL	CL	SSIE	SSIS SSIC	SSQN SSQS HADS USER-P WHOQOL
Sociodemographics	Gender	1									
	Age	164**	1								
	Education (Edu)	050	128 [*]	1							
	Marital status (MS)	063 .3	355	.033	1						
Lesion-related	Time since injury (TSI)	084 .2	268 ^{**} ·	010	.067	1					
	Level of lesion (LL)	086	.105	.042	033	.079	1				
	Completness of lesion (CL)	.005 .1	147 ^{**} ·	049	.065	180	.109	1			
Social skills	Expressivity (SSIE)	.022	128	.056	.111	.070	040	060	1		
	Sensitivity (SSIS)	.167	.101 .	173	.025	.030	.068	.071	.277	[*] 1	
	Control (SSIC)	034	125	.138 [*]	.052	.146 [*]	010	085	.426	.139 [*] 1	
Social support	Number (SSQN)	.1612	206	.059	075	026	014	145	.260	.137 [*] .203 ^{***}	1
	Satisfaction (SSQS)	.155 [*]	.029	.003	108	.023	010	089	.054	005 .139 [*]	.338 1
Outcomes	Depression (HADS)	010 .	084 ·	007	.075	228**	.082	.095	371 [*]	*029460	·.245 ^{°′′} 320 ^{°′′′} 1
	Participation (USER-P)	113:	322 .	162	053	.054	188	.009	.217	.050 .192	.161 .019375 1
	Quality of life (WHOQOL)	011	.003 ·	010	004	.204	147 [*]	124	.258	·062 .347	.213 .305687 .420 1

** Correlation is significant at the 0.01 level. * Correlation is significant at the 0.05 level.

VII. General discussion

VII. General discussion

The general aim of the present thesis is to understand how social skills and social support interrelate and how they are associated with depression, participation and QoL in persons living with SCI. To address this aim the thesis is divided into four parts.

The first study has ascertained in a sample of 102 persons with SCI that depression can be measured appropriately in this population using the HADS. The results of the Rasch analyses support the validity and reliability of the anxiety and depression subscales. However, based on the results an overall summary score should not be used.

As a second part, a systematic literature review of 58 studies showed that social support is positively related to physical and mental health, to pain, coping, adjustment, and QoL in SCI. Eleven studies showed that social skills (mainly problem-solving skills and assertiveness) are related to better mental health outcomes, to health prevention behaviour and less secondary conditions. Sociodemographic and lesion-related characteristics were rarely associated with social support but can be related with social skills. Findings about the relations of social support and social skills to participation is fragmented. The review identified only one study, which examined the relationship between social skills and social support in SCI.

A case study complemented the literature review regarding the generation of the hypotheses. It illustrated a patient's social skills, the need for their adaptation after SCI, their association to the social support network as well as to functional independence which would facilitate participation.

The systematic review of the literature and the case study taken together have led to the generation of the hypotheses that (1) social skills relate to social support, (2) that social support has a positive effect on depression, participation and QoL, and (3) that the

relationship between social skills and depression, participation and QoL is mediated by social support.

The fourth study used empirical data to test these hypotheses. SEM revealed that social skills were related to social support in a sample of 311 persons with SCI living in Switzerland. Thereby the social skills dimension expressivity holds the strongest relation to more social support. Social skills are directly related to depression and QoL. Social support did not act as a mediator between social skills on one hand and participation and depression on the other hand. However, social support partially mediated the relationship between social skills and QoL. No direct positive effect of social support on depression and participation was found.

A strong positive effect of social support on depression and QoL was found in the literature review, in contrast, the empirical study showed no or only small effects of social support on these outcomes. Time since injury seems to be one reason of the inconsistent results. Social support buffers against negative consequences of stressful life events such as SCI. ¹¹⁰ However, persons adjust to SCI, and the buffering effect of social support might diminish.

More important seems to be a person's social skills. This thesis showed that social skills are an important resource in persons with SCI as they play a key role in relation to physical and mental health and QoL. According to the literature review specific social skills, such as effective social problem-solving skills, are linked to lower depression. Self-monitoring is related to higher levels of participation and verbal communication skills correlate with QoL. The case study could elaborate that social skills can mobilize social support, which positively effects functional independence and ultimately participation. The empirical study confirmed that higher levels of social skills relate to more social support, lower levels of depression and higher QoL.

Persons can only use their social skills when actively interacting with others. Thus, high levels of social skills are linked to active interaction and frequently investing in social relations. Positive experiences with this social relations provides a sense of satisfaction with life and QoL and protects from the development of depression.^{384, 385} It can be concluded, that social skills facilitate social interactions and ultimately foster social relationships which in turn positively impacts well-being.

Participation is an important rehabilitation outcome.⁵³ However, social skills and social support do not explain its variation. Fragmented findings from the literature review indicate some relations of social skills and social support to participation, however, no relationship was found in the empirical study.

Participation is known to be affected by many factors. Research in SCI shows that the severity of the injury (i.e. level and completeness of injury and pain) and psychological morbidity (i.e. anxiety and depression) do not or only to a small extent explain the level of participation.⁸³ But for example, physical activity, environmental facilitators (e.g. mobility devices), a person's self-efficacy, self-esteem and neuroticism explain a considerable amount of participation in persons living with SCI.^{83, 84, 386} Still, these findings about determinants of participation are fragmented and further research is needed to explain participation in persons with SCI.

VII.1. Clinical implications of this thesis

Social skills seem not to change in SCI, and scores in social skills of the participants of the empirical study do not differ compared to norms of the general population.³⁸⁷ However, newly spinal cord injured individuals need to learn to deal with a changed social environment, e.g. differential behavioural patterns of abled-bodied people towards people with a disability, special social situations that apply to SCI and decreased general

assertiveness, which was also shown in the case study.¹⁴⁹ Therefore, strengthening social skills is important in SCI rehabilitation. However, a rehabilitation setting with little behavioral independence might undermine social competence because there is little opportunity to practice social skills which would be useful after discharge. Therefore, social skills training is offered by psychologists at the rehabilitation center, which aims at a realistic preparation of the patient to a life after discharge. Specific goals of these trainings are to increase the capacity to act, to expand the use of social skills and decrease feelings of helplessness in social situations, which are more difficult or at least changed due to SCI. But also to strengthen the belief in one's own social skills, which would prevent the patient from self-depreciation and withdrawal.³⁸⁸

The successful training of social skills is widely used in different psychological disorders in children and adults.^{135, 281-286} However, studies in the field of social skills are more focused on examining the negative impact of social skills deficits. Social skills as a strength or resource and their potential positive impact has been understudied in the general population as well as in the field of SCI. In SCI research, two studies with small sample size of persons with SCI and others depending on a wheelchair, examined social skills training by focusing on assertiveness. ^{150, 287} Both studies found improvements in behavioral measures of social skills after the intervention.

According to the findings of this thesis, interventions targeted at social skills should focus on being expressive and having emotional and social control in social situations. Training in expressivity could include learning to be "effective", which means to be able to inform others about one's emotional state by using appropriate verbal and non-verbal communication, to tell others about personal needs, to ask for help and also to engage others in social interactions. Training in control would focus on the "appropriateness", which implies learning to be able to regulate emotions, to promote skills in selfpresentation and adjustment to certain social situations.

Strengthening the social support system of a newly injured person is vital. Social support interventions have been shown their effectiveness in different health conditions.²⁸⁸ In SCI, one randomized controlled trial was found which provided supportive group therapy to persons with SCI.²⁰⁴ The results showed that supportive group therapy was equally effective in reducing depression and anxiety as cognitive effectiveness training. However, matching specific forms of support interventions may be of particular importance, as different types of social support from different sources have different impacts on a person with SCI. For example, emotional support from family protects from developing depression and support from peers is linked to higher levels of participation. In contrast, instrumental and informational support from friends negatively impacts QoL and increases pain. ^{229, 236}

VII.2. Conclusions

This thesis provides clearer understanding of the associations of social skills and social support with mental health, participation and QoL in persons with SCI. Social skills play a key role in mental health and QoL. Social support may be beneficial at different points in time. Future research endeavor in longitudinal studies can answer the question of how social support impacts adjustment to SCI. In addition, further studies are needed to examine determinants of participation, as social skills and social support seem not to contribute to the level of participation.

This thesis can provide some information about what to target in interventions. In specific, to train being socially and emotionally expressive and able to adequately control emotions and "fit" a social situation may counteract the negative consequences of SCI by lowering levels of depression and enhance QoL in persons with SCI.

VIII. Summary

VIII. Summary

1. Background

Along with physical impairments, spinal cord injury (SCI) is associated with an increased risk for psychological morbidity, affects participation in social life and quality of life (QoL). Social support and social skills could act as resources to meet these challenges. Both are known to positively influence depression, participation and QoL in the general population.

Social support is defined as an exchange of resources between individuals intended to enhance the well-being of the recipient. It acts as a buffer to protect people against negative effects of stressors. Different types (i.e. instrumental, informational, emotional) of social support from different sources (e.g. family, friends) and seen from different perspectives (e.g. quantity and quality) can be distinguished.

Social skills are defined as the ability to interact with other people in a way that is appropriate and effective. They are, according to evolutionary theory, prerequisites for survival and adaptation. They comprise aspects of verbal and non-verbal communication. They include, for example, styles of social problem-solving (e.g. rational, impulsive, or avoidant), assertiveness, goal-direction, or self-monitoring. In addition, emotional as well as relationship aspects of social skills can be described (e.g. expressivity, sensitivity and control).

Research in general population shed light on the relevance of social support and social skills. However, it is unclear how relevant they are in SCI and how they influence depression, participation and QoL. This thesis tries to answer the question how social skills and social support influence depression, participation and QoL in persons with SCI. Before addressing this question, psychometrically sound working measurement instruments need to be available to ascertain valid and reliable assessment of the

outcomes depression, participation and QoL. Valid and reliable measurement instruments exist to assess participation and QoL in persons with SCI. However, it is unclear if measuring depression and anxiety with the Hospital Anxiety and Depression Scale (HADS) is applicable in a population of persons with SCI.

2. Aims and outline of the thesis

The objective of this thesis is to understand how social skills and social support interrelate and how they are associated with depression, participation and QoL in persons living with SCI.

The following specific aims are addressed:

- a) To evaluate the psychometric properties of the Hospital Anxiety and Depression Scale (HADS) applied in a SCI population using Rasch analysis.
- b) To examine the current knowledge from the scientific literature of how social support and social skills are relevant in SCI and obtain first hints and generate hypotheses about the association of these factors with depression, participation and QoL of persons living with SCI.
- c) To complement the literature review (b) regarding the generation of hypotheses about the influencing pathways of social skills and social support on participation by using data of a case study.
- d) To test the following hypotheses generated in b) and c) using empirical data
 - 1) Higher levels of social skills relate to higher levels of social support.
 - Higher levels of the social skills dimensions expressivity, sensitivity and control are related to higher levels of social support.
 - The relationship between social skills and depression, participation and QoL is mediated by social support.

4) Social support shows a direct positive effect on depression, participation and QoL.

This thesis is divided in four parts each of which addresses one of the specific aims.

3. Understanding the associations of social skills and social support with mental health, participation and quality of life in persons with spinal cord injury

a) Psychometric study: Rasch analysis of the Hospital Anxiety and Depression scale in spinal cord injury

The purpose of the first study is to evaluate the psychometric properties of the HADS applied in a SCI population using Rasch analysis.

Secondary analysis of a cross-sectional multi-center study was conducted and the data of 102 persons with SCI were analyzed. Rasch analyses were performed to assess dimensionality, overall and individual item fit, response scale structure, targeting and differential item functioning (DIF).

The anxiety and depression subscales showed unidimensionality, i.e. model and item fit. The two subscales are reliable (r=0.72, 0.82) in SCI. No disordered structure of the response scales or differential item functioning in age, gender, education, relationship status, level of spinal lesion was found. Stepwise deletion of the misfitting items did not produce a total score that fulfilled the statistical criteria for unidimensionality.

The results of the Rasch analyses support the use of the anxiety and depression subscales among persons with SCI. However, further research is needed to confirm these findings and examine sensitivity to change of the HADS in SCI, which would support its use in longitudinal observational and intervention studies.

b) Systematic literature review: The role of social support and social skills in persons with SCI

The aim of the second study is to examine the current knowledge from the scientific literature of how social support and social skills are relevant in SCI and to obtain first hints and generate hypotheses about the association of these factors with depression, participation and QoL of persons living with SCI.

A systematic literature review was conducted. The literature search was carried out in Pubmed, PsycINFO, ERIC, CINAHL, Embase and SSCI. Publications were identified according to predefined eligibility criteria, study qualities were evaluated, study results extracted, and a narrative synthesis was compiled.

Fifty-eight publications about social support and SCI were included. Social support was positively related to physical and mental health, to pain, coping, adjustment, and life satisfaction. Social skills were assessed in 11 studies: social problem-solving (n=7), assertiveness (n=3), verbal communication (n=1) and self-monitoring (n=1) were examined. Effective problem-solving skills were related to better mental health outcomes, to health prevention behaviour and less secondary conditions. Assertiveness was related to higher depression in rehabilitation setting. Sociodemographic and lesion-related characteristics were rarely associated with social support but can be related with social skills. Findings about the relations of social support and social skills were scarcely studied. Only one study examined the relationship between social skills and social support in SCI.

It can be concluded, that the relationship between social skills and social support, and how this interrelation operates with depression, participation and QoL have not been fully understood in SCI. The following hypotheses should be tested by further studies: social skills relate to social support and social support has a positive effect on depression,
participation and QoL; the relationship between social skills and depression, participation and QoL is mediated by social support.

c) Case study: Social support and functional independence in a person with SCI - the role of social skills

This case study complements the literature review regarding the generation of hypotheses about the influencing pathways of social skills and social support on participation by using data of a case study.

Qualitative (i.e. observation, structured and open interviews with the patient and health professionals) and quantitative data (i.e. SCIM, medical records) were collected. Content analysis of the interviews was performed to identify aspects of social skills and social support. An ICF-based documentation tool (i.e. ICF Assessment Sheet) was used to structure information about the level of functioning regarding body functions and structures, activity and participation, environmental and personal factors of a 57-year old male with incomplete paraplegia during first rehabilitation.

The patient presented a variety of effective social skills (i.e. assertiveness, goaldirection). However, the adaptation of skills, such as asking for help social problemsolving, sensitivity and expressivity in social relations became necessary to acquire. The patient received different types of social support (i.e. emotional, informational, instrumental) from different sources (e.g. family and friends). The qualitative interviews provided indications for an interaction between social skills and social support. The impact of social skills and social support on participation is discussed.

This case study generates the hypothesis that social skills relate to social support and that social support has a positive effect on participation. It is also hypothesized that the relationship between social skills and participation is mediated by social support.

d) Empirical study: Social skills - A resource for more social support and better mental health, participation and quality of life in persons with spinal cord injury?

The aim of the fourth study is to test the hypotheses generated according to findings of the systematic literature review and the case study using empirical data.

A cross-sectional observational study nested in Swiss Spinal Cord Injury Cohort Study (SwiSCI) was conducted with persons (N=311) aged 16 years or older with a permanent residence in Switzerland with traumatic or non-traumatic SCI. Social skills were measured using the Social Skills Inventory (SSI) and a short version of the Social Support Questionnaire (SSQ6) was used to assess social support. To measure the outcome variables depression, participation and QoL, the Hospital Anxiety and Depression Scale (HADS), the Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) and the World Health Organization Quality of Life Scale - BREF (WHOQOL), were applied.

Structural equation modeling revealed that social skills relate to social support (β = 0.31 / R^2 = .10) with the social skills dimension expressivity showing the highest path coefficient (β = .20). Social skills are directly related to depression (β = -.38 / R^2 = .43) and QoL (β = -.36 / R^2 = .17) but not to participation. Significant path coefficients between social skills dimension expressivity and depression (β = -.11) and QoL (β = .14) and control an depression (β = -.21) and QoL (β = -.25) were revealed. The social skills dimension sensitivity indicates a significant negative path coefficient of -.14 to QoL. Social support did not mediate the relationship between social skills on one hand and participation and depression on the other. Yet, social support partially mediated the relationship between social skills and QoL (Model 1: β = .16 / Model 2: β = .21 / p= .03). No direct positive effect of social support on depression and participation was found.

It can be concluded, that social skills are a resource for more social support and better mental health and QoL. In this study, social support seems not to play a key role in determining depression, participation and QoL. Instead, being socially and emotionally expressive and able to adequately control emotions and "fit" a social situation are important skills in persons with SCI. The findings of this study could inform clinical practice by providing information about what to target in interventions to enhance mental health and QoL of persons living with SCI.

4. Discussion

The general aim of the present thesis is to understand how social skills and social support interrelate and how they are associated with depression, participation and QoL in persons living with SCI. To address this aim the thesis is divided into four studies. The first study has ascertained, that the HADS is an appropriate measure to assess depression in SCI population. According to the systematic literature review and the case study, the hypotheses were generated, that social skills relate to social support, that the relationship between social skills and depression, participation and QoL is mediated by social support and that social support has a direct positive effect on depression, participation and QoL. The last study found a direct effect of social skills on social support, depression and QoL, but no relation of social skills and social support on participation, no mediating or direct effect of social support but a direct and partially mediating effect of social support between social skills and QoL.

To conclude, social skills play a key role in mental health and QoL. Social support seems to be beneficial at different points in time. Future research endeavor in longitudinal studies can answer the question of how social support impacts adjustment to SCI. In addition, further studies are needed to examine determinants of participation, as social skills and social support seem not to contribute to the level of participation.

This thesis can provide some information about what to target in interventions. In specific, to train being socially and emotionally expressive and able to adequately control

emotions and "fit" a social situation may counteract the negative consequences of SCI by lowering levels of depression and enhance QoL in persons with SCI.

IX. Zusammenfassung

IX. Zusammenfassung

1. Hintergrund

Neben der physischen Behinderung ist eine Rückenmarksverletzung mit dem erhöhten Risiko einer psychologischen Erkrankung sowie einem negativen Einfluss auf Partizipation und Lebensqualität verbunden. Soziale Unterstützung als auch soziale Kompetenzen gelten dabei als wichtige Ressourcen um diesen Belastungen entgegenzuwirken. In der Allgemeinbevölkerung konnte ein positiver Effekt dieser beiden Faktoren auf depressive Erkrankungen, Partizipation und Lebensqualität gezeigt werden.

Soziale Unterstützung wird definiert als der Austausch von Ressourcen zwischen Individuen mit dem Ziel das Wohlbefinden des Empfängers zu erhöhen. Sie wirkt dabei wie ein "Puffer", der die Menschen vor den negativen Effekten von Stress schützt. Es können verschiedene Arten sozialer Unterstützung (z.B. instrumentell, informatorisch, emotional) von verschiedenen Quellen (z.B. Familie, Freunde) und unter verschiedenen Gesichtspunkten betrachtet (z.B. Quantität und Qualität) unterschieden werden.

Soziale Kompetenzen werden definiert als die Fähigkeit mit anderen Menschen angemessen und effektiv zu interagieren. Aus evolutionstheoretischer Sicht sind diese die Grundvoraussetzung für Überleben und Anpassung. Soziale Kompetenzen umfassen verbale und non-verbale Kommunikation als auch Strategien zur Problemlösung (rational, impulsiv oder vermeidend), Durchsetzungsfähigkeit, Zielorientiertheit und Selbstbeobachtung. Ebenso werden soziale Kompetenzen im Zusammenhang mit sozialen und emotionalen Beziehungen beschrieben (Expressivität, Sensibilität und Kontrolle).

Studien aus der Allgemeinbevölkerung deuten auf die Relevanz von sozialer Unterstützung und sozialen Kompetenzen hin. Es ist jedoch unklar welche Rolle diese bei Personen mit Rückenmarksverletzung spielen und wie sie depressive Erkrankungen,

Partizipation und Lebensqualität beeinflussen können. Deshalb versucht diese Arbeit die Frage zu beantworten, wie soziale Kompetenzen und soziale Unterstützung Depression, Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung beeinflussen. Zuvor muss jedoch sichergestellt sein, dass psychometrisch einwandfrei funktionierende Instrumente zur Messung der Zielvariablen Depression, Partizipation und Lebensqualität vorhanden sind. Es existieren valide und reliable Messinstrumente zur Menschen Messung von Partizipation und Lebensqualität bei mit einer Rückenmarksverletzung. Hingegen ist unklar, ob die Hospital Anxiety and Depression Scale mit (HADS) Depression bei Menschen einer Rückenmarksverletzung psychometrisch einwandfrei messen kann.

2. Ziele und Gliederung der Doktorarbeit

Das Hauptziel dieser Doktorarbeit ist zu verstehen wie soziale Kompetenzen und soziale Unterstützung miteinander verknüpft sind und wie diese Depression, Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung beeinflussen.

Folgende spezifischen Ziele werden dabei behandelt:

- a) Die psychometrische Analyse des Hospital Anxiety and Depression Scales (HADS) basierend auf dem Rasch Modell, angewendet in einer Stichprobe mit Menschen mit einer Rückenmarksverletzung.
- b) Die Untersuchung des aktuellen Wissensstandes in der wissenschaftlichen Literatur zur Relevanz sozialer Unterstützung und sozialer Kompetenzen im Bereich der Rückenmarksverletzung sowie darauf basierend die Generierung von Hypothesen zur Assoziation dieser beiden Faktoren mit Depression, Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung.

- c) Die Ergänzung der systematischen Literaturauswertung (b) betreffend Generierung von Hypothesen über die Beeinflussung von sozialen Kompetenzen und sozialer Unterstützung auf Partizipation anhand von Daten aus einer Fallstudie.
- d) Die Prüfung der folgenden Hypothesen, generiert in b) und c), anhand von empirischen Daten.
 - 1) Mehr soziale Kompetenzen hängen mit mehr sozialer Unterstützung zusammen.
 - 2) Mehr soziale Kompetenzen wie Expressivität, Sensitivität und Kontrolle hängen mit mehr sozialer Unterstützung zusammen.
 - Der Zusammenhang zwischen sozialen Kompetenzen und Depression, Partizipation und Lebensqualit\u00e4t wird durch soziale Unterst\u00fctzung mediiert.
 - Soziale Unterstützung hat einen direkten positiven Effekt auf Depression, Partizipation und Lebensqualität.

Um diese spezifischen Ziele zu behandeln wurde die Doktorarbeit in vier Teile gegliedert.

3. Der Zusammenhang von sozialen Kompetenzen und sozialer Unterstützung mit Depression, Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung

a) Psychometrische Studie: Rasch Analysen des Hospital Anxiety and Depression Scale Fragebogens, angewendet bei Menschen mit einer Rückenmarksverletzung

Der Zweck der ersten Studie ist die psychometrische Evaluation des Hospital Anxiety and Depression Scale (HADS) Fragebogens anhand von Rasch Analysen welcher in einer Stichprobe von Menschen mit Rückenmarksverletzung angewendet wurde. Es wurden Zweitanalysen einer multi-center Querschnittstudie durchgeführt. Dabei wurden Daten von 102 Personen mit einer Rückenmarksverletzung analysiert. Anhand von Rasch Analysen wurde die Dimensionalität, der Modell- und Itemfit, die Struktur der Antwortskalen sowie Targeting und Differential item functioning (DIF, gruppenabhängige Funktionsweise von Items) untersucht.

Die Angst- und Depressionssubskalen des HADS sind eindimensional (gemäss Modell- und Item-fit), und lieferten reliable Ergebnisse (r=0.72 bzw. 0.82) in einer Stichprobe mit Menschen mit einer Rückenmarksverletzung. Es wurden weder ungeordnete Strukturen der Antwortskalen noch DIF bezüglich Alter, Geschlecht, Ausbildung, Beziehungsstatus oder Läsionshöhe gefunden. Durch schrittweises Löschen nicht-fittender Items konnten die beiden Subskalen nicht auf eine einzelne Skala gekürzt werden, welche den statistischen Kriterien der Eindimensionalität entspricht.

Die Resultate der Rasch Analysen unterstützen den Gebrauch der beiden HADS Subskalen Angst und Depression bei Menschen mit einer Rückenmarksverletzung. Jedoch sind weitere Studien nötig um diese Resultate zu bestätigen. Ebenso muss die Veränderungssensitivität des HADS bei Menschen mit einer Rückenmarksverletzung untersucht werden um dessen Gebrauch in Längsschnitt- und Interventionsstudien zu bestätigen.

b) Systematische Literaturauswertung: Die Rolle von sozialer Unterstützung und sozialen Kompetenzen bei Menschen mit einer Rückenmarksverletzung

Das Ziel der zweiten Studie ist die Untersuchung des aktuellen Wissensstandes anhand der wissenschaftlichen Literatur zur Relevanz sozialer Unterstützung und sozialer Kompetenzen im Bereich Rückenmarksverletzung und das darauf basierende Generierung von Hypothesen über die Assoziation dieser beiden Faktoren mit Depression, Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung.

Es wurde eine systematische Literatursuche in Pubmed, PsycINFO, ERIC, CINAHL, Embase und SSCI durchgeführt. Anhand von vordefinierten Eignungskriterien wurden Publikationen identifiziert, die Qualität der Studien evaluiert, die Studienresultate extrahiert, und eine narrative Synthese erstellt.

58 Publikationen über soziale Unterstützung und Rückenmarksverletzung wurden eingeschlossen. Diese zeigten, dass soziale Unterstützung positiv mit physischer und mentaler Gesundheit, weniger Schmerz, effektive Bewältigungsstrategien, Anpassung und Lebenszufriedenheit zusammenhängt. Elf Studien berichten über soziale Kompetenzen: Problemlösungsstrategien Durchsetzungsfähigkeit soziale (n=7), (n=3), verbale Kommunikation (n=1), und Selbstbeobachtung (n=1). Folgende Zusammenhänge wurden gefunden: effektive Problemlösungsstrategien hängen mit besserer mentaler Gesundheit, präventivem Gesundheitsverhalten und weniger Nebenerkrankungen zusammen; Durchsetzungsfähigkeit im Rehabilitations-Setting geht mit erhöhter Depression einher. Interventionsstudien zur Stärkung des sozialen Netzwerks und sozialer Kompetenzen wurden nur selten durchgeführt. Nur eine Studie untersuchte den Zusammenhang zwischen sozialen Kompetenzen und sozialer Unterstützung bei Menschen mit einer Rückenmarksverletzung.

Schlussfolgernd kann gesagt werden, dass die Beziehung zwischen sozialen Kompetenzen und sozialer Unterstützung, und wie diese beiden mit Depression, Partizipation und Lebensqualität bei Personen mit Rückenmarksverletzung zusammenhängen, noch unklar ist. Die folgenden Hypothesen sollten in weiteren Studien getestet werden: soziale Kompetenzen hängen mit sozialer Unterstützung zusammen; soziale Unterstützung hat einen positiven Effekt auf Depression, Partizipation und Lebensqualität; der Zusammenhang zwischen sozialen Kompetenzen und Depression, Partizipation und Lebensqualität wird durch soziale Unterstützung mediiert.

c) Fallstudie: Soziale Unterstützung und Selbstständigkeit bei einer Person mit Rückenmarksverletzung – die Rolle sozialer Kompetenzen

Die Fallstudie ergänzt die Literaturauswertung betreffend Generierung von Hypothesen über die Beeinflussung von sozialen Kompetenzen und sozialer Unterstützung auf Partizipation.

Es wurden qualitative (Beobachtungen, strukturierte und offene Interviews mit dem Patient und dem Gesundheitspersonal) als auch quantitative Daten (SCIM, medizinische Akten) gesammelt. Anhand von Inhaltsanalysen der Interviews wurden Aspekte sozialer Kompetenzen und sozialer Unterstützung identifiziert. Zudem diente ein ICF-basiertes Dokumentationsinstrument (ICF Assessment Sheet) um Informationen zur Funktionsfähigkeit auf der Ebene der Körperfunktionen und –strukturen, Aktivitäten und Partizipation, umwelt- und personenbezogene Faktoren eines 57-jährigen männlichen Patienten mit inkompletter Paraplegie während der Rehabilitation zu strukturieren.

Patient Vielfalt Der zeigte eine von sozialen Kompetenzen (z.B. Durchsetzungsvermögen, Zielorientierung). Jedoch musste an bestimmten sozialen Kompetenzen, wie um Hilfe fragen, soziale Problemlösungsstrategien, Sensitivität und Expressivität in sozialen Situationen gearbeitet werden. Der Patient erhielt verschiedene Arten von sozialer Unterstützung (instrumentelle, informatorisch und emotionale) von verschiedenen Quellen (z.B. Familie und Freunde). Die gualitativen Interviews lieferten Hinweise über die Interaktion zwischen sozialen Kompetenzen und sozialer Unterstützung. Der Einfluss von sozialer Kompetenzen und sozialer Unterstützung auf die Partizipation wurde diskutiert.

Basierend auf der Fallstudie wurde die Hypothese generiert, dass soziale Kompetenzen mit sozialer Unterstützung zusammenhängen und dass soziale Unterstützung einen positive Effekt auf Partizipation hat. Es wird ebenfalls angenommen,

dass der Zusammenhang zwischen sozialer Kompetenzen und Partizipation durch soziale Unterstützung mediiert wird.

d) Empirische Studie: Soziale Kompetenzen - eine Ressource für mehr soziale Unterstützung, bessere mentale Gesundheit, höhere Partizipation und Lebensqualität bei Menschen mit einer Rückenmarksverletzung?

Das Ziel der vierten Studie ist die Prüfung der Hypothesen, welche aus der systematischen Literaturauswertung und der Fallstudie gewonnen wurden.

Eine Querschnittstudie, eingebettet in der Schweizer Studie für Personen mit Rückenmarksverletzungen (SwiSCI), mit 311 Personen, 16-jährig oder älter, mit festem Wohnsitz in der Schweiz und einer traumatische oder nicht-traumatischer Rückenmarksverletzung, wurde durchgeführt.

Soziale Kompetenzen wurden anhand des Social Skills Inventory (SSI) Fragebogens, soziale Unterstützung anhand des Social Support Questionnaire (SSQ6) gemessen. Die Hospital Anxiety and Depression Scale (HADS), Utrecht Scale for Evaluation of Rehabilitation-Participation (USER-P) und World Health Organization Quality of Life Scale - BREF (WHOQOL) Fragebögen wurden verwendet um die Zielvariablen Depression, Partizipation und Lebensqualität zu messen.

Strukturgleichungsmodelle zeigten, dass soziale Kompetenzen mit sozialer Unterstützung zusammenhängen (β = 0.31 / R² = .10). Expressivität wies dabei den stärksten Zusammenhang auf (β = .20). Es fand sich ein direkter Effekt von sozialen Kompetenzen auf Depression (β = -.38 / R² = .43) und Lebensqualität (β = -.36 / R² = .17), jedoch keiner auf Partizipation. Die Pfadkoeffizienten zwischen Expressivität und Depression (β = -.11) und Lebensqualität (β = .14) waren signifikant, sowie zwischen Kontrolle und Depression (β = -.21) und Lebensqualität (β = -.25). Ein negativer Pfadkoeffizienten wurde zwischen Sensitivität und Lebensqualität (β = -.14) gefunden. Soziale Unterstützung mediiert nicht den Zusammenhang zwischen sozialen Kompetenzen auf der einen Seite und Partizipation und Depression auf der anderen. Jedoch mediiert soziale Unterstützung partiell den Zusammenhang zwischen sozialen Kompetenzen und Lebensqualität (Model 1: β = .16 / Model 2: β = .21 / p= .03). Es konnte kein direkter positiver Effekt von sozialer Unterstützung auf Depression und Partizipation gezeigt werden.

Zusammenfassend kann gesagt werden, dass soziale Kompetenzen eine wichtige Ressource für mehr soziale Unterstützung, eine bessere mentale Gesundheit und höhere Lebensqualität ist. Soziale Unterstützung nahm in dieser Studie keine Schlüsselrolle bei der Bestimmung von Depression, Partizipation und Lebensqualität ein. Hingegen sind soziale und emotionale Expressivität, die Fähigkeit Emotionen angemessen zu kontrollieren und in einer sozialen Situation geeignet zu interagieren wichtige Kompetenzen bei Menschen mit einer Rückenmarksverletzung. Die Resultate dieser Studie können in die klinische Praxis integriert werden, da aufgezeigt werden konnte welche Aspekte in der Intervention anvisiert werden sollten um mentale Gesundheit und Lebensqualität bei Menschen mit einer Rückenmarksverletzung zu erhöhen.

4. Diskussion

Das Hauptziel dieser Arbeit ist zu verstehen wie soziale Kompetenzen und soziale Unterstützung verknüpft sind und wie diese Depression, Partizipation und Lebensqualität beeinflussen. Dazu wurde die Doktorarbeit in vier Studien eingeteilt. Die erste Studie zeigte, dass Depression bei Menschen mit einer Rückenmarksverletzung psychometrisch einwandfrei mit dem HADS gemessen werden kann. Anhand der systematischen Literaturauswertung und der Fallstudie wurden die Hypothesen aufgestellt, dass soziale Kompetenzen mit sozialer Unterstützung zusammenhängen, dass die Beziehung zwischen sozialen Kompetenzen und Depression, Partizipation und Lebensqualität durch

IX. Zusammenfassung

soziale Unterstützung mediiert wird und dass soziale Unterstützung einen positiven Effekt auf Depression, Partizipation und Lebensqualität hat. Die letzte Studie fand einen direkten Effekt von sozialen Kompetenzen auf soziale Unterstützung, auf Depression und Lebensqualität. Hingegen fand sich kein Einfluss von sozialen Kompetenzen und sozialer Unterstützung auf Partizipation, genauso wenig wie ein mediierender oder direkter Effekt von sozialer Unterstützung. Lediglich ein partiell mediierender Effekt von sozialer Unterstützung zwischen sozialen Kompetenzen und Depression, Partizipation und Lebensqualität wurde nachgewiesen.

Abschliessend kann gesagt werden, dass soziale Kompetenzen eine wichtige Rolle im Zusammenhang mit mentaler Gesundheit und Lebensqualität einnehmen. Soziale Unterstützung scheint zu verschiedenen Zeitpunkten positiv zu wirken. Längsschnittstudien könnten die Frage beantworten, wie soziale Unterstützung den Anpassungsprozess an eine Rückenmarksverletzung beeinflusst. Ausserdem sind weitere Studien nötig um Faktoren zu finden, welche die Partizipation bestimmen (da soziale Kompetenzen und soziale Unterstützung diese scheinbar nicht beeinflussen).

Diese Arbeit liefert Resultate, welche der klinischen Praxis dienen können. Denn das Training von spezifischen sozialen Kompetenzen wie soziale und emotionale Expressivität, der Fähigkeit Emotionen zu kontrollieren und in einer sozialen Situation angepasst zu interagieren könnte den negativen Konsequenzen einer Rückenmarksverletzung entgegenwirken. Somit könnte das Risiko einer depressiven die Lebensqualität Menschen Erkrankung verringert und bei mit einer Rückenmarksverletzung verbessert werden.

X. References

- 1 Furlan J, Krassioukov A, Miller WC, von Elm E Epidemiology of traumatic SCI. Vancouver2010.
- 2 Albert T, Ravaud, JF, Tetrafigap group. Rehabilitation of spinal cord injury in France: a nationwide multicentre study of incidence and regional disparities. *Spinal Cord* 2005;**43**:357-65.
- 3 Caldana L, Lucca, L. Epidemiological remarks on traumatic spinal cord injuries and non- traumatic spinal cord diseases in Veneto 1994-1995. *Europa Medicophysica* 1998;**34**:159-68.
- 4 Koning W, Frowein, RA. . Incidence of spinal cord injury in the Federal Republic of Germany. *Neurosurg Rev* 1989;**12**:562-6.
- 5 Ahoniemi E, Alaranta, H, Hokkinen, EM, Valtonen, K, Kautiainen, H. Incidence of traumatic spinal cord injuries in Finland over a 30-year period. *Spinal Cord* 2008;**46**:781-4.
- 6 van Asbeck F, Post M, Pangalila, RF. An epidemiological description of spinal cord injuries in The Netherlands in 1994. *Spinal Cord* 2000;**38**:420-4.
- 7 Strauss DJ, Devivo MJ, Paculdo DR, Shavelle RM. Trends in life expectancy after spinal cord injury. *Arch Phys Med Rehabil* 2006;**87**:1079-85.
- 8 Dawodu ST. Spinal Cord Injury Definition, Epidemiology, Pathophysiology. 2011 [Sept 4, 2012]; Available from: <u>http://emedicine.medscape.com/article/322480-overview</u>.
- 9 van den Berg ME, Castellote JM, Mahillo-Fernandez I, de Pedro-Cuesta J. Incidence of spinal cord injury worldwide: a systematic review. *Neuroepidemiology* 2010;**34**:184-92; discussion 92.
- 10 American Spinal Injury Association. International Standards for Neurological Classification of Spinal Cord Injury, revised 2002. Chicago, IL: American Spinal Injury Association; 2002.
- 11 Benevento BT, Sipski ML. Neurogenic bladder, neurogenic bowel, and sexual dysfunction in people with spinal cord injury. *Phys Ther* 2002;**82**: 601-12.
- 12 Adams MM, Hicks AL. Spasticity after spinal cord injury. *Spinal Cord* 2005;**43.**:577-86.
- 13 Teasell R, Mehta S, Aubut J, Foulon BL, Wolfe DL, Hsieh JTC, Townson AF, Short C Pain Following Spinal Cord Injury. 2010 [cited 2011].
- 14 Siddall PJ, Loeser JD. Pain following spinal cord injury. *Spinal Cord* 2001;**39**:63-73.
- 15 Gélis A, Dupeyron A, Legros P, Benaim C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with SCI: part I: acute and rehabilitation stages. *Spinal Cord* 2009;**47**:99-107.
- 16 Gélis A, Dupeyron A, Legros P, Benaim C, Pelissier J, Fattal C. Pressure ulcer risk factors in persons with spinal cord injury Part 2: the chronic stage. *Spinal Cord* 2009;**47**:651-61.
- 17 Jiang S-D, Dai L-Y, Jiang L-S. Osteoporosis after spinal cord injury. *Osteoporos Int* 2006;**17**:180-92.
- 18 Eser P, Frotzler A, Zehnder Y, Schiessl H, Denoth J. Assessment of anthropometric, systemic, and lifestyle factors influencing bone status in the legs of spinal cord injured individuals. *Osteoporos Int* 2005;**16**:26-34.
- 19 Esclarin De Ruz A, Garcia Leoni E, Herruzo Cabrera R. Epidemiology and risk factors for urinary tract infection in patients with spinal cord injury. *J Urol* 2000;**164**:1285-9.

- 20 Schilero GJ, Spungen AM, Bauman WA, Radulovic M, Lesser M. Pulmonary function and spinal cord injury. *Respir Physiol Neurobiol* 2009;**166**:129-41.
- 21 Krause JS, Saunders LL, Newman S. Posttraumatic stress disorder and spinal cord injury. *Arch Phys Med Rehabil* 2010;**91**:1182-7.
- 22 Heinemann AW, Doll MD, Armstrong KJ, Schnoll S, Yarkony GM. Substance Use and Receipt of Treatment by Persons with Long-Term Spinal-Cord Injuries. *Archives of physical medicine and rehabilitation* 1991;**72**:482-7.
- 23 Charlifue SW, Gerhart KA. Behavioral and Demographic-Predictors of Suicide after Traumatic Spinal-Cord Injury. *Archives of physical medicine and rehabilitation* 1991;**72**:488-92.
- 24 Malec J, Neimeyer, R. . Psychological prediction of duration of inpatient spinal cord injury rehabilitation and performance of self-care. *Archives of Physical Medicine and Rehabilitation* 1983;**64**:
- 25 MacDonald MR, Nielson, W.R., Cameron, M.G.P. Depression and activity patterns of spinal cord injured persons living in the community. *Archives of Physical Medicine and Rehabilitation* 1987;**68**:339-43.
- 26 Zimmerman M, Lish, J.D., Farber, N. J., Hartung, J., Lush, D., Kuzma, M.A., Plescia, G. Screening for depression in medical patients. Is the focus too narrow? *General Hospital Psychiatry* 1994;**16**:388 - 96.
- 27 Craig A, Tran Y, Middleton J. Psychological morbidity and spinal cord injury: a systematic review. *Spinal Cord* 2009;**47**:108-14.
- 28 Orenczuk S, Slivinski, J., Mehta, S., Teasell, R.W. . Depression Following Spinal Cord Injury. 2010.
- 29 Kennedy P, Rogers, B. A. . Anxiety and depression after spinal cord injury: a longitudinal analysis. *Archive of Phsyical Medicine and Rehabilitation* 2000;**81**:932-7.
- 30 Galvin L, Godfrey, HP. The impact of coping on emotional adjustment to spinal cord injury (SCI): review of the literature and application of a stress appraisal and coping formulation. *Spinal Cord* 2001;**39**:615-27.
- 31 Craig AR, Hancock, K.M., Dickson, H., Martin, J., Chang, E. Psychological consequences of spinal injury: A review of the literature. *Australian and New Zealand Journal of Psychiatry* 1990;**24**:418 25.
- 32 APA. Diagnostic and Statistical Manual of Mental Disorders: DSM-IV. Washington (DC): American Psychiatric Association; 1994.
- 33 Radloff LS. The CES-D scale: A self report depression scale for research in the general population. *Applied Psychological Measurement* 1977;**1**:385-401.
- 34 Beck AT, Steer RA, Brown GK. The Beck Depression Inventory II. Manual. San Antonio: The Psychological Corporation, Harcourt Brace, & Co.; 1996.
- 35 Spitzer RL, Kroenke K, Williams JB. Validation and utility of a self-report version of PRIME-MD: the PHQ primary care study. Primary Care Evaluation of Mental Disorders. Patient Health Questionnaire. *JAMA* 1999;**282**:1737-44.
- 36 Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 1983;**67**:361-70.
- 37 Bjelland I, Dahl AA, Tangen Haug T, Neckelmann D. The validity of the Hospital Anxiety and Depression Scale An updated literature review. *Journal of Psychosomatic Research* 2002;**52**:69-77.
- 38 Herrmann C. International experiences with the Hospital Anxiety and Depression Scale A review of validation data and clinical results. *Journal of Psychosomatic Research* 1997;**42**:17-41.
- 39 Heutink M, Post MW, Luthart P, Pfennings LE, Dijkstra CA, Lindeman E. A multidisciplinary cognitive behavioural programme for coping with chronic

neuropathic pain following spinal cord injury: the protocol of the CONECSI trial. *BMC Neurol* 2010;**10**:96.

- 40 Tasiemski T, Kennedy P, Gardner BP, Taylor N. The association of sports and physical recreation with life satisfaction in a community sample of people with spinal cord injuries. *NeuroRehabilitation* 2005;**20**:253-65.
- 41 Ng C, Prott G, Rutkowski S, Li Y, Hansen R, Kellow J, et al. Gastrointestinal symptoms in spinal cord injury: relationships with level of injury and psychologic factors. *Dis Colon Rectum* 2005;**48**:1562-8.
- 42 Glickman S, Kamm MA. Bowel dysfunction in spinal-cord-injury patients. *Lancet* 1996;**347**:1651-3.
- 43 Woolrich RA, Kennedy P, Tasiemski T. A preliminary psychometric evaluation of the Hospital Anxiety and Depression Scale (HADS) in 963 people living with a spinal cord injury. *Psychology, Health & Medicine* 2006;**11**:80-90.
- 44 WHO. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization; 2001. p. 10.
- 45 Waters RL, Adkins RH, Yakura JS, Sie I. Motor and sensory recovery following incomplete tetraplegia. *Arch Phys Med Rehabil* 1994;**75**:306-11.
- 46 Penrod LE, Hegde SK, Ditunno JF, Jr. Age effect on prognosis for functional recovery in acute, traumatic central cord syndrome. *Arch Phys Med Rehabil* 1990;**71**:963-8.
- 47 Crozier KS, Cheng LL, Graziani V, Zorn G, Herbison G, Ditunno JF, Jr. Spinal cord injury: prognosis for ambulation based on quadriceps recovery. *Paraplegia* 1992;**30**:762-7.
- 48 Crozier KS, Graziani V, Ditunno JF, Jr., Herbison GJ. Spinal cord injury: prognosis for ambulation based on sensory examination in patients who are initially motor complete. *Arch Phys Med Rehabil* 1991;**72**:119-21.
- 49 Gerhart KA, Bergstrom E, Charlifue SW, Menter RR, Whiteneck GG. Longterm spinal cord injury: functional changes over time. *Arch Phys Med Rehabil* 1993;**74**:1030-4.
- 50 Thompson L. Functional changes in persons aging with spinal cord injury. *Assist Technol* 1999;**11**:123-9.
- 51 Bombardier CH, Richards JS, Krause JS, Tulsky D, Tate DG. Symptoms of major depression in people with spinal cord injury: implications for screening. *Arch Phys Med Rehabil* 2004;**85**:1749-56.
- 52 Schonherr MC, Groothoff JW, Mulder GA, Schoppen T, Eisma WH. Vocational reintegration following spinal cord injury: expectations, participation and interventions. *Spinal Cord* 2004;**42**:177-84.
- 53 Wade DT, de Jong BA. Recent advances in rehabilitation. *BMJ* 2000;**320**:1385-8.
- 54 Whiteneck GG, Charlifue SW, Gerhart KA, Overholser JD, Richardson GN. Quantifying handicap: a new measure of long-term rehabilitation outcomes. *Arch Phys Med Rehabil* 1992;**73**:519-26.
- 55 Hammel J, Magasi S, Heinemann A, Whiteneck G, Bogner J, Rodriguez E. What does participation mean? An insider perspective from people with disabilities. *Disabil Rehabil* 2008;**30**:1445-60.
- 56 Fougeyrollas P, Noreau L, Bergeron H, Cloutier R, Dion SA, St-Michel G. Social consequences of long term impairments and disabilities: conceptual approach and assessment of handicap. *Int J Rehabil Res* 1998;**21**:127-41.
- 57 Lemmens J, E ISMvE, Post MW, Beurskens AJ, Wolters PM, de Witte LP. Reproducibility and validity of the Dutch Life Habits Questionnaire (LIFE-H 3.0) in older adults. *Clin Rehabil* 2007;**21**:853-62.

- 58 Poulin V, Desrosiers J. Reliability of the LIFE-H satisfaction scale and relationship between participation and satisfaction of older adults with disabilities. *Disabil Rehabil* 2009;**31**:1311-7.
- 59 Gray DB, Hollingsworth HH, Stark SL, Morgan KA. Participation survey/mobility: psychometric properties of a measure of participation for people with mobility impairments and limitations. *Arch Phys Med Rehabil* 2006;**87**:189-97.
- 60 Gandek B, Sinclair SJ, Jette AM, Ware JE, Jr. Development and initial psychometric evaluation of the participation measure for post-acute care (PM-PAC). *Am J Phys Med Rehabil* 2007;**86**:57-71.
- 61 Brown M, Dijkers MP, Gordon WA, Ashman T, Charatz H, Cheng Z. Participation objective, participation subjective: a measure of participation combining outsider and insider perspectives. *J Head Trauma Rehabil* 2004;**19**:459-81.
- 62 Post M, van de Port, IGL, Kap, B, Berdenis van Berlekom, SH. Development and validation of the Utrecht Scale for Evaluation of Clinical Rehabilitation (USER). *Clin Rehabil* 2009 **23**:909-17.
- 63 van der Zee C, Priesterbach, AR, van der Dussen, L, Kap, A, Schepers, VP, Visser-Meily, JM, Post MW. Reproducibility of three self-report participation measures: The ICF Measure of Participation and Activities Screener, the Participation Scale, and the Utrecht Scale for Evaluation of Rehabilitation-Participation. *Journal of Rehabilitation Medicine* 2010;**42**:752-7.
- 64 Post MW, van der Zee CH, Hennink J, Schafrat CG, Visser-Meily JM, van Berlekom SB. Validity of the utrecht scale for evaluation of rehabilitation-participation. *Disabil Rehabil* 2012;**34**:478-85.
- 65 Taylor K. Paternalism, participation and partnership the evolution of patient centeredness in the consultation. *Patient Educ Couns* 2009;**74**:150-5.
- 66 Higginson IJ, Carr AJ. Measuring quality of life: Using quality of life measures in the clinical setting. *BMJ* 2001;**322**:1297-300.
- 67 Group W. WHOQOL Measuring QoL. Geneva1997; Available from: <u>http://www.who.int/mental_health/media/68.pdf</u>.
- 68 Dijkers MP. Individualization in quality of life measurement: instruments and approaches. *Arch Phys Med Rehabil* 2003;**84**:S3-14.
- 69 Miller WC, Sakakibara BM, Noonan VK, Kawashy AE, Aubut JL, Connolly SJ, et al. Outcome Measures. In: Eng JJ TR, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Connolly SJ, Mehta S, Sakakibara BM, editor. *Spinal Cord Injury Rehabilitation Evidence Version 30* Vancouver2010. p. 127.
- 70 Post MW, de Witte LP, Schrijvers AJ. Quality of life and the ICIDH: towards an integrated conceptual model for rehabilitation outcomes research. *Clin Rehabil* 1999;**13**:5-15.
- 71 Diener E, Emmons RA, Larsen RJ, Griffin S. The Satisfaction With Life Scale. *J Pers Assess* 1985;**49**:71-5.
- Fugl-Meyer AR, Bränholm IB, Fugl-Meyer KS. Happiness and domainspecific life satisfaction in adult northern Swedes. *Clinical rehabilitation* 1991;**5**:25-33.
- 73 Miller WC, Sakakibara BM, Noonan VK, Kawashy AE, Aubut JL, Connolly SJ, et al. Outcome Measures. In: Eng JJ TR, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Connolly SJ, Mehta S, Sakakibara BM, editor. *Spinal Cord Injury Rehabilitation Evidence Version 30* Vancouver2010. p. 128.
- 74 Wood-Dauphinee S, Exner G, Bostanci B, Glass C, Jochheim KA, Kluger P, et al. Quality of life in patients with spinal cord injury--basic issues, assessment, and recommendations. *Restor Neurol Neurosci* 2002;**20**:135-49.

- 75 WHOQOL Group. Development of the World Health Organization WHOQOL-BREF quality of life assessment. . *Psychol Med* 1998;**28**:551-8.
- 76 WHOQOL Group. The World Health Organization Quality of Life Assessment (WHOQOL): development and general psychometric properties. *Soc Sci Med* 1998;**46**:1569-85.
- 77 Geyh S, Fellinghauer BAG, Kirchberger I, Post MWM. Cross-cultural validity of four quality of life scales in persons with spinal cord injury. *Health and Quality of Life Outcomes* 2010;**8**:1-16.
- 78 Bombardier CH, Fann JR, Tate DG, Richards JS, Wilson CS, Warren AM, et al. An exploration of modifiable risk factors for depression after spinal cord injury: which factors should we target? *Arch Phys Med Rehabil* 2012;**93**:775-81.
- 79 Arango-Lasprilla JC, Ketchum JM, Starkweather A, Nicholls E, Wilk AR. Factors predicting depression among persons with spinal cord injury 1 to 5 years post injury. *NeuroRehabilitation* 2011;**29**:9-21.
- 80 Ataoglu E, Tiftik T, Kara M, Tunc H, Ersoz M, Akkus S. Effects of chronic pain on quality of life and depression in patients with spinal cord injury. *Spinal Cord* 2012;
- 81 Hoffman JM, Bombardier CH, Graves DE, Kalpakjian CZ, Krause JS. A longitudinal study of depression from 1 to 5 years after spinal cord injury. *Arch Phys Med Rehabil* 2011;**92**:411-8.
- 82 Pollard C, Kennedy P. A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: A 10-year review. *British Journal of Health Psychology* 2007;**12**:347-62.
- 83 Geyh S, Nick E, Stirnimann D, Ehrat S, Michel F, Peter C, et al. Self-efficacy and self-esteem as predictors of participation in spinal cord injury-an ICFbased study. *Spinal Cord* 2012;
- 84 Van Leeuwen CM, Post MW, Westers P, Van der Woude LH, De Groot S, Sluis T, et al. Relationships between activities, participation, personal factors, mental health, and life satisfaction in persons with spinal cord injury. *Arch Phys Med Rehabil* 2012;**93.** :82-9
- 85 Boschen KA, Gargaro J, Tonack MI. Community integration and quality of life comparisons among spinal cord injured, support provider and comparative samples. *Top Spinal Cord Inj Rehabil* 2005;**10**:116-34.
- 86 Whiteneck GG, Meade MA, Dijkers M, Tate DG, Bushnik T, Forchheimer MB. Environmental factors and their role in participation and life satisfaction after spinal cord injury. *Arch Phys Med Rehabil* 2004;**85**:1793-803.
- 87 Valtonen K, Karlsson AK, Alaranta H, Viikari-Juntura E. Work participation among persons with traumatic spinal cord injury and meningomyelocele. *J Rehabil Med* 2006;**38**:192-200.
- 88 Conroy L, McKenna K. Vocational outcome following spinal cord injury. *Spinal Cord* 1999;**37**:624-33.
- 89 Dijkers MPJM, Yavuzer G, Ergin S, Weitzenkamp D, Whiteneck GG. A tale of two countries: environmental impacts on social participation after spinal cord injury. *Spinal Cord* 2002;**40**:351-62.
- 90 Boschen KA, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. *Int J Rehabil Res* 2003;**26**:157-64.
- 91 Noreau L, Fougeyrollas P. Long-term consequences of spinal cord injury on social participation: the occurrence of handicap situations. *Disabil Rehabil* 2000;**22**:170-80.

- 92 Noreau L, Fougeyrollas P, Boschen KA. The perceived influence of the environment on social participation among individuals with spinal cord injury. *Top Spinal Inj Rehabil* 2002;**7**:56-72.
- 93 Chaves ES, Boninger ML, Cooper R, Fitzgerald SG, Gray DB, Cooper R. Assessing the influence of wheelchair technology on perception of participation in spinal cord injury. *Arch Phys Med Rehabil* 2004;**85**:1854-8.
- 94 Larrson Lund M, Nordlund A, Nygard L, Lexell J, Bernspang B. Perceptions of participation and predictors of perceived problems with participation in persons with spinal cord injury. *J Rehabil Med* 2005;**37**:3-8.
- 95 Keysor JJ, Jette AM, Coster W, Bettger JP, Haley SM. Association of environmental factors with levels of home and community participation in an adult rehabilitation cohort. *Arch Phys Med Rehabil* 2006;**87**:1566-75.
- 96 Johnson RL, Gerhart KA, McCray J, Menconi JC, Whiteneck GG. Secondary conditions following spinal cord injury in a population based sample. *Spinal Cord* 1998;**36**:45-50.
- 97 Dijkers MP. Quality of life of individuals with spinal cord injury: a review of conceptualization, measurement, and research findings. *J Rehabil Res Dev* 2005;**42**:87-110.
- 98 Post M, Noreau L. Quality of life after spinal cord injury. *J Neurol Phys Ther* 2005;**29**:139-46.
- 99 Lucke KT, Coccia H, Goode JS, Lucke JF. Quality of life in spinal cord injured individuals and their caregivers during the initial 6 months following rehabilitation. *Qual Life Res* 2004;**13**:97-110.
- 100 Kennedy P, Rogers B. Reported quality of life of people with spinal cord injuries: a longitudinal analysis of the first 6 months post-discharge. *Spinal Cord* 2000;**38**:498-503.
- 101 Mortenson WB, Noreau L, Miller WC. The relationship between and predictors of quality of life after spinal cord injury at 3 and 15 months after discharge. *Spinal Cord* 2010;**48**:73-9.
- 102 van Leeuwen CM, Post MW, van Asbeck FW, Bongers-Janssen HM, van der Woude LH, de Groot S, et al. Life satisfaction in people with spinal cord injury during the first five years after discharge from inpatient rehabilitation. *Disabil Rehabil* 2012;**34**:76-83.
- 103 Putzke JD, Barrett JJ, Richards JS, Underhill AT, Lobello SG. Life satisfaction following spinal cord injury: long-term follow-up. *J Spinal Cord Med* 2004;**27**:106-10.
- 104 van Koppenhagen CF, Post MW, van der Woude LH, de Groot S, de Witte LP, van Asbeck FW, et al. Recovery of life satisfaction in persons with spinal cord injury during inpatient rehabilitation. *Am J Phys Med Rehabil* 2009;**88**:887-95.
- 105 van Leeuwen CM, Post MW, Hoekstra T, van der Woude LH, de Groot S, Snoek GJ, et al. Trajectories in the course of life satisfaction after spinal cord injury: identification and predictors. *Arch Phys Med Rehabil* 2011;**92**:207-13.
- 106 Chang FH, Wang YH, Jang Y, Wang CW. Factors Associated With Quality of Life Among People With Spinal Cord Injury: Application of the International Classification of Functioning, Disability and Health Model. *Arch Phys Med Rehabil* 2012;
- 107 Uchino BN. Social support and health: a review of physiological processes potentially underlying links to disease outcomes. *J Behav Med* 2006;**29**:377-87.

- 108 Grav S, Hellzen O, Romild U, Stordal E. Association between social support and depression in the general population: the HUNT study, a cross-sectional survey. *J Clin Nurs* 2012;**21**:111-20.
- 109 Berkman LF, Glass T, Brissette I, Seeman TE. From social integration to health: Durkheim in the new millennium. *Soc Sci Med* 2000;**51**:843-57.
- 110 Cohen S, Wills T. Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;**98**:310-57.
- 111 Helgeson V. Social support and quality of life. *Qual Life Res* 2003;**12**:25-31.
- 112 Berkman LF, Syme SL. Social networks, host resistance, and mortality: a nineyear follow-up study of Alameda County residents. *Am J Epidemiol* 1979;**109**:186-204.
- 113 Holt-Lunstad J, Smith TB, Layton JB. Social relationships and mortality risk: a meta-analytic review. *PLoS Med* 2010;**7**:e1000316.
- 114 Shumaker S, Brownel IA. Toward a theory of social support: closing conceptual gaps. *Journal of Social Issues* 1984;**40**:11-36.
- 115 Taylor SE, Dickerson SS, Klein LC. Toward a biology of social support. In: Snyder CR, Lopez SJ, editors. *Handbook of positive psychology*. New York, NY, US: Oxford University Press; 2002. p. 556-69.
- 116 Caporael LR. The evolution of truly social cognition: the core configurations model. *Pers Soc Psychol Rev* 1997;**1**:276-98.
- 117 DiMatteo MR. Social support and patient adherence to medical treatment: a meta-analysis. *Health Psychol* 2004;**23**:207-18.
- 118 Lewis MA, Rook KS. Social control in personal relationships: impact on health behaviors and psychological distress. *Health Psychol* 1999;**18**:63-71.
- 119 Umberson D. Family status and health behaviors: social control as a dimension of social integration. *J Health Soc Behav* 1987;**28**:306-19.
- 120 Uchino BN, Bowen K, Carlisle M, Birmingham W. Psychological pathways linking social support to health outcomes: a visit with the "ghosts" of research past, present, and future. *Soc Sci Med* 2012;**74**:949-57.
- 121 Cobb S. Social support as a moderator for life stress. *Psychosomatic Medicine* 1976;**38**:300-14.
- 122 Antonucci T. Personal characteristics, social support, and social behavior. In: Binstock R, Shanas, A, editor. *Handbook of aging and the social sciences*. New York: Van Nostrand-Reinhold; 1985. p. 94-128.
- 123 House J, Kahn, RL. Measures and concepts of social support. In: Cohen J, Syme, SL, editor. *Social support and health*. New York: Academic Press; 1985. p. 83-108.
- 124 Kahn R, Antonucci, TC. Convoys over lifecourse: attachment, roles and social support. In: Baltes P, Brim O, editor. *Life-span development and behavior*. New York Academic Press; 1980. p. 253-86.
- 125 Sarason I, Sarason B, Shearing E, Pierce G. A brief measure of social support: practical and theoretical implications. *Journal of Social and Personal Relationships* 1987;**4**:497-510.
- 126 Dunkel-Schetter C, Bennett TL. Differentiating the cognitive and behavioral aspects of social support. In: Sarason BR, Sarason IG, Pierce GR, editors. *Social support: An interactional view*. New York: John Wiley and Sons; 1990. p. 267-96.
- 127 Uchino BN. Understanding the links between social support and physical health: a lifespan perspective with emphasis on the separability of perceived and received support. *Perspectives in Psychological Science* 2009;**4**:236-55.

- 128 Brown S, Nesse R, Vinokur A, Smith D. Providing social support may be more beneficial than receiving it: results from a prospective study of mortality. *Psychol Sci* 2003;**14**:320-7.
- 129 Sherman J, DeVinney DJ, Sperling KB. Social support and adjustment after spinal cord injury: influence of past peer-mentoring experiences and current live-in partner. *Rehabilitation Psychology* 2004;**49**:140-9.
- 130 Beedie A, Kennedy P. Quality of social support predicts hopelessness and depression post spinal cord injury. *J Clin Psychol Med S* 2002;**9**:227-34.
- 131 Post MWM, Ros, W. J. G., Schrijvers, A. J. P. . Impact of social support on health status and life satisfaction in people with a spinal cord injury. *Psychology and Health* 1999;**14**:679-95.
- 132 Bar-On R. The Bar-On model of emotional-social intelligence (ESI). *Psicothema* 2006;**18** 13-25.
- 133 Segrin C. Social skills deficits associated with depression. *Clinical Psychology Review* 2000;**20**:379-403.
- 134 Segrin C, Rynes KN. The mediating role of positive relations with others in associations between depressive symptoms, social skills, and perceived stress. *J Res Pers* 2009;**43**:962-71.
- 135 Tse W, Bond AJ. The impact of depression on social skills. *Journal of Nervous and Mental Disease* 2004;**192**:260-8.
- 136 Lewinsohn PM. A behavioral approach to depression. In: Friedman RJ, Katz MM, editors. *The psychology of depression: Contemporary theory and research*. Washington, D.C.: Winston-Wiley; 1974. p. 157-85.
- 137 Stravynski A, Amado D. Socia phobia as a deficit in social skills. In: Hofmann SG, Marten DiBatrol, P., editor. *From social anxiety to social phobia*. Bosten: Allyn and Bacon; 2001.
- 138 Monti P, O'Leary TA. Coping and social skills training for alcohol and cocaine dependence. *Psychiat Clin N AM* 1999;**22**:447-69.
- 139 Johnson M, Elliott TR, Neilands TB, Morin SF, Chesney MA. A Social Problem-Solving Model of Adherence to HIV Medications. *Health Psychology* 2006;**25**:355-63.
- 140 Cacioppo JT, Hawkley LC. Perceived social isolation and cognition. *Trends Cogn Sci* 2009;**13**:447-54.
- 141 Segrin C, Taylor M. Positive interpersonal relationships mediate the association between social skills and psychological well-being. *Pers Indiv Differ* 2007;**43**:637–46.
- 142 Kopelowicz A, Liberman RP, Zarate R. Recent advances in social skills training for schizophrenia. *Schizophr Bull* 2006;**32 Suppl 1**:S12-23.
- 143 Van Overwalle F. Social cognition and the brain: a meta-analysis. *Hum Brain Mapp* 2009;**30**:829-58.
- 144 Thorndike RK. Intelligence and Its Uses. *Harper's Magazine* 1920;**140**:227-335.
- 145 Salovey P, Mayer JD. Emotional intelligence. *Imagination, Cognition, and Personality* 1990;**9**:185-211.
- 146 Segrin C. Specifying the nature of social skill deficits associated with depression. *Hum Commun Res* 1992;**19**:89–123.
- 147 Liberman RP. Assessment of social skills. *Schizophrenia Bulletin* 1982;**8**:62-83.
- 148 Riggio R. The social skills inventory (SSI): measuring nonverbal and social skills. In: Manusov V, editor. *The sourcebook of nonverbal measures: Going beyond words*. Mahwah: Lawrence Erlbaum Associates Publishers; 2005.

- 149 Dunn M, Herman S. . Social skills and physical disability. In: Doleys D, Meredith, R. , editor. *Behavioral medicine: assessment and treatment strategies* New York: Plenum Press; 1982. p. 117-44.
- 150 Glueckauf R, Quittner AL. Assertiveness training for disabled adults in wheelchairs: Self-report, role-play, and activity pattern outcomes. *J Consult Clin Psych* 1992;**60**:419-25.
- 151 Elliott T, Godshall FJ, Herrick SM, Witty TE. Problem-solving appraisal and psychological adjustment following spinal cord injury. *Cognitive Therapy and Research* 1991;**15**:387-98.
- 152 Elliott T, Bush BA, Chen Y. Social problem-solving abilities predict pressure sore occurrence in the first 3 years of spinal cord injury *Rehabilitation Psychology* 2006;**51**:69-77.
- 153 Dreer L, Elliott TR, Tucker E. Social problem-solving abilities and health behaviors among persons with recent-onset spinal cord injury. *Journal of Clinical Psychology in Medical Settings* 2004;**11**:7-13.
- 154 Elliott T. Social problem-solving abilities and adjustment to recent-onset spinal cord injury. *Rehabilitation Psychology* 1999;**44**:315-32.
- 155 Lee Y. Does self-monitoring influence the experience of leisure for individuals with spinal cord injury? *Annual in Therapeutic Recreation* 2008;**16**:39-48.
- 156 Chase B, Cornille TA, English RW. Life satisfaction among persons with spinal cord injuries. *Journal of Rehabilitation* 2000;**66**:14-20.
- 157 Geyh S, Nick E, Stirnimann D, Ehrat S, Muller R, Michel F. Biopsychosocial outcomes in individuals with and without spinal cord injury: a Swiss comparative study. *Spinal Cord* 2012;
- 158 Herrmann C, Buss U, Snaith RP. HADS-D. Hospital Anxiety and Depression Scale - Deutsche Version. Ein Fragebogen zur Erfassung von Angst und Depressivität in der somatischen Medizin. Bern: Huber; 1995
- 159 Herrmann C, Buss U. Description and validation of a German version of the Hospital Anxiety and Depression Scale (HADS): A questionnaire for identifying emotional disorders in physically ill patients. *Diagnostica* 1994;**40**:143-54.
- 160 Siegert RJ, Tennant A, Turner-Stokes L. Rasch analysis of the Beck Depression Inventory-II in a neurological rehabilitation sample. *Disability & Rehabilitation* 2010;**32**:8-17.
- 161 Bateman A, Teasdale TW, Willmes K. Assessing construct validity of the selfrating version of the European Brain Injury Questionnaire (EBIQ) using Rasch analysis. *Neuropsychological Rehabilitation* 2009;**19**:941-54.
- 162 Hawthorne G, Densley K, Pallant JF, Mortimer D, Segal L. Deriving utility scores from the SF-36 health instrument using Rasch analysis. *Quality of Life Research: An International Journal of Quality of Life Aspects of Treatment, Care & Rehabilitation* 2008;**17**:1183-93.
- 163 Tennant A, Conaghan PG. The Rasch measurement model in rheumatology: what is it and why use it? When should it be applied, and what should one look for in a Rasch paper? *Arthritis Rheum* 2007;**57**:1358-62.
- 164 Andrich D. Controversy and the Rasch model: a characteristic of incompatible paradigms? . *Medical care* 2004;**42**:16-7.
- 165 Bond TG, Fox CM. Applying the Rasch model: Fundamental measurement in the human sciences. Mahwah, NJ: Lawrence Erlbaum Associates; 2001.
- 166 Andrich D. Rasch Models for Measurement Newbury Park: Sage 1988.
- 167 Andrich D, Sheridan B, Luo G. RUMM 2030 (Beta Version for Windows). Perth, Western Australia: RUMM Laboratory Pty Ltd; 2009.
- 168 Wright BD, Masters GN. Rating Scale Analysis. Chicago: MESA; 1982.

- 169 Smith RM, Miao CY. Assessing unidimensionality for Rasch measurement. In: Wilson M, editor. *Objective measurement: theory into Practice*. Norwood: Ablex; 1994. p. 316-27.
- 170 Raîche G. Critical eigenvalue sizes in standardized residual principal components analysis. *Rasch Measurement Transactions* 2005;**19**:1012.
- 171 Tennant A, Pallant JF. Unidimensionality matters! A tale of two Smiths?). *Rasch Measurement Transactions* 2006;**20**:1048-51.
- 172 Smith EV, Jr. Detecting and evaluating the impact of multidimensionality using item fit statistics and principal component analysis of residuals. *J Appl Meas* 2002;**3**:205-31.
- 173 Linacre JM. Optimizing rating scale category effectiveness. *Journal of Applied Measurement* 2002;**3**:85-106.
- 174 Fisher WP. Reliability statistics. *Rasch Measurement Transactions* 1992;**6**:238.
- 175 Andrich D. An index of person separation in latent trait theory, the traditional KR.20 index, and the Guttman scale response pattern. *Education Research and Perspectives* 1982;**9**:95-104.
- 176 Tennant A, Penta M, Tesio L, Grimby G, Thonnard JL, Slade A, et al. Assessing and adjusting for cross-cultural validity of impairment and activity limitation scales through differential item functioning within the framework of the Rasch model: the PRO-ESOR project. *Medical care* 2004;**42**:137-48.
- 177 Parker G, Brotchie H. Gender differences in depression. *Int Rev Psychiatry* 2010;**22**:429-36.
- 178 McLean CP, Anderson ER. Brave men and timid women? A review of the gender differences in fear and anxiety. *Clin Psychol Rev* 2009;**29**:496-505.
- 179 Pulkki-Raback L, Kivimaki M, Ahola K, Joutsenniemi K, Elovainio M, Rossi H, et al. Living alone and antidepressant medication use: a prospective study in a working-age population. *BMC Public Health* 2012;**12**:236.
- 180 Bjelland I, Krokstad S, Mykletun A, Dahl AA, Tell GS, Tambs K. Does a higher educational level protect against anxiety and depression? The HUNT study. *Soc Sci Med* 2008;**66**:1334-45.
- 181 Jorm AF. Does old age reduce the risk of anxiety and depression? A review of epidemiological studies across the adult life span. *Psychol Med* 2000;**30**:11-22.
- 182 Hinz A, Schwarz R. Anxiety and depression in the General Population: Standardised values of the Hospital Anxiety and Depression Scale. *Psychother Psych Med* 2001;**51**:193-200.
- 183 Bland JM, Altman DG. Multiple significance tests: the Bonferroni method. *BMJ* (*Clinical research ed*) 1995;**310**:
- 184 Tang WK, Wong E, Chiu HFK, Ungvari GS. Rasch analysis of the scoring scheme of the HADS Depression subscale in Chinese stroke patients. *Psychiatry Research* 2007;**150**:97-103.
- 185 Smith AB, Wright EP, Rush R, Stark DP, Velikova G, Selby PJ. Rasch analysis of the dimensional structure of the Hospital Anxiety and Depression Scale. *Psychooncology* 2006;**15**:817-27.
- 186 Kendel F, Wirtz M, Dunkel A, Lehmkuhl E, Hetzer R, Regitz-Zagrosek V. Screening for depression: Rasch analysis of the dimensional structure of the PHQ-9 and the HADS-D. *Journal of Affective Disorders* 2010;**122**:241-6.
- 187 Forjaz MJ, Rodriguez-Blazquez C, Martinez-Martin P. Rasch analysis of the Hospital Anxiety and Depression Scale in parkinson's disease. *Movement Disorders* 2009;**24**:526-32.

- 188 Gibbons CJ, Mills RJ, Thornton EW, Ealing J, Mitchell D, Shaw PJ, et al. Rasch analysis of the Hospital Anxiety and Depression Scale (HADS) for use in motor neuron disease. *Health and Quality of Life Outcomes* 2011;**9**:2-8.
- 189 Nunnally JC, Bernstein IH. Psychometric theory (3rd ed.). New York: McGraw-Hill; 1994.
- 190 Guilford JP. Fundamental statistics in psychology and education, 4th edn. New York: McGraw-Hill; 1965.
- 191 Tesio L, Alpini D, Cesarani A, Perucca L. Short form of the Dizziness Handicap Inventory: construction and validation through Rasch analysis. . *American Journal of Physical Medicine and Rehabilitation* 1999;233-41.
- 192 Fox CM, Dedeon J, Dinero T. The use of Rasch analysis to establish the reliability and validity of a paper-and-pencil stimulation. Presented at the Annual Meeting of the Midwestern Educational Research Association. 1994.
- 193 Gough K, Hudson P. Psychometric properties of the Hospital Anxiety and Depression Scale in family caregivers of palliative care patients. *J Pain Symptom Manage* 2009;**37**:797-806.
- 194 Mykleutun A, Stordal E, Dahl AA. Hospital Anxiety and Depression (HAD) Scale: Factor structure, item analysis and internal consistency in a large population. . *British Journal of Psychiatry* 2001;**179**:540-4.
- 195 Pallant JF, Tennant A. An introduction to the Rasch measurement model: An example using the Hospital Anxiety and Depression Scale (HADS). *British Journal of Clinical Psychology* 2007;**46**:1-18.
- 196 Lambert S, Pallant J, Girgis A. Rasch analysis of the Hopital Anxiety and Depression Scale among caregivers of cancer survivors: implications for its use in psycho-oncology. *Psycho-Oncology* 2011;**20**:919-25.
- 197 Dunbar M, Ford G, Hunt K, Der G. A confirmatory factor analysis of the Hospital Anxiety and Depression Scale: Comparing empirically and theoretically derived structures. *British Journal of Clinical Psychology* 2000;**36**:79-94.
- 198 Smith AB, Selby PJ, Velikova G, Stark D, Wright EP, Gould A, et al. Factor analysis of the Hospital Anxiety and Depression Scale from a large cancer population. *Psychol Psychother* 2002;**75**:165-76.
- 199 Vandenbroucke J, von Elm E, Altman DG, Gotzsche PC, Mulrow CD, Pocock SJ, Pool C, Schlesselman JJ, Egger M. Strengthening the Reporting of Observational Studies in Empidemiology (STROBE): Explanation and Elaboration. *PLoS Medicine* 2007;**4**:1628-54.
- 200 <u>http://www.pedro.org.au/english/downloads/pedro-scale/</u>. [cited 2010 July 30].
- 201 Popay J, Roberts H, Sowden A, Petticrew M, Arai L, Rodgers M, Britten N, Roen K, Duffy S. Guidance on the conduct of narrative synthesis in systematic reviews http://www.lancs.ac.uk/shm/research/nssr/research/dissemination/publications

<u>http://www.lancs.ac.uk/shm/research/nssr/research/dissemination/publications</u> /NS_Synthesis_Guidance_v1.pdf. 2006.

- 202 Cohen S, Mermelstein R, Kamarck T, Hoberman HM. Measuring the functional components of social support. In: Sarason I, Sarason BR., editor. *Social support: Theory, Research and Applications*. Boston: Martinus Nijhoff; 1985.
- 203 D'Zurilla T, Nezu AM, Meydeu-Olivares A. Social Problem-Solving (SPSI-R): Technical manual. North Tonawanda, NY: Multi-Health Systems; 2002.
- 204 Duchnick J, Letsch EA, Curtiss G. Coping effectiveness training during acute rehabilitation of spinal cord injury/dysfunction: a randomized clinical trial *Rehabilitation Psychology* 2009;**54**:123-32.

- 205 Elliott T, Herrick SH, Patti AM, Witty TE, Godshall FJ, Spruell M. Assertiveness, social support, and psychological adjustment following spinal cord injury. *Behaviour Research and Therapy* 1991;**29**:485-93.
- 206 Elfstrom M, Ryden A, Kreuter M, Taft C, Sullivan M. Relations between coping strategies and health-related quality of life in patients with spinal cord lesion Focus on coping. *Journal of Rehabilitation Medicine* 2005;**37**:9-16.
- 207 Kennedy P, Rogers BA. Anxiety and depression after spinal cord injury: a longitudinal analysis. *Archives of Physical Medicine and Rehabilitation* 2000;**81**:932-7.
- 208 McColl M, Rosenthal C. . A model of resource needs of aging spinal cord injured men. *Paraplegia* 1994;**32**:261-70.
- 209 Kishi Y, Robinson RG, Forrester AW. Prospective longitudinal study of depression following spinal cord injury. *Journal of Neuropsychiatry* 1994;**6**:2-9.
- 210 Rintala D, Robinson-Whelen S, Matamoros R. Subjective stress in male veterans with spinal cord injury. *Journal of Rehabilitation Research and Development* 2005;**42**:291-304.
- 211 Elliott T, Herrick SM, Witty TE, Godshall F, Spruell M. Social support and depression following spinal cord injury. *Rehabilitation Psychology* 1992;**37**:37-48.
- 212 Hughes R, Swedlund N, Petersen N, Nosek MA. Depression and women with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 2001;**7**:16-24.
- 213 Radnitz C, Danner G. Recovery from posttraumatic stress disorder in veterans with spinal cord injury. *SCI Psychosocial Process* 2002;**15**:190-7.
- 214 Coyle C, Shank JW, Kinney W, Hutchins DA. Psychosocial functioning and changes in leisure lifestyle among individuals with chronic secondary health problems related to spinal cord injury. *Therapeutic Recreation Journal* 1993;**27**:239-52.
- 215 Herrick S, Elliott TR, Crow F. Social support and the prediction of health complications among persons with spinal cord injuries. *Rehabilitation Psychology* 1994;**39**:231-50.
- 216 Rintala D, Young ME, Hart KA, Clearman RR, Fuhrer MJ. Social support and the well-being of persons with spinal cord injury living in the community. *Rehabilitation Psychology* 1992;**37**:155-63.
- 217 Stroud M, Turner JA, Jensen MP, Cardenas DD. Partner responses to pain behaviors are associated with depression and activity interference among persons with chronic pain and spinal cord injury *Journal of Pain* 2006;**7**:91-9.
- 218 Elfstrom M, Kreuter M, Ryden A, Persson LO, Sullivanand M. . Effects of coping on psychological outcome when controlling for background variables: a study of traumatically spinal cord lesioned persons Focus on coping. *Spinal Cord* 2002;**40**:408-15.
- 219 Agar E, Kennedy P, King NS. The role of negative cognitive appraisals in PTSD symptoms following spinal cord injuries. *Behavioural and Cognitive Psychotherapy* 2006;**34**:437-52.
- 220 Hatcher M, Whitaker C, Karl A. What predicts post-traumatic stress following spinal cord injury? *British Journal of Health Psychology* 2009;**14**:541-61.
- 221 Kishi Y, Robinson RG. Suicidal plans following spinal cord injury. *Journal of Neuropsychiatry* 1996;**8**:443-5.
- 222 Elliott T, Herrick SM, Witty TE, Godshall F, Spruell M. Social relationship and psychosocial impairment of person with SCI. *Psychology and Health* 1992;**7**:55-67.

- 223 McColl M, Arnold R, Charlifue S, Gerhart K. Social support and aging with a spinal cord injury: Canadian and British experiences. *Topics in Spinal Cord Injury Rehabilitation* 2001;**6**:83-101.
- 224 Nielsen M. Prevalence of posttraumatic stress disorder in persons with spinal cord injuries: the mediating effect of social support. *Rehabilitation Psychology* 2003;**48**:289-95.
- 225 Danner G, Radnitz CL. Protective factors and posttraumatic stress disorder in veterans with spinal cord injury. *International Journal of Rehabilitation and Health* 2000;**5**:195-203.
- 226 Nielsen M. Crisis support and coping as mediators of well-being in persons with spinal cord lesion. *Journal of Clinical Psychology in Medical Settings* 2003;**10**:91-9.
- 227 Boraz M, Heinemann AW. The relationship between social support and alcohol abuse in people with spinal cord injuries. *International Journal of Rehabilitation and Health* 1996;**2**:189-98.
- 228 Fuhrer M, Rintala DH, Hart KA, Clearman R, Young ME. Relationship of life satisfaction to impairment, disability, and handicap among persons with spinal cord injury living in the community life satisfaction. *Archives of Physical Medicine and Rehabilitation* 1992;**73**:552-7.
- 229 Post M, Ros WJG, Schrijvers AJP. Impact of social support on health status and life satisfaction in people with a spinal cord injury. *Psychol Health* 1999;**14**:679-95.
- 230 Hampton N. The affective aspect of subjective well-being among Chinese people with and without spinal cord injuries. *Disability and Rehabilitation* 2008;**30**:1473-9.
- 231 Hampton N. Subjective well-being among people with spinal cord injuries: the role of self-efficacy, perceived social support, and perceived health. *Rehabilitation Counseling Bulletin* 2004;**48**:31-7.
- 232 Forchheimer M, Tate DG. The relationship of spirituality and depression to health among people with spinal cord injury. *Topics in Spinal Cord Injury Rehabilitation* 2007;**12**:23-34.
- 233 Krause J, Carter RE. Risk of mortality after spinal cord injury: relationship with social support, education, and income. *Spinal Cord* 2009;1-5.
- 234 Raichle K, Hanley M, Jensen MP, Cardenas DD. Cognitions, coping, and social environment predict adjustment to pain in spinal cord injury. *Journal of Pain* 2007;**8**:718-29.
- 235 Suzuki R, Krahn GL, McCarthy MJ, Adams EJ. Understanding health outcomes: Physical secondary conditions in people with spinal cord injury. *Rehabilitation Psychology* 2007;**52**:338-50.
- 236 Anson C, Stanwyck DJ, Krause JS. Social support and health status in spinal cord injury. *Paraplegia* 1993;**31**:632-8.
- 237 Saladin L, Krause JS. Pressure ulcer prevalence and barriers to treatment after spinal cord injury: Comparisons of four groups based on race-ethnicity. *NeuroRehabilitation* 2009;**24**:57-66.
- 238 Widerstrom-Noga E, Cruz-Almeida Y, Felix ER, Adcock JP. Relationship between pain characteristics and pain adaptation type in persons with SCI. *Journal of Rehabilitation Research and Development* 2009;**46**:43-56.
- 239 Rintala D, Hart KA, Priebe MM. Predicting consistency of pain over a 10-year period in persons with spinal cord injury. *Journal of Rehabilitation Research and Development* 2004;**41**:75-88.

- 240 Pang M, Eng JJ, Lin KH, Tang PF, Hung C, Wang YH. Association of depression and pain interference with disease-management self-efficacy in community-dwelling individuals with spinal cord injury. *Journal of Rehabilitation Medicine* 2009;**41**:1068-73.
- 241 Piazza D, Holcombe J, Foote A, Paul P, Love S, Daffin P. Hope, social support and self-esteem of patients with spinal cord injuries. *Journal of Neuroscience Nursing* 1991;**23**:224-30.
- 242 Song H. Modeling social reintegration in persons with spinal cord injury. *Disability and Rehabilitation* 2005;**27**:131-41.
- 243 Chan R, Lee PWH, Lieh-Mak F. The pattern of coping in persons with spinal cord injuries. *Disability and Rehabilitation* 2000;**22**:501-7.
- 244 McColl M, Lei H, Skinner H. Structural relationships between social support and coping. *Social Science and Medicine* 1995;**41**:395-407.
- 245 Loy D, Dattilo J, Kleiber DA. Exploring the influence of leisure on adjustment: Development of the leisure and spinal cord injury adjustment model. *Leisure Sciences* 2003;**25**:231-55.
- 246 Rintala D, Young ME, Hart KA, Fuhrer MJ. The relationship between the extent of reciprocity with social supporters and measures of depressive symptomatology, impairment, disability, and handicap in persons with spinal cord injury. *Rehabilitation Psychology* 1994;**39**:15-27.
- 247 McColl M, Friedland J. The effects of age and disability on social support. International Journal of Rehabilitation Research 1995;**18**:325-40.
- 248 McShane S, Karpand J. Employment following spinal cord injury: A covariance structure analysis. *Rehabilitation Psychology* 1993;**38**:27-40.
- 249 Benony H, Daloz L, Bungener C, Chahraoui K, Frenay C, Auvin J. Emotional factors and subjective quality of life in subjects with spinal cord injuries *American Journal of Physical Medicine and Rehabilitation* 2002;**18**:437-45.
- 250 Hanley M, Raichle K, Jensen M, Cardenas DD. Pain catastrophizing and beliefs predict changes in pain interference and psychological functioning in persons with spinal cord injury. *Journal of Pain* 2008;**9**:863-71.
- 251 Boschen K, Tonack M, Gargaro J. Long-term adjustment and community reintegration following spinal cord injury. *International Journal of Rehabilitation Research* 2003;**26**:157-64.
- 252 Anzai K, Young J, McCallum J, Miller B, Jongbloed L. Factors influencing discharge location following high lesion spinal cord injury rehabilitation in British Columbia, Canada. *Spinal Cord* 2006;**44**:11-8.
- 253 Shanmugham K, Elliott TR, Palmatier A. . Social problem solving abilities and psychosocial impairment among individuals recuperating from surgical repair for severe pressure sores. *NeuroRehabilitation* 2004;**19**:259-69.
- 254 Berry J, Elliott TR, Rivera P. Resilient, undercontrolled, and overcontrolled personality prototypes among persons with spinal cord injury. *Journal of Personality Assessment* 2007;**89**:292-302.
- 255 Herrick S, Elliott TR, Crow F. Self-appraised problem-solving skills and the prediction of secondary complications among persons with spinal cord injuries. *Journal of Clinical Psychology in Medical Settings* 1994;**1**:269-83.
- 256 Bloemen-Vrencken J, de Witte LP. Post-discharge nursing problems of spinal cord injured patients: on which fields can nurses contribute to rehabilitation? *Clinical Rehabilitation* 2003;**17**:890-8.
- 257 Riggio R, Warting KP, Throckmorton B. Social skills, social support, and psychosocial adjustment. *Pers Indiv Differ* 1993;**15**:275-80.

- 258 Segrin C, Taylor M. Positive interpersonal relationships mediate the association between social skills and psychological well-being. *Pers Indiv Differ* 2007;**43**:637–46.
- 259 Macdonald E, Jackson HJ, Hayes RL, Baglioni Jr, AJ, Madden C. Social skill as a determinant of social networks and perceived social support in schizophrenia. *Schizophr Res* 1998;**29**:275-86.
- 260 MSKTC. http://msktc.washington.edu/sci/findms.asp. [cited 2010].
- 261 Post M, Brinkhof MWG, von Elm E, Boldt C, Brach M, Muff C, Eriks-Hoogland I, Curt A, Stucki G, for the SwiSCI study group. Design of the Swiss Spinal Cord Injury Cohort Study (SwiSCI). American Journal of Physical Medicine and Rehabilitation [serial on the Internet]. 2010; submitted.
- 262 Berkman L, Syme SL. Social networks, host resistance, and mortality: A nine year follow up study of Alameda County residents. *American Journal of Epidemiology* 1979;**109**:186 204.
- 263 Gruenewald T, Karlamangla AS, Greendale GA, Singer BH, Seeman TE. Feelings of usefulness to others, disability, and mortality in older adults: the MacArthur Study of successful aging. *Journals of Gerontology Series B, Psychological Sciences and Social Sciences* 2007;**62**:28-37.
- 264 Steptoe A, Lundwall K, Cropley M. Gender, family structure and cardiovascular activity during the working day and evening. *Social Science and Medicine* 2000;**50**:531-9.
- 265 Ali S, Merlo J, Rosvall M, Lithman T, Lindström M. Social capital, the miniaturisation of community, traditionalism and first time acute myocardial infarction: a prospective cohort study in southern Sweden. *Social Science and Medicine* 2006;**63**:2204-17.
- 266 Brown G, Bhrolchain MN, Harris T. Social class and psychiatric disturbance among women in an urban population. *Sociology* 1975;**9**:225-54.
- 267 Norbeck J. Types and sources of social support for managing job stress in critical care nursing. *Nursing Research* 1985;**34**:225-30.
- 268 Paykel E. Life events, social support and depression. *Acta Psychiatrica Scandinavica* 1994; **Suppl 377**:50-8.
- 269 Munir S, Jackson DW. Social support, need for support, and anxiety among women graduate students. *Psychological Reports* 1997;**80**:383-6.
- 270 Abrahamsen FE RG, Pensgaard AM, Ronglan LT. Perceived ability and social support as mediators of achievement motivation and performance anxiety. *Scandinavian Journal of Medicine and Science in Sports* 2008;**18**:810-21.
- 271 Lazarus R, Folkman S. Stress, appraisal and coping. New York: Springer; 1984.
- 272 Folkamn S, Lazaru, R.S. Coping as a mediator of emotion. *Journal of Personality and Social Psychology* 1988;**54**:466-75.
- 273 Thoits P. Social support as coping assistance. *Journal of Consulting and Clinical Psychology* 1986;**54**:416-23.
- 274 Wonderlich-Tierney A, Vander Wal JS. The effects of social support and coping on the relationship between social anxiety and eating disorders. *Eating Behaviors* 2010;**11**:85-91.
- 275 Mehnert A, Lehmann C, Graefen M, Huland H, Koch U. Depression, anxiety, post-traumatic stress disorder and health-related quality of life and its association with social support in ambulatory prostate cancer patients. *European Journal of Cancer Care* 2010;**19**:736-45.

- 276 Koivula M, Paunonen-Ilmonen M, Tarkka MT, Tarkka M, Laippala, P. Social support and its relation to fear and anxiety in patients awaiting coronary artery bypass grafting. *Journal of Clinical Nursing* 2002;**11**:622-33.
- 277 Elliott T, Hurst M. Social Problem Solving and Health. *Bienn Rev Couns Psychol* 2008;**1**:295-309.
- 278 Heppner P. The problem-solving inventory: manual. Palo Alto, CA: Consulting Psychologists Press; 1988.
- 279 Gambrill E, Florian V, Splaver G. . Assertion, loneliness and perceived control among students with and without physical disabilities. *Rehabil Couns Bull* 1986;**30**:4-12.
- 280 Platt J, Hermalin J. Social skills deficit interventions for substance abusers. *Psychol Addict Behav* 1989;**3**:114-33.
- 281 Lopes P, Salovey P. Toward a broader education: Social, emotional and practical skills. In: Zins J, Weissberg RP, Wang MC, Walberg HJ editor. *Building academic success on social and emotional learning: What does the research say?* New York: Teachers College Press; 2004. p. 76-93.
- 282 Foster S, Bussman JR. Evidence-based approaches to social skills training with children and adolescents. In: Steele R, Elkin TD, Roberts MC editor. Handbook of evidence-based therapies for children and adolescents: Bridging science and practice. New York: Springer Science + Business Media; 2008. p. 409-27.
- 283 Kopelowicz A, Liberman RP, Zarate R. Recent advances in social skills training for schizophrenia. *Schizophrenia Bulletin* 2006;**32**:S12-S23.
- 284 Liberman R, Kopelowicz A, Silverstein SM. Psychiatric rehabilitation. In: Sadock B, Sadock VA, editor. *Comprehensive Textbook of Psychiatry*. Baltimore: Lippincott Williams & Wilkins; 2005. p. 3884-930.
- 285 Hersen M, Bellack AS, Himmelhoch JM. Treatment of unipolar depression with social skills training. *Behavior Modification* 1980;**4**:547-56.
- 286 O'Malley S, Jaffe AJ, Chang G, Schottenfeld RS, Meyer RE, Rounsaville B. Naltrexone and coping skills therapy for alcohol dependence: A controlled study. *Archives of General Psychiatry* 1992;**49**:881.
- 287 Dunn M, Van Horn E, Herman SH. Social skills and spinal cord injury: A comparison of three training procedures. *Behavior Therapy* 1989;**12**:153-64.
- 288 Hogan B, Linden W, Najarian B. Social support intervention: Do they work? *Clinical Psychology Review* 2002;**22**:383-442.
- 289 Ullrich R, de Muynck R. Aufbau sozialer Kompetenz: Selbstsicherheitstraining, Assertiveness-Training. In: Linden M, Hautzinger M., editor. *Verhaltenstherapiemanual*. Heidelberg: Springer Medizin Verlag; 2005.
- 290 Meier J, Hope DA. Assessment of socal skills. In: Bellack A, editor. *Behavioral Assessment*. Boston: Allyn and Bacon; 1998.
- 291 Dunn M, Herman S. Social skills and physical disability. In: Doleys D, Meredith, R., editor. *Behavioral medicine: Assessment and treatment strategies*. New York: Plenum Press; 1982. p. 117-44.
- 292 Derevensky J, Tsanos AP, Handman M. Children with cancer: an examination of their coping and adaptive behavior. *Journal of Psychosocial Oncology* 1998;**16**:37-61.
- 293 Gazzaniga M, Heatherton TF, Halpern D. Psychological Science. New York: Norton & Company; 2009.
- 294 Kiecolt-Glaser J, Newton TL. Marriage and health: his and hers. *Psychological Bulletin* 2001;**127**:472-503.

- Kreuter M. Spinal cord injury and partner relationships. *Spinal Cord* 2000;**38**:2-6.
- 296 Weitzenkamp D, Gerhart KA, Charlifue SW, Whiteneck GG. Spouses of spinal cord injured survivors: the added impact of caregiving. *Archive of Physical Medicine and Rehabilitation* 1997;**78**:
- 297 Kester B, Rothblum ED, Lobatro D, Milhous RL. Spouse adjustment to spinal cord injury: long-term medical and psychosocial factors. *Rehabilitation Counseling Bulletin* 1988;**32**:4-21.
- 298 Burg M, Seeman TE. Families and Health: the negative side of social ties. *Annals of Behavioral Medicine* 1994;**16**:109-15.
- 299 Fincham F, Linfield KJ. A new look at marital quality: Can spouses feel positive and negative about their marriage? *Journal of Family Psychology* 1997;**11**:489-502.
- 300 McNett SC. Social support, threat, and coping responses and effectiveness in the functionally disabled. *Nurs Res* 1987;**36**:98-103.
- 301 WHO. International Classification of Functioning, Disability and Health: ICF. Geneva: World Health Organization; 2001.
- 302 Semrud-Clikeman M. Social competence in children. New York: Springer Science + Business Media; 2007.
- 303 Kasten H. Soziale Kompetenzen, Entwicklungspsychologische Grundlagen und Frühpädagogische Konsequenzen. Berlin Düsseldorf Mannheim: Cornelsen Verlag Scriptor GmbH & Co. KG; 2008.
- 304 Malti T, Perren S. Soziale Kompetenzen bei Kindern und Jugendlichen, Entwicklungsprozesse und Förderungsmöglichkeiten. Stuttgard: Kohlhammer; 2008.
- 305 Kelle U. Combining qualitative and quantitative methods in research practice: Purposes and advantages. *Qualitative Research in Psychology* 2006;**3**:
- 306 Sitgreaves R. How large should the sample be? Statistical power and sample size.1978.
- 307 Medeiros L, Rosa DD, Bozzetti MC, Rosa MI, Edelweiss MI, Stein AT, Zelmanowicz A, Ethur AB, Zanini RR. Laparoscopy versus laparotomy for FIGO Stage I ovarian cancer. *Cochrane Database of Systematic Reviews* 2008;CD005344.
- 308 Huynh J, Howard M, Lytwyn A. Self-collection for vaginal human papillomavirus testing: systematic review of studies asking women their perceptions. *Journal of Lower Genital Tract Disease* 2010;**14**:356-62.
- 309 Orriols L, Salmi LR, Philip P, Moore N, Delorme B, Castot A, Lagarde E. The impact of medicinal drugs on traffic safety: a systematic review of epidemiological studies. *Pharmacoepidemiol Drug Saf* 2009;**18**:647-58.
- 310 Sanderson S, Tatt ID, Higgins JP. Tools for assessing quality and susceptibility to bias in observational studies in epidemiology: a systematic review and annotated bibliography. *International Journal of Epidemiology* 2007;**36**:666-76.
- 311 Schulz R, Decker S. Long-term adjustment to physical disability: The role of social support, perceived control, and self-blame. *Journal of Personality and Social Psychology* 1985;**48**:62-72.
- 312 Procidano M, Heller K. Measures of perceived social support from friends and from family: Three validation studies. *American Journal of Community Psychology* 1983;**11**:1-24.

- 313 Cutrona C, Russell DW. The provisions of social relationships and adaptation to stress. In: Jones W, Perlman D., editor. *Advances in personal relationships*. Greenwich, CT: JAI; 1987. p. 37-67.
- 314 Joseph S, Yule W, Williams R, Yule W. Crisis support and psychiatric symptomatology in adult survivors of the Jupiter Cruise ship disaster. *British Journal of Clinical Psychology* 1993;**32**:177-85.
- 315 Starr L, Robinson RG, Price TR. The Social Functioning Exam: an assessment of stroke patients. *Social Work Research and Abstracts* 1983;**18**:28-33.
- 316 Weinert C. Measuring social support: PRQ2000. In: Dilorio OSC, editor. *Measurement of nursing outcomes: Self-care and coping*. New York: Springer; 2003. p. 161-72.
- 317 Zimet G, Dahlem NW, Zimet SG, Farley GK. The multidimensional scale of perceived socail support. *Journal of Personality Assessment* 1988;**52**:30-41.
- 318 Gilad D, Lavee Y, Innes-Kenig O. The structure of dyadic support among couples with and without long-term disability. *Journal of Behavioral Medicine* 2009;**32**:453-65.
- 319 Komproe I, Rijken PM, Hoeks IAML, Ros WJG. Sociale steun en welbevinden (social support and well-being). 1991.
- 320 Vaux A, Philipps J, Holly L, Thomson B, Williams D, Stewart D. The Social Support Appraisals (SS-A) scale: Studies of reliability and validity. *American Journal of Community Psychology* 1989;**14**:195-219.
- 321 Turner R, Frankel BG, Levin DM. Social support: conceptualization, measurement, and implications for mental health. *Research in Community and Mental Health* 1983;**3**:67-111.
- 322 Henderson S, Duncan-Jones P, Byrne DG, Scott R. Measuring social relationships. The interview schedule for social interaction. *Psychological Medicine* 1980;**10**:723-34.
- 323 Epstein N, Baldwin LM, Bishop DS. The McMaster Family Assessment Device. *Journal of Marital and Family Therapy* 1983;**9**:171-80.
- 324 Snyder M. Public appearances, private realities: The psychology of selfmonitoring. New York: Freeman; 1987.
- 325 Liberman R. Assessment of social skills. *Schizophrenia Bull* 1982;8:62-83.
- 326 Catz A, Itzkovich M, Agranov E, Ring H, Tamir A. SCIM--spinal cord independence measure: a new disability scale for patients with spinal cord lesions. *Spinal Cord* 1997;**35**:850-6.
- 327 Rauch A, Cieza A, Stucki G. How to apply the International Classification of Functioning, Disability and Health (ICF) for rehabilitation management in clinical practice. *Eur J Phys Rehab Med* 2008;**44**:329-42.
- 328 King LA. The health benefits of writing about life goals. *Personality and Social Psychology Bulletin* 2001;**27**:798-807.
- 329 Snyder CR, Lehman KA, Kluck B, Monsson Y. Hope for rehabilitation and vice versa. *Rehabiliation Psychology* 2006;**51**:89-112.
- 330 King LA. Interventions for enhancing subjective well-being. In: Larsen RJ, editor. *The science of subjective well-being*. New York: Guildford Press; 2008.
- 331 Bloemen-Vrencken J, de Witte LP. Post-discharge nursing problems of spinal cord injured patients: on which fields can nurses contribute to rehabilitation? *Clin Rehabil* 2003;**17**:890-8.
- 332 Gouldner A. The Norm of Reciprocity: A PreliminaryStatement. *American Sociological Review* 1960;**25**:

- 333 Dunn M. Social discomfort in the patient with spinal cord injury. *Arch Phys Med Rehab* 1977;**58**:257-60.
- Thorndike E. Intelligence and its use. *Harper's Magazine* 1920;**140**:227-35.
- 335 Salovey P, Mayer JD. Emotional intelligence. *Imagination, Cognition, and Personality* 1990;**9**:185-211.
- 336 Johnson M, TR E, TB N, SF M, MA. C. A Social Problem-Solving Model of Adherence to HIV Medications. *Health Psychol* 2006;**25**:355-63.
- 337 Elliott T. Social problem-solving abilities and adjustment to recent-onset spinal cord injury. *Rehabil Psychol* 1999;**44**:315-32.
- 338 Elliott T, Bush BA, Chen Y. . Social problem-solving abilities predict pressure sore occurrence in the first 3 years of spinal cord injury *Rehabil Psychol* 2006;**51**:69-77.
- 339 Herrick S, Elliott TR, Crow F. . Self-appraised problem-solving skills and the prediction of secondary complications among persons with spinal cord injuries. *J Clin Psychol Med S* 1994;**1**:269-83.
- 340 Elliott T, Godshall FJ, Herrick, SM, Witty TE. . Problem-solving appraisal and psychological adjustment following spinal cord injury. *Cognitive Ther Res* 1991;**15**:387-98.
- 341 Dreer L, Elliott TR, Tucker E. Social problem-solving abilities and health behaviors among persons with recent-onset spinal cord injury. *J Clin Psychol Med S* 2004;**11**:7-13.
- 342 Cohen S, Wills TA. . Stress, social support, and the buffering hypothesis. *Psychol Bull* 1985;**98**:310-57.
- 343 Antonovsky A. Conceptual and methodological problems in the study of resistance resources and stressful life events. In: Dohrenwend BS DB, editor. *Stressful Life Events: Their Nature and Effects*. New York: Wiley; 1974.
- 344 Caplan G. Support Systems and Community Mental Health. New York: Behavioral Publications; 1974.
- 345 Cassel J. The contribution of the social environmet to host resistance. *American Journal of Epidemiology* 1976;**104**:107-23.
- 346 Cobb S. Social support as amoderator of life stress. *Psychosomatic Medicine* 1976;**38**:300-14.
- 347 Agar E, Kennedy P, King NS. The role of negative cognitive appraisals in PTSD symptoms following spinal cord injuries. *Behavioral and Cognitive Psychotherapy* 2006;**34**:437-52.
- 348 Nielsen M. Prevalence of Posttraumatic Stress Disorder in persons with spinal cord injuries: The mediating effect of social support. *Rehabiliation Psychology* 2003;**48**:289-95.
- 349 van Leeuwen C, Post, MWM, van Asbeck, FWA., van der Woude, LHV, de Groot, S, LIndeman, E. Social support and life satisfaction in spinal cord injury during and up to one year after inpatient rehabilitation. *Journal of Rehabilitation Medicine* 2010;**42**:265-71.
- 350 Segrin C, Rynes KN. The mediating role of positive relations with others in associations between depressive symptoms, social skills, and perceived stress. *J Res Pers* 2009;**43**:962-71.
- 351 Miller WC, Sakakibara BM, Noonan VK, Kawashy AE, Aubut JL, Connolly SJ, et al. Outcome Measures. In: Eng JJ TR, Miller WC, Wolfe DL, Townson AF, Hsieh JTC, Connolly SJ, Mehta S, Sakakibara BM, editor. *Spinal Cord Injury Rehabilitation Evidence Version 30* Vancouver2010. p. 1-147.

- 352 Post M, Brinkhof MWG, von Elm E, Boldt C, Brach M, Muff C, Eriks-Hoogland I, Curt A, Stucki G, for the SwiSCI study group. Design of the Swiss Spinal Cord Injury Cohort Study (SwiSCI). *Am J Phys Med Rehabil* 2011;[in press].
- 353 Muller R, Peter C, Cieza A, Geyh S. The role of social support and social skills in people with spinal cord injury--a systematic review of the literature. *Spinal Cord* 2012;**50**:94-106.
- 354 Zigmond AS, Snaith, R.P. . The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica* 1983;**67**:361-70.
- 355 Bjelland I, Dahl, A.A., Tangen Haug, T., Neckelmann, D. The validity of the Hospital Anxiety and Depression Scale - An updated literature review. *Journal* of Psychosomatic Research 2002;**52**:69-77.
- 356 Müller R, Cieza A, Geyh S. Rasch Analysis of the Hospital Anxiety and Depression Scale in Spinal Cord Injury. *Rehabil Psychol* 2012;**[accepted]**:
- 357 Van der Zee CH, M.W.M. P, Kap A, Schouten E, van Royen R, Rambaran Mishre R, et al. Het meten van participatie als uitkomst van poliklinische revalidatiebehandeling: Meten is Weten 2; een prospectieve multi-centre studie. Measurement of participation as an outcome of outpatient rehabilitation: A prospective multi-centre study. *Revalidata* 2008;**146**:10-4.
- 358 Van der Zee CH, Kap A, Rambaran Mishre R, Schouten EJ, Post MWM. Responsiveness of four participation measures for outcomes of outpatient rehabilitation. *J Rehabil Med* 2011;**43**:1003-9.
- 359 Weston R, Gore JPA, Chan F, Catalano D. An introduction to using structural equation models in rehabilitation psychology. *Rehabilitation Psychology* 2008;**53**:340-56.
- 360 Curran PJ, West SG, Finch J. The robustness of test statistics to nonnormality and specification error in confirmatory factor analysis. *Psychological Methods* 1996;**1**:16-29.
- 361 Schafer JL, Graham JW. Missing data: our view of the state of the art. *Psychol Methods* 2002;**7**:147-77.
- 362 Little RJA. A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association* 1988;**83**:1198-202.
- 363 Jöreskog KG, Sörbom D. LISREL (LInear Structural RELations). Scientific Software Int Inc, 7383 N Lincoln Ave, Ste 100, Lincolnwood, IL 60712-1747; 2007.
- 364 Jöreskog KG. A General Method for Estimating a Linear Structural Equation System. In: Goldberger AS, Duncan OD, editors. *Structural Equation Models in the Social Sciences*. New York: Academic Press; 1973.
- 365 Enders CK, Bandalos DL. The relative performance of full information maximum likelihood estimation for missing data in strucutal equation models. *Structural Equation Modeling* 2001;**8**:430-57.
- 366 Finney SJ, DiStefano C. Non-normal and categorical data in structural equation modeling. In: Hancock GR, Mueller RO, editors. *Structural equation modeling: A second course*. Greenwich, CT: Information Age Publishing; 2006. p. 269-314.
- 367 Coffman DL, MacCallum RC. Using parcels to convert path analysis models into latent variable models. *Multivariate Behavioral Research* 2005;**40**:235-59.
- 368 Kishton JM, Widaman KF. Unidimensional verses domain representative parceling of questionnaire items: An empirical example. *Educational and Psychological Measurement* 1994;**54**:757-65.

- 369 Bandalos DL. The effects of item parceling on goodness-of-fit and parameter estimate bias in structural equation modeling. *Structural Equation Modeling* 2002;**9**:78-102.
- 370 Hu L, Bentler PM. Fit indices in covariance structure modeling: Sensitivity to underparameterized model misspecification. *Psychological Methods* 1998;**3**:424-53.
- 371 Hu L, Bentler PM. Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives. *Structural Equation Modeling* 1999;**6**:1-55.
- 372 Macdonald E, Jackson HJ, Hayes RL, Baglioni Jr AJ, Madden C. . Social skill as a determinant of social networks and perceived social support in schizophrenia. *Schizophrenia Res* 1998;**29**:275-86.
- 373 Kessler RC, Kendler KS, Heath A, Neale MC, Eaves LJ. Social support, depressed mood, and adjustment to stress: a genetic epidemiologic investigation. *J Pers Soc Psychol* 1992;**62**:257-72.
- 374 Bowlby J. Attachment. London: Pelican; 1971.
- 375 Taylor J, Turner RJ. A longitudinal study of the role and significance of mattering to others for depressive symptoms. *J Health Soc Behav* 2001;**42**:310-25.
- 376 Youngren MA, Lewinsohn PM. The functional relation between depression and problematic interpersonal behavior. *J Abnorm Psychol* 1980;**89**:333-41.
- 377 Lewinsohn PM, Hoberman H, Teri L, Hautzinger M. An integrative theory of depression. In: Reiss S, Bootzin RR, editors. *Theoretical issues in behavior therapy*. New York: Academic Press; 1985. p. 331-59.
- 378 Segrin C, Hanzal A, Donnerstein C, Taylor M, Domschke TJ. Social skills, psychological well-being, and the mediating role of perceived stress. *Anxiety Stress Coping* 2007;**20**:321-9.
- 379 Trunzo JJ, Pinto BM. Social support as a mediator of optimism and distress in breast cancer survivors. *J Consult Clin Psychol* 2003;**71**:805-11.
- 380 Khan A, Husain A. Social support as a moderator of positive psychological strengths and subjective well-being. *Psychol Rep* 2010;**106**:534-8.
- 381 Taylor SE. Social support: A Review. In: Friedman MS, editor. *The Handbook of Health Psychology*. New York, NY: Oxford University Press; 2011.
- 382 Sarason BR, Sarason IG, Gurung RAR. Close personal relationships and health outcomes: A key to the role of social support. In: Sarason BR, Duck S, editors. *Personal relationships: Implications for clinical and community psychology*. New York, NY: John Wiley & Sons Ltd; 2001. p. 15-41.
- 383 Fekete C, Segerer W, Brinkhof MWG, Group atSS. Participation rates and nonresponse analysis in an epidemiologic study on functioning: The baseline recruitment of the Swiss Spinal Cord Injury Cohort Study (SwiSCI) community survey. 2012.
- 384 Ryff CD, Singer BH, Wing E, Love GD. Elective affinity and uninvited agonies: mapping emotion with significant others onto health. In: Ryff CD, Singer BH, editors. *Emotion, social relationships, and health*. New York: Oxford University Press; 2001. p. 133-75.
- 385 Segrin C. Interpersonal processes in psychological problems. Mahwah, NJ: Lawrence Erlbaum; 2001.
- 386 Crawford A, Hollingsworth HH, Morgan K, Gray DB. People with mobility impairments: Physical activity and quality of participation. *Disabil Health J* 2008;**1**:7-13.

- 387 Riggio RE, Canary, D.R. . Social skills inventory manual (2nd ed.). Redwood City, CA: MindGarden; 2003.
- 388 Schöler L, Lindenmeyer J, Schöler H. Das alles soll ich nicht mehr können? Weinheim und Basel: Beltz Verlag; 1981.

XI. Appendix

Appendix 1: Illustration of the concept of social skills


Appendix 2: The Hospital Anxiety and Depression Scale (German Version)

ANGST UND DEPRESSIONS-SKALA

Bitte lesen Sie die folgenden Aussagen und <u>UNTERSTREICHEN SIE DIE ANTWORT</u>, welche am besten beschreibt, wie Sie sich in der letzten Woche gefühlt haben. Ignorieren Sie die Zahlen in den grauen Feldern am Rande der Tabelle.

Überlegen Sie nicht lange. Ihre spontane Reaktion auf jede Aussage wird wahrscheinlich zutreffender sein, als eine lang überlegte Antwort.

Α	D			Α	D
		1. Ich bin angespannt oder überreizt	8. Ich fühle mich in meinen		
3		Meistens	Aktivitäten gebremst		
2		Oft	Fast immer		3
1		Gelegentlich / von Zeit zu Zeit	Sehr oft		2
0		Überhaupt nicht	Manchmal		1
			Überhaupt nicht		0
		2. Ich kann mich heute noch so	9. Ich habe manchmal ein		
		freuen wie früher	ängstliches Gefühl in der		
	0	Ganz genau so	Magengegend	0	
	1	Nicht ganz so sehr	Überhaupt nicht	1	
	2	Nur noch ein wenig	Gelegentlich	2	
	3	Kaum oder gar nicht	Ziemlich oft	3	
		Ū.	Sehr oft		
		3. Mich überkommt eine ängstliche	10. Ich habe das Interesse an		
		Vorahnung, dass etwas	meiner äusseren Erscheinung		
		Schreckliches passieren könnte	verloren		3
3		Ja, sehr stark	Ja, stimmt genau		2
2		Ja, aber nicht allzu stark	Ich kümmere mich nicht so sehr darum,		
1		Etwas, aber es macht mir keine Sorgen	wie ich sollte		1
0		Überhaupt nicht	Möglicherweise kümmere ich mich zu		
			wenig darum		0
			Ich kümmere mich so viel darum wie		
			immer		
		4. Ich kann lachen und die lustige	11. Ich fühle mich rastlos, muss		
		Seite der Dinge sehen	immer in Bewegung sein		
	0	Ja, so viel wie immer	Ja, tatsächlich sehr	3	
	1	Nicht mehr ganz so viel	Ziemlich	2	
	2	Inzwischen viel weniger	Nicht sehr	1	
	3	Uberhaupt nicht	Uberhaupt nicht	0	
		5 Mir gobon bounrubigondo	12 Joh blicko mit Froudo in dio		
		5. Mill genen beunfungende Godankon durch den Konf	12. ICH DIICKE IIIIt Freude III die Zukunft		0
3		Einen Grossteil der Zeit			1
2		Verhältnismässig oft	5a, sein Eber weniger als früher		2
1		Von Zoit zu Zoit, aber nicht allzu oft	Viel weniger als früher		2
		Nur gelegentlich nie	Kaum bis gar nicht		5
0		6 Ich fühle mich alücklich	13 Mich überkommt plötzlich ein		
	3	Überhaunt nicht	nanikartiger Zustand		
	2	Selten	Ja tatsächlich sehr oft	3	
	1	Manchmal	Ziemlich oft	2	
	0	Meistens	Nicht sehr oft	1	
	Ŭ			0	
		7. Ich kann behaglich dasitzen und	14. Ich kann mich an einem guten	0	
		mich entspannen	Buch. einer Radio- oder		
0		Ja. natürlich	Fernsehsendung freuen		0
1		Gewöhnlich schon	Oft		1
2		Nicht oft	Manchmal		2
3		Überhaupt nicht	Eher selten		3
			Sehr selten		

Appendix 3: Eligibility criteria for the systematic literature review

Eligibility criteria for systematic literature review on the role of social support and social skills in persons with SCI

- Studies are included that generate first-hand data on social support and/or social skills in SCI
- Articles are included if they fulfill all inclusion criteria and none of the exclusion criteria

INCLUSION CRITERIA

Incl.1: Study population

- human
- age >=13
- Patients with a damage or injury of the spinal cord due to a rapid-onset singular event resulting in lasting paralysis within a short period of time after the event and corresponding to the level of the spinal lesion. Etiologies include injuries, iatrogenic or comiogenic causes (e.g. surgical procedures, radiation, or medical complication), and acute and non-progressive diseases (e.g. infection, bleeding, or ischemic event affecting the spinal cord)

AND

Incl.2: Social support

- See annotation 1 for Incl.2 about social support.
- Articles which generate data on **social support**. Papers are selected if they
 - o include social support in the aim of the study OR
 - **assess** social support OR
 - o administer a social support intervention to persons with SCI

OR / AND

Incl.3: Social skills / social competence

- See annotation 1 for Incl.2 about **social skills**.
- Articles which generate data on social skills should be selected. Papers are selected if they
 - o include social skills / social competence in the aim of the study OR
 - o **assess** social skills / social competence OR
 - o administer intervention in social skills / social competence to persons with SCI

AND

Incl.4: Study design

One of the following study designs implemented:

- Randomized controlled trial or randomized clinical trial
- Clinical controlled trial
- Cross-sectional study
- Longitudinal observational study
- Diagnostic efficacy evaluation
- Register study / Chart review
- Epidemiological trial
- Economic evaluation / Decision analyses based on first hand data not reviews or meta Analyses

AND

Incl.5: Formal criteria

- Publication type: journal article
- Language: English
- Publications in scientific journals available in English language are included
- Year of publication: 20 years (1990 2010)

 Multiple publications: Journal with the highest impact factor in the case of multiple publications. In case of publications in the same journal (e.g. follow-up study) the most recent publication will be considered

EXCLUSION CRITERIA

Excl.1: Main criteria

• The article does not fulfil Incl.2: Social support and Incl.3: Social skills / social competence

Excl.2: Study population

- Non-human population (animal study / cadaver study / laboratory / in-vitro study
- Patients at age < 13 years included
- Sample size: N <=30 with SCI
- Studies unclear about the target population should be excluded (e.g. study sample consists of patients with spinal fractures is excluded in a review of SCI)
- Studies in which persons with SCI are not the main target population (e.g. case-control study about persons with multiple sclerosis in which SCI-population is the control group)

Excl.3: Study design

- Review or Meta-Analysis
- Qualitative study
- Psychometric study
- Case report / case series
- Primary prevention study
- Ecologic study
- Economic evaluation study or decision analysis (cost, cost / benefit, cost / effectiveness, cost / utility, modelling, simulation) based on review or meta-analyses
- Study protocol

Excl.4: Formal criteria

- Publication type:
 - Review (topic overview) or meta-analyses
 - o Comment
 - o Letter
 - Editorial
 - o Guideline
 - Conference report
 - o Book chapter
 - o Dissertation
- Language: other than English
- Year of publication: other than last 40 years
- Multiple publication: Journal with lower than the highest impact factor in the case of multiple publications. In case of publications in the same journal (e.g. follow-up study) the less recent publications will be excluded

ANNOTATIONS

Annotation 1 for Incl.2

• For the decision the following synonyms and related constructs of social support can be considered:

Social support	Attachment	
Social network(s)	Peer relation(s)	
Social exchange(s) (of resources)	Family relationship	
Social relationship(s)	Marital relation(s)	
Social interaction(s)	Parental relation(s)	
Interpersonal interaction(s)	Sibling relation(s)	
Social behavior(u)r	Inter-personal	
Support system(s)	Interpersonal support	

Social group(s)	Interpersonal network(s)		
Prosocial behavior(u)r	Interpersonal exchange(s)		
Altruism	Interpersonal relationship(s)		
	Interpersonal behavio(u)r		

Annotation 2 for Incl.2

- Social support is defined as exchange of resources between at least two individuals intended to enhance the wellbeing of the individuals... (1). This exchange includes the possible negative effect of social support.
- Social support can be seen from different perspectives:

structural (quantity, e.g. network size, frequency of interaction with friends, marital status)

functional

instrumental: i.e. tangible aid, e.g. help with household chores, running errands *emotional*: i.e. social exchange e.g. expressing affection and concerns to a friend) *informational*: i.e. advice, guidance, feedback, e.g. information from the doctor about disease)

- qualitative (e.g. satisfaction, appraisal, adequacy) perspective.
- Social support can be received from different sources, e.g. from family, friends, health professionals, people at work. However, professional and institutional support should be excluded, as it is too broad (e.g. receiving physical therapy, special teaching for children with SCI)

Annotation 3 for Incl.3

• For the decision the following synonyms and related constructs of social skills can be considered:

Social skill(s)	Assertive(ness)
Social competenc(y)(ies)	Social engagement
Social cognition	Authentic(ity)
Social abilit(y)(ies)	Self-disclosure
Communication skill(s)	Social understanding
Social intelligence	Impression management
Social performance	Self presentation
Interpersonal communication	Relationship management
Nonverbal communication	Social awareness
Verbal communication	Persua(sive)(sion)
Social adapt(ive)(ation)	Negotiat(ive)(ion)
Adaptive behavio(u)r	Social abilit(y)(ies)
(Social) problem-solving (abilities)	

Annotation 4 for Incl.3

- Social skills / social competence are defined as the ability to interact with other people in a
 way that is both appropriate and effective (2)(3)(4).
 - o Appropriateness: behavior of actor not evaluated negatively by others
 - Effectiveness: behavior of the actor achieves the intended goal
- Differentiating social skills and social competence:
 - **Social skills** represent the constituent behaviors which, when used in appropriate ways and places, enable an individual to have the success in daily living reflected by **social competence** (5)

Social competence is the ability to achieve goals through interacting with others (6) and highlights the evaluative judgments of others (7)

Social skills can be seen as raw material of social competence (8).

References:

(1) Shumaker, S.A. & Brownell A. (1984). Toward a theory of social support: closing conceptual gaps. Journal of Social Issues 40 (4), 11-36.

(2) Segrin, C. (1992). Specifying the nature of social skill deficits associated with depression. Human Communication Research, 19, 89–123

(3) Spitzberg, B. H., & Cupach, W. R. (1985). Conversational skill and locus of perception. Journal of Psychopathology and Behavioral Assessment, 7, 207–220.

(4) Spitzberg, B. H., & Cupach, W. R. (1989). Handbook of interpersonal competence research. New York: Springer-Verlag.

(5) Bellak AS, Mueser KT, Gingerich S, Agresta J. Social skills training for Schizophrenia. new York, NY: Guilford Press; 2004

(6) Knapczyk D & Rodes P. Teaching Social Competence. Champaign, Ill: Research Press; 2001.

(7) Gresham, FM (1986). Conceptual issues in the assessment of social competence in children. In Strain, PS, Guralnick, MJ, Walker, HM (Eds.), Children's social behavior: Development, assessment, and modification (pp. 143-179). New York: Academic Press.

(8) Kopelowicz, A, Liberman, RP, Zarate, R (2006). Recent advances in social skills training for schizophrenia. Schizophrenia Bulletin, 32, 12–23.

Appendix 4: Social Skills Inventory (SSI) Framework, scale definitions and sample items¹⁴⁸

Nonverbal / Emotional Domain (Emotional Skills)	Verbal / Social Domain (Social Skills)
(related to Emotional Intelligence)	(related to Social Intelligence)

Emotional Expressivity (EE)

Skill in nonverbal encoding. Ability to accurately express felt emotional states.

- I am able to liven up a dull party.
- I have been told that I have expressive eyes.

Emotional Sensitivity (ES)

Skill in nonverbal decoding. Being attentive to subtle emotional cues; being empathic.

- I sometimes cry at sad movies.
- I am often told that I am a sensitive, understanding person.

Emotional Control (EC)

Skill in regulating and controlling emotional expressions. Hiding felt emotions behind an emotional "mask".

- I am easily able to make myself look happy one minute and sad the next.
- I am very good at maintaining a calm exterior even if I am upset.

Social Expressivity (SE)

Skill in verbal encoding and ability to engage others in social interaction. Associated with verbal fluency.

- When telling a story, I usually use a lot of gestures to help get the point across.
- I usually take the initiative to introduce myself to strangers.

Social Sensitivity (SS)

Skill in verbal decoding. Sensitivity to and understanding of norms governing appropriate social behavior. Ability to decode social situations.

- I'm generally concerned about the impression I'm making on others.
- Sometimes I think that I take things other people say to me too personally.

Social Control (SC)

Skill in social role-playing and social self-presentation. Social adeptness and tact. "Savoir-faire".

- I am usually very good at leading group discussions.
- I can easily adjust to being in just about any social situation.

Appendix 5: The Short Form Social Support Questionnaire (SSQ6)

Unterstützung durch Andere

In den folgenden Fragen geht es um die Menschen, die Ihnen Hilfe und Unterstützung geben. Jede Frage hat zwei Teile. Im ersten Teil nennen Sie bitte alle Personen, die Sie kennen, ausser sich selbst, auf deren Hilfe oder Unterstützung Sie in der beschriebenen Form zählen können. Nennen Sie jede Person mit ihren Initialen und der Beziehung, die sie zu Ihnen hat (siehe Beispiel).

Im zweiten Teil kreuzen Sie bitte an, wie zufrieden Sie insgesamt mit der Unterstützung sind, die Sie erfahren.

Wenn es bei einer Frage niemanden gibt, der Sie unterstützt, kreuzen Sie das Kästchen beim Wort "Niemand" an, geben Sie aber dennoch Ihre Zufriedenheit an. Nennen Sie nicht mehr als neun Personen pro Frage.

Beispiel:

O Niemand

Wem können Sie heikle Informationen anvertrauen?

💢 Folgende	Personen:						
Ø T.N. (E	PT.N. (Bruder)			🖉 L.M. (Arbeítgeber)			
Ø T.N. (V	PT.N. (Vater)			PR.S. (Freund)			
1 L.M. (7	L.M. (Freund)			P			
P			β				
Ø							
Wie zufrieden sind Sie damit?							
Sehr <u>zufrieden</u>	Ziemlich zufrieden	Ein wenig zufrieden	Ein wenig unzufrieden	Ziemlich unzufrieden	Sehr <u>unzufrieden</u>		
0	0	X	0	0	0		

1) Auf wen können Sie sich wirklich verlassen, wenn Sie Hilfe brauchen? O Niemand O Folgende Personen: *P*_____ P _____ P _____ P _____ *P*_____ P _____ P _____ *P*_____ P _____ b) Wie zufrieden sind Sie damit? Sehr Ziemlich Ein wenig Ein wenig Ziemlich Sehr unzufrieden unzufrieden unzufrieden zufrieden zufrieden zufrieden 0 0 Ο Ο Ο 0

2) Wer hilft Ihnen wirklich, sich entspannter zu fühlen, wenn Sie unter Druck oder Anspannung stehen?

NiemandFolgende	e Personen:					
P			P			
P			P			
P						
Ø			Ø			
Ø						
b) Wie zufrie	eden sind Sie dami	it?				
Sehr <u>zufrieden</u>	Ziemlich zufrieden	Ein wenig zufrieden	Ein wenig unzufrieden	Ziemlich unzufrieden	Sehr <u>unzufrieden</u>	
0	0	0	0	0	0	

3) Wer akzeptiert Sie wirklich vollkommen, mit all Ihren guten und schlechten Seiten?



4) Wer kümmert sich wirklich um Sie, egal was Ihnen geschieht?

NiemandFolgende	l e Personen:					
P			Ø			
P			Ø			
P			Ø			•
Ø			Ø			
P						
b) Wie zufri	eden sind Sie dam	it?				
Sehr	Ziemlich	Ein wenig	Ein wenig	Ziemlich	Sehr	
<u>zufrieden</u>	zufrieden	zufrieden	unzufrieden	unzufrieden	<u>unzufrieden</u>	
0	0	0	0	0	0	

5) Wer hilft Ihnen wirklich, sich besser zu fühlen, wenn Sie allgemein niedergeschlagen sind?

O Niemand	l							
O Folgende	e Personen:							
Ø			Ø					
Ø	P			P				
Ø			Ø					
0			P					
P								
b) Wie zufri	eden sind Sie dam	it?						
Sehr	Ziemlich	Ein wenig	Ein wenig	Ziemlich	Sehr			
<u>zufrieden</u>	zufrieden	zufrieden	unzufrieden	unzufrieden	<u>unzufrieden</u>			
0	0	0	0	0	0			
6) Wer besänftigt S	6) Wer besänftigt Sie, wenn Sie sehr aufgebracht sind?							
O Niemand	l							
O Folgende	e Personen:							
Ø			Ø					
Ø			Ø					
Ø			Ø					
Ø			Ø					
Ø								
b) Wie zufrie	eden sind Sie dam	it?						
Sehr	Ziemlich	Ein wenig	Ein wenig	Ziemlich	Sehr			
<u>zufrieden</u>	zufrieden	zufrieden	unzufrieden	unzufrieden	<u>unzufrieden</u>			
0	0	0	0	0	0			