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SYSTEMATIC REVIEW

A systematic review of outcome measures in initial rehabilitation of individuals with newly acquired spinal cord injury: providing evidence for clinical practice guidelines

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ABSTRACT

INTRODUCTION: A newly acquired spinal cord injury (SCI) has an impact on various aspects of a patients' functioning. Outcome measures represent an important component of initial rehabilitation to assess patients' overall status and their progress, simplify clinical communication and support clinical decision-making. The aim of this review was to create an evidence base for developing clinical practice guidelines using systematic literature review to evaluate assessment instruments used in acute/subacute SCI rehabilitation.

EVIDENCE ACQUISITION: PubMed, CINAHL, Cochrane Library and LIVIVO databases were searched using the MeSH terms and key words of the Spinal Cord Injury Research Evidence (SCIRE). Studies on outcome measures with patients in the acute/subacute phase of SCI, published in English or German from January 2013 until December 2018 were included. Two reviewers independently screened articles and when a consensus was not reached two further reviewers were consulted. To determine publication quality of systematic reviews, validation and observation studies, AMSTAR, COSMIN and STROBE checklists were applied.

EVIDENCE SYNTHESIS: A total of 2533 records were retrieved, 71 potentially eligible articles identified, and 33 articles finally included. One validation and one observational study met all quality criteria. One systematic review received eight from a maximum of 11 points for publication quality (AMSTAR). Ten of 19 validation studies were deemed as "excellent" or "good" (COSMIN), but some were hampered by the low number of study participants. From the 29 reviewed assessments 28 were recommended and one was not. Seven of 13 observational studies received a rating equal or higher to 20 out of a maximum of 22 points (STROBE). Assessments covered neuro-musculoskeletal, sensory and pain, mental and skin structures and functions, as well as activity, participation and quality of life.

CONCLUSIONS: In the field of initial SCI rehabilitation, scientifically sound assessments covering different aspects of the bio-psychosocial model of the ICF are available. According to COSMIN, validation studies struggled with quality, whereas observational studies and systematic studies performed well. The review results support the evidence-based selection of outcome measures for assessing the initial rehabilitation of patients with acute and subacute SCI. These results represent an update for recommendations for clinical guidelines on standardized rehabilitation outcome documentation.

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KEY WORDS: Outcome assessment; Psychiatric rehabilitation; Evidence-based practice; International Classification of Functioning, Disability and Health.

Introduction

A spinal cord injury (SCI) results in a complex medical condition that elicits changes to many levels of the individual's functioning.[1-4] It is important to start rehabilitation of patients as early as possible after SCI to reach their highest level of independence and autonomy with regard to all influencing factors according to the bio-psychosocial model and to avoid long-term complications.[5] Besides the highest possible level of functioning, the main goal of rehabilitation is to gain the highest possible participation in society.[4, 6]

Quality of health services can be measured on the level of its structure, processes and outcomes.[7, 8] Outcome measures have been widely accepted as a key concept of good clinical practice. However, outcome measures' use among SCI practitioners varies widely, potentially due to the large number of available assessments. The use of standardized assessments enables health professionals to evaluate patient progress, allows for comparison and simplifies clinical communication.[9] Furthermore, an unique assessment scheme allows management of the quality of rehabilitation and may be used for benchmarking.[10] Standardized reporting provides the basis for collection and comparison of functioning and disability data on a national level and across health systems.[11] The International Classification of Functioning, Disability and Health (ICF), represents a comprehensive taxonomy to categorize assessments for reporting functioning and disability, including various health states across different health care systems and levels.[11, 12]

A considerable amount of research to examine and summarize the pool of assessments in SCI rehabilitation has been published in the past. Most initiatives target single functions and describe categories of outcomes for clinical practice and research settings.[1, 13, 14] Others focus on developing ICF core sets to highlight important domains that need to be addressed in the conduct of studies and clinical trials within the different phases after SCI.[2, 15] One comprehensive systematic review, the Spinal Cord Injury Research Evidence (SCIRE) initiative, summarizes evidence from validated and scientifically rigorous interventions and assessments used in the field of interprofessional, comprehensive SCI therapy and rehabilitation. SCIRE also provides a web-based toolkit summarizing recommendable assessments based on expert consensus.[16] The current systematic review was undertaken as the basis of a development process for clinical practice guidelines within the German-speaking Medical SCI Society (*Deutschsprachige Medizinische Gesellschaft für Paraplegiologie*, DMGP). The aim of one of those clinical guidelines is to recommend validated outcome measures and assessments to be used in the initial inpatient rehabilitation of patients with acute or subacute SCI.[17] Although this review is based on an initiative of the DMGP, it is intended to serve as a general source of objective information for development or update of clinical practice guidelines of other societies worldwide. Based on the search strategy from SCIRE's systematic review process,[18] the current review sought to identify literature from 2013 onwards to serve as an evidence-base for this guideline. Additionally to SCIRE's search strategy, publications in German language were also included in the literature search.

As a basis for this review the following research questions were defined:

- which assessments and outcome measures have been validated for patients with a newly acquired SCI during initial rehabilitation?
- what is the literatures' scientific quality?
- which assessments can be recommended for patients with a newly acquired SCI during initial rehabilitation?

Thus, the overall intent of this work was to present an up-to-date literature review of outcome measures and assessments used during initial rehabilitation of patients with a newly acquired SCI and to systematically evaluate their scientific quality.

Evidence acquisition

Search strategy

The process of conducting this systematic review was based on the Liverpool Reviews and Implementation Group's[19, 20] approach. The Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines were applied. The search strategy was based on the one used for the SCIRE research team's review[16, 18] and was adjusted with regard to the research questions listed above. The following databases were searched: PubMed, CINAHL, Cochrane Library and LIVIVO. Searches were carried out in September 2017 and one additional search in December 2018, with the following search terms: (validation studies OR instrument validation OR external validity OR internal validity OR criterion-related validity OR concurrent validity OR discriminant validity OR content validity OR face validity OR predictive validity OR reliability OR inter-rater reliability OR intra-rater reliability OR test-retest reliability OR reproducibility OR responsiveness OR sensitivity to change OR evidence-based

medicine OR Outcome measures OR clinical assessment tools OR scales and measures AND spinal cord injuries [MeSH] AND acute OR subacute OR inpatient). The search strategy was adjusted for each database with regard to filters or limits.

Inclusion process and data extraction

General inclusion criteria were defined following the extended PICO-format (patient, intervention, comparison, outcome, study design) (Table I).[19, 20]

Additionally to the criteria presented in Table I, literature has been included in the selection process if it was: 1) published between January 2013 and December 2018; 2) written in English or German language; 3) a study involving humans. Validation studies, observational studies or systematic reviews were included, if they referred to patients with SCI in an acute/subacute inpatient setting. Articles were excluded if the study either did not investigate an assessment or did investigate an assessment, but in patients with different health conditions or in the chronic phase of SCI. Literature was labeled as "not initial rehabilitation phase" when the phase of SCI was chronic (when the time after injury of all study participants was larger than six months) or not identifiable. We excluded studies primarily focusing on investigating therapies or interventions but not assessments. One reviewer (R.T., a health scientist) screened titles and abstracts of retrieved records for eligibility. Two independent reviewers (A.S., an experienced SCI physician; R.T.) read the full texts of eligible articles and decided on the articles' inclusion. In case no agreement was achieved between the two primary reviewers, decision on articles' inclusion was made by a third and fourth reviewer (R.R., an experienced SCI scientist, V.G., an experienced SCI nurse scientist). Articles' information about authors, title, study design, aims, ICF category, psychometric properties, results of the study and recommendations given for assessments' application were summarized into a standardized digital template. Digital templates for the methodological assessment were compiled for structured documentation of the scientific quality evaluation process and evidence synthesis. Literatures' information about the assessments was summarized in a narrative style. The order of presented information was based on the ICF similar to SCIRE's approach.

TABLE I.—*Inclusion criteria according to PICO.*

Criteria	Description
Population	Patients with acute and subacute SCI during initial rehabilitation
Interventions	Assessments for all functioning aspects of patients with an acute or subacute SCI during initial rehabilitation
Comparators	No comparator Assessments for all functioning aspects of patients with an acute or subacute SCI during initial rehabilitation
Outcomes	Psychometric properties Recommendations concerning the use of outcome measures and assessments
Study design	All

SCI: spinal cord injury.

Methodological assessment

In the context of the current review and in preparing the clinical guideline, the methodological quality of the included articles was evaluated.[20] As the systematic search identified three types of literature (validation studies, observational studies and systematic reviews) various critical appraisal tools were deployed. The COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) checklist represents a tool developed by an international multidisciplinary research initiative to assess the methodological quality of studies examining the psychometric properties of assessments.[21, 22] The Strengthening The Reporting of OBservational Studies in Epidemiology (STROBE) statement combines quality criteria for different types of observational studies[23] and was used to determine the quality of the identified observational studies. Finally, the AMSTAR (A MeaSurement

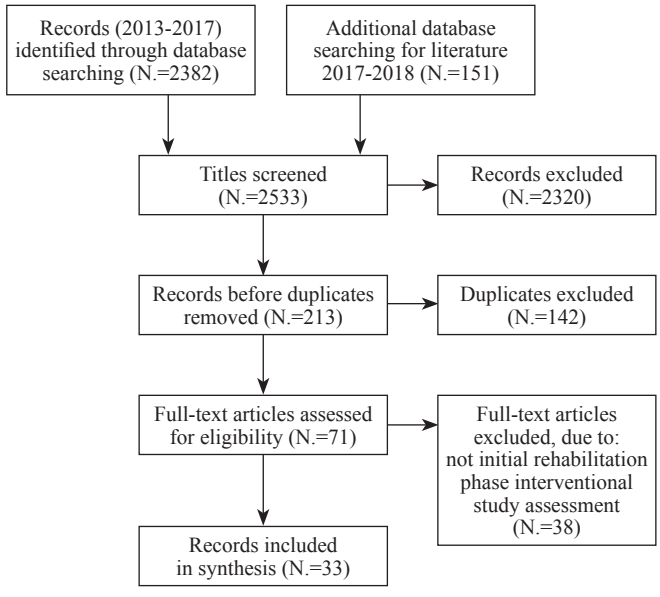

Figure 1.—Flow diagram summarizing the search and inclusion process of this review.

Tool to Assess Systematic Reviews) appraisal tool was used to examine the methodological quality of systematic reviews.[24, 25] Quality assessments were carried out by one reviewer (R.T.) and discussed with an experienced SCI physician (A.S.) when there were uncertainties.

Evidence synthesis

Selection of studies

The electronic search identified 2533 articles in total. Seventy-one full-text publications were further analyzed after application of the general inclusion criteria and removal of duplicates. Finally, 33 articles were deemed as eligible. Figure 1 summarizes the consecutive process of literature identification and inclusion in a PRISMA diagram.

One study was excluded, because it comprised an abstract in conference proceedings, and did not provide sufficient information for inclusion. The agreement rate between the first two reviewers (R.T., A.S.) was 95.7%. Consensus between the two first reviewers (R.T., A.S.) was not achieved in three instances. After consultation, two members of the clinical guideline development group (R.R., V.G.) excluded two of those articles and one was included.

Study characteristics

An overview of the included studies is provided in Table II.[26-58] From the 33 studies that were included, 19 studies assessed the psychometric properties of an assessment in the context of a validation study and 14 articles provided recommendations for assessments' utilization in the patient group of interest either within a systematic review or an observational study. Study populations ranged from nine[26] to 1357 patients.[27] Seven studies investigated pa-

TABLE II.—*Characterization of eligible studies.*[26-58]

Reference	Year	Study design	Sample size	Phase after SCI
Systematic reviews				
Ditunno[45]	2013	Systematic review	NA	Mixed
Validation studies				
Aigner[46]	2016	Validation study: criterion validity	146	Mixed
Akpinar[55]	2017	Validation study: inter-rater, test-retest reliability	47	Mixed
Akpinar[44]	2017	Validation study: inter-rater and test-retest reliability	58	Mixed
Chan[43]	2017	Validation study: internal consistency, construct validity	30	Acute, subacute
Delparte[47]	2016	Validation study: interrater reliability	759	Mixed
Fekete[48]	2014	Validation study: criterion validity	99	Mixed
Gagnon[35]	2016	Validation study: responsiveness and concurrent validity	14	Subacute
Glennie[49]	2014	Validation study: intra- and interrater reliability	10	Mixed
Jette[50]	2015	Validation study: internal consistency	460	Mixed
Kalsi-Ryan[40]	2016	Validation study: responsiveness	53	Acute, subacute
Krishnan[28]	2016	Validation study: criterion validity	41	Acute
Marino[29]	2016	Validation study: test-retest reliability, validity	125	Acute
Marino[58]	2018	Validation study: responsiveness	69	Mixed (mainly acute)
Misirlioglu[52]	2016	Validation study: internal consistency, construct validity	40	Mixed
Bergamaschi[26]	2014	Validation study: content validity	9	Acute, subacute
Scivoletto[41]	2014	Validation study: test-retest and intra- and interrater reliability	33	Acute, subacute
Unalan[53]	2015	Validation study: cross-cultural validity, test-retest reliability, inter-rater reliability, internal consistency	204	Mixed
Velstra[42]	2015	Validation study: responsiveness	74	Mixed
Walden[54]	2016	Validation study: criterion validity	108	Mixed
Observational studies				
Anton[39]	2017	Prospective cohort study	55	Acute
Eaton[38]	2018	Retrospective cross-sectional study	374	Subacute
Freund[30]	2013	Prospective longitudinal study	13	Acute
Klyce[32]	2015	Cross-sectional survey	206	Acute
Krause[51]	2015	Cross-sectional study	208	Mixed
Nooijen[36]	2015	Cross-sectional study	36	Subacute
Rognoni[56]	2014	Cross-sectional study	82	Mixed
Street[33]	2015	Prospective cohort study	171	Acute
Kalsi-Ryan[31]	2014	Observational longitudinal cohort study	53	Acute
Tate[34]	2013	Cross-sectional study	100	Acute
van Diemen[37]	2017	Longitudinal inception cohort study	134	Subacute
Velstra[57]	2014	Prospective longitudinal multicenter study	61	Acute, subacute
Zanca[27]	2013	Prospective observational study and retrospective chart review	1357	Mixed

SCI: spinal cord injury; mixed: patient sample included patients in all phases after SCI; NA: not available.

tients with acute SCI,[28-34] whereas four investigated patients in the subacute phase between six to eight months after onset of SCI[35-38] and eight studies combined both phases.[26, 29, 39-44] All remaining articles included patients within all phases of SCI.[27, 42, 45-56]

Methodological assessment

After review of the 33 identified studies with the suitable methodological quality assessment tool (COSMIN, STROBE or AMSTAR), three studies met all the criteria of the quality assessments.[36, 43, 57]

The results of the quality assessment of studies presenting psychometric properties with the COSMIN checklist are summarized in Table III and were categorized "poor" or "fair" in ten out of 19 studies.[26, 28, 29, 31, 35, 41-44, 46-50, 52, 54, 57] One study was rated as "Excellent"[43] and therefore, fulfilled all standards set by COSMIN for examining internal consistency.[22, 59]

Total quality scores ranged from 15[37, 56] to a maximum of 22 points.[36, 57] Two out of 13 observational studies reported in a sub-item of "Methods" on how potential bias was addressed. These studies,[36, 57] therefore, fulfilled all quality standards set by STROBE.[23] The results of the quality assessment of observational studies with STROBE are summarized in Table IV.[27, 30-34, 36-39, 51, 55, 56]

One systematic review was identified in the search[45] and its quality was assessed with the AMSTAR tool.[25] AMSTAR items not fully addressed in this publication were: "7. Was the scientific quality of the included studies assessed and documented?", "8. Was the scientific quality of the included studies used appropriately in formulating conclusions?", and "9. Were the methods used to combine the findings of studies appropriate?". Table V summarizes the critical appraisal with AMSTAR.[25, 45]

Assessment characteristics

Twenty-nine assessments were identified from current evidence as potential outcome measures in the acute and subacute phases after SCI. Identified assessments were categorized according to the ICF. Assessments focused on the ICF domains Body Functions and Structure, Activity and Participation. Quality of life (QoL) was added, as it was examined in some studies even though it is not part of the ICF taxonomy. Three assessments were recently de-

TABLE III.—*Methodological quality of included validation studies based on COSMIN ranked for methodological quality rating.*[26, 28, 29, 31, 35, 41-44, 46-50, 52, 54, 57]

Reference	Year	Assessed psychometric property	Statistical method	Methodological quality rating*
Chan[43]	2017	Construct (convergent) validity	IRT (Good)	Excellent
Akpinar[44]	2017	Interrater reliability	CTT	Good
		Test-retest reliability	CTT	Good
Delparte[47]	2016	Interrater reliability	CTT	Good
Jette[50]	2015	Internal consistency	IRT (Good)	Good
Marino[29]	2016	Test-retest reliability, validity	CTT	Good
Marino[58]	2018	Responsiveness	CTT	Good
Bergamaschi[26]	2014	Content validity	CTT	Good
Velstra[42]	2015	Responsiveness	CTT	Good
Walden[54]	2016	Criterion validity	CTT	Good
Akpinar[55]	2017	Interrater reliability	CTT	Fair
		Test-retest reliability	CTT	Fair
Krishnan[28]	2016	Criterion validity	CTT	Fair
Misirlioglu[52]	2016	Internal consistency	CTT	Fair
		Structural (construct) validity	CTT	Fair
Scivoletto[41]	2014	Test-retest reliability	CTT	Fair
		Intra- and interrater reliability	CTT	Fair
Kalsi-Ryan[31]	2016	Responsiveness	CTT	Fair
Unalan[53]	2015	Test-retest reliability	IRT (Good)	Fair
		Inter-rater reliability	IRT (Good)	Fair
		Internal consistency	IRT (Good)	Fair
Chan[43]	2017	Internal consistency	IRT (Good)	Poor
Aigner[46]	2016	Criterion validity	CTT	Poor
Fekete[48]	2014	Criterion validity	CTT	Poor
Gagnon[35]	2016	Responsiveness	CTT	Poor
		Concurrent validity	CTT	Poor
Glennie[49]	2014	Intra- and interrater reliability	CTT	Poor
Unalan[53]	2015	Cross-cultural validity	IRT (Good)	Poor

CTT: Classical Test Theory; IRT: Item Response Theory.
If IRT was applied, a Box for General Requirements was addressed. Quality level of IRT application is indicated in brackets.
*Quality Levels range from excellent through good, fair, to poor, and are reported with the worst result from the applicable box.

TABLE IV.—*Methodological quality of included observation studies based on STROBE ranked for methodological quality rating.*[27, 30-34, 36-39, 51, 55, 56]

Reference	Title and abstract	Introduction	Methods	Results	Discussion	Other information	Total*
Nooijen[36]	✓	✓	✓	✓	✓	✓	22
Velstra[57]	✓	✓	✓	✓	✓	✓	22
Freund[30]	✓	✓	×	✓	✓	✓	21
Kalsi-Ryan[31]	✓	✓	×	✓	✓	✓	21
Tate[34]	✓	✓	×	✓	✓	✓	21
Eaton[38]	✓	✓	×	✓	✓	×	20
Klyce[32]	✓	✓	×	✓	✓	×	20
Anton[39]	✓	✓	×	✓	×	✓	19
Zanca[27]	✓	✓	×	✓	✓	×	19
Street[33]	✓	✓	×	✓	×	✓	18
Krause[51]	×	✓	×	×	✓	×	16
Rognoni[56]	✓	✓	×	×	×	×	15
van Diemen[37]	✓	✓	×	×	✓	×	15

✓: all items were adequately addressed; ×: one or more items were not adequately addressed.
*Total score can range from 0 to 22.

TABLE V.—*Methodological quality of included systematic reviews based on AMSTAR.*[45]

Reference	Item											Total score*
	1	2	3	4	5	6	7	8	9	10	11	
Ditunno[45]	✓	✓	✓	✓	✓	✓	×	×	×	✓	✓	8

✓: all items were adequately addressed; ×: one or more items were not adequately addressed.
*Total score can range from 0 to 11.

veloped and their initial validation was described.[48, 50, 54] Five validated assessments seemed to be used regularly within the field of acute and subacute SCI rehabilitation.[31, 33, 40-42, 45, 46, 58] Some assessments were even implemented in multicenter projects (*e.g.* European Multicenter Study about Spinal Cord Injury - EMSCI)[57] indicating a wider use of assessments as compared to assessments used within only one registry of patients with SCI.[54]

Body functions and structure

Fourteen assessments measured outcomes of body functions and structure, from which nine assessments examined different mental and sensory functions.[27, 32, 34, 36-39, 44] Like in SCIRE, the order of the assessments presented in more detail below follows the ICF structure and not clinical relevance.[16]

Fatigue was measured using the Fatigue Severity Scale (FSS), to estimate its prevalence in patients within the acute[39] or subacute[36] phase of SCI. Studies discussed the construct of fatigue as a complex emotion including tiredness, lack of energy and exhaustion[39] or in relation to initiated or sustained voluntary activities[36] regardless of the physical or psychological origin of this feeling. Assessing fatigue is important as Noijen *et al.* concluded that patients in the subacute phase of SCI are already at risk of fatigue and early detection and treatment can prevent the development of severe cases of fatigue in patients with chronic SCI later on.[36] Anton *et al.* used the FSS and additionally the Modified Fatigue Impact Scale for SCI (MFIS-SCI) that was originally developed to assess fatigue in persons with multiple sclerosis but was adapted for SCI. The authors decided to use two measures for fatigue, because they measure different aspects of fatigue. The FSS seemed to be short and easy to administer, but the MFIS-SCI was described as more comprehensive and allowed to measure effects of rehabilitation more sensitive.[39]

Van Diemen *et al.* described the course of body image of 134 patients with acute SCI during their first rehabilitation. Body image was of research interest as it was found to be associated with psychosocial functioning and emotional stability in earlier literature.[60, 61] The study recommends to measure it as a "variance in depression and anxiety"[37] with the Body Experience Questionnaire even though the internal consistency was found to be low. However, this recommendation is based on the fact that this questionnaire is currently the only tool available and it can

help to identify people experiencing and reporting the process of alienation.[37]

To measure depression the abbreviated version of the Patient-Health Questionnaire (PHQ-9) was used as it was validated with regard to construct validity and internal consistency in SCI.[32] The 12-item Prolonged Grief Disorder interview was adapted and validated in a sample of 206 patients with an acute SCI with regard to its ability to measure grief as a concept different to depression. Grief researchers agreed that the interview measures informative and unbiased predictors of grief rated by patients on a scale from zero to five. However, the original interview questions were adapted to refer to SCI as the type of loss. The study concludes that the adapted version of the 12-item grief measure provides adequate internal consistency.[32]

Depression was also measured with the PHQ-9 in a study on pain and depression by Tate *et al.* and was chosen due to excellent psychometric properties that were assessed in prior validation studies. A distinction could be made between patients in inpatient rehabilitation reporting a moderate-to-severe depression according to the PHQ-9 compared to patients with lower PHQ-9 scores with regard to pain.[34] Pain was assessed in this study using the 0-10 numeric rating scale, as it is a widely used pain assessment tool.[34] Zanca *et al.* described pain during inpatient rehabilitation also with the numerical rating scale and self-reported locations of pain and were able to describe the impact of pain on the service delivery within SCI rehabilitation.[27]

Eaton *et al.* used the Appraisals of Disability Scale Primary and Secondary Scale short form (ADAPSS-SF) in a sample of 371 subacute patients to test for indicators of negative appraisals in a clinical setting. On the basis of the validity testing, Eaton *et al.* recommend to "use of the ADAPSS-SF as a clinical measure of appraisals in acute rehabilitation."[38]

Within the range of neuro-musculoskeletal functions, assessments classifying the severity and level of SCI,[29-31, 54] spasticity,[55] skin condition[47, 62] and adverse events[33, 49] were identified. Seven assessments were used to measure functioning information in nine studies.

The International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) was used in a study by Kalsi-Ryan *et al.* to define a study population according to their severity of injury and document it with an internationally accepted standard.[31] The ISNCSCI provides a common language to describe the extent of motor and sensory dysfunction due to SCI. For matters of standardization, minimizing the impact of human error and "to accurately derive the level and severity of SCI from the raw data of the ISNCSCI examination,"[54] Walden *et al.* established a computer algorithm for a prospective, observational registry. Like other implementations before,[63] this computer algorithm was validated and demonstrated to detect the level and severity of SCI within the range of this registry well.[54] The validity and reliability of the pressure sensation in the S3 dermatome as a neurological classification was investigated in 125 persons with SCI at least one month post injury. It was found to be an "alternative test of sensory sacral sparing for supraconus SCI at least in cases where [deep anal pressure] cannot be tested" by Marino *et al.*[29]

Akpinar *et al.* examined the Spinal Cord Assessment Tool for Spastic Reflexes (SCATS) for its inter-rater and test-retest reliability. In a sample of 47 patients, the SCATS measuring three subscales on a scale from zero to ten was found a reliable tool to examine spasm activity.[55] In another study from 2017, the research team compared the Modified Ashworth Scale (MAS) and the Tardieu Scale (TS) with regard to their inter-rater and test-retest reliability. The MAS was found to be a reliable assessment tool of the lower extremities of people with SCI, even though they recommend that the same examiner carries out the test due to a lower inter-rater reliability than test-retest reliability. The TS showed excellent reliability as long as all muscles were testes, and not only specific ones (*e.g.* hip adductor and knee extensor muscles). As a result, the TS is recommended as a complimentary tool for diagnosis and assessment of spasticity.[44]

The only included assessment on skin condition was the Spinal Cord Injury Pressure Ulcer Scale (SCIPUS) that was applied in two studies.[28, 47] According to Krishnan *et al.*, SCIPUS could predict the risk for pressure ulcer "occurring within 2-3 days following administration during acute but was unable to predict over a long-term within acute or inpatient rehabilitation."[28] The examination of the inter-rater reliability in 759 patient in inpatient rehabilitation by Delparte *et al.* concluded accordingly that the SCIPUS cannot be recommended for patients in inpatient rehabilitation because of limited specificity and needs to be adjusted.[47]

Glennie *et al.* found the spine adverse events severity system (SAVES) to have acceptable intra- and inter-rater reliability and thus, "could be implemented in acute clinical settings working with a t[raumatic] SCI population" to classify adverse events in elective spinal surgery as there is blood loss, vascular injury, wound complication or neurological deterioration.[49] Street *et al.* confirmed this conclusion by relating occurrence of adverse events to acute

patients' QoL and length of stay. "Implementation of the SAVES as a standardized method for documenting [adverse events] would ensure that the data obtained can be assimilated, compared among studies and ultimately used toward informing clinical practice."[33]

Freund *et al.* examined neural atrophy of the spinal cord in a sample of 13 patients with acute SCI by using magnet resonance tomography (MRI). They indicated that assessments of changes at lesion level are difficult to assess and may be interpreted with the use of SCI-specific measures such as the ISNCSCI. Progressive structural changes were associated with neurological, as well as functional improvement. The study concluded that "the finding of a systematic degenerative pattern with time suggests that non-invasive MRI measures could be used for prediction of outcome, identification of patients most likely to benefit from different interventions, and as potential markers of treatment effects of interventions."[30]

Activity and participation

The Walking Index for Spinal Cord Injury (WISCI) was examined with regard to its psychometric properties twice[41, 46] and its use and misuse was summarized in a systematic review.[45] The WISCI was proven to have a supporting concurrent validity,[46] a high inter- and intra-rater reliability, as well as good reproducibility.[41] It was recommended by all three studies due to" unique characteristics as a capacity measure of walking function and its strong metric properties."[45]

In general, the Graded and Redefined Assessment of Strength, Sensibility, and Prehension (GRASSP) for the subgroup of patients with cervical SCI was reviewed five times.[31, 40, 42, 57, 58] It is a measure for upper limb functions of patients with tetraplegia and contains the following subtests: strength, dorsal sensation, palmar sensation, prehension ability, and prehension performance.[31] "GRASSP showed excellent responsiveness, detecting distinct changes in strength and prehension" by Velstra *et al.*[42] and its "sensitivity […] make[s] it a valuable condition-specific measure" according to Kalsi-Ryan *et al.*[40] The GRASSP assessment at one month after onset of injury was able to accurately predict upper limb function in a subgroup of individuals with tetraplegia in a study by Velstra *et al.*[57] For this subgroup the comprehensive and standardized application of the following four outcome measures was recommended: GRASSP, ISNCSCI, Spinal Cord Independence Measure (SCIM) III and the Capabilities of Upper Extremity Questionnaire (CUE-Q).[31] The CUE-Q is a 32-item questionnaire and validated with regard to test-retest reliability and concurrent validity. In this study, Kalsi-Ryan *et al.* chose the CUE-Q to examine the relationship between impairment and self-perceived upper limb function. The SCIM III was used in their study to assess function and independence in a sample of acute cervical SCI patients.[31] They concluded that the GRASSP was a sensitive and responsive measure for measuring neurological and functional outcomes related to the upper limb in tetraplegia.[31] Also Marino *et al.* tested the GRASSP with regard to its responsiveness in comparison to the CUE-T. "The CUE-T evaluates UE actions such as reaching, lifting, pulling, and pushing in addition to various grasp patterns."[58] Both tests show large responsiveness and are recommended for use in acute patients with tetraplegia.[58]

A patient-reported German version of the SCIM III was developed and its criterion validity was evaluated in a cross-sectional validation study in two Swiss SCI rehabilitation centers. Its use was recommended for hospitalized patients with SCI and described as resource-efficient even though some limitations were identified (*e.g.* problems in self-reporting residual urine volume).[48]

Misirlioglu *et al.* validated the Duruöz Hand Index (DHI) and showed significant correlations with commonly used outcome measures for hand function in SCI rehabilitation. The study recommends the patient-reported questionnaire's use in the subgroup of patients with a tetraplegia to assess hand-related functions and activities of daily living.[52]

Gagnon *et al.* compared different types of wheelchair propulsion tests with regard to their responsiveness. As a conclusion, the slalom and 6-minute propulsion were proposed as a measure of mobility which "best document wheelchair propulsion performance change over the course of inpatient rehabilitation" and the 20-m propulsion test was recommended as a complimentary assessment to estimate performance change.[35]

The Community Balance and Mobility Scale (CB&M) was analyzed for its validity and internal consistency in patients with incomplete SCI (iSCI). Initially, it was developed for patients with traumatic brain injury. According to Chan *et al.* the generalizability of the CB&M was questionable as the use in their facility was already established for a long time and validity was not tested in other centers. Overall, it was rated as "valid measure in high-functioning individuals with iSCI."[43]

The Spinal Cord Injury Functional Index (SCI-FI) measures functional performance in the general population and lacks sensitivity for meaningful differences in specific populations (*e.g.* patients with SCI). The SCI-FI for assess-

ing the use of Assistive Technology (SCI-FI/AT) especially considers the use of assistive technologies and its ranking system was adjusts for patients using additional technologies. Jette *et al.* concluded that the multidimensional assessment scale was useful for clinicians and researchers for assessing functional capacity in the domains of Basic Mobility, Ambulation, Self-care, and Fine Motor Function.[50]

The Work Rehabilitation Questionnaire-Self-Report Version (WORQ-SELF) examines vocational rehabilitation in the subacute phase of SCI. The WORQ was established from the need for a specific assessment for vocational rehabilitation for persons with a disability and was proven to have good content validity in patients with acute SCI.[26]

Quality of life

Outcome measures for QoL were applied and investigated in three studies.[33, 51, 56]

Krause *et al.* investigated newly injured individuals' perceptions of the permanence of their injuries and the extent to which they maintain hope for recovery with the Illness Perception Questionnaire. As this questionnaire seems to lack a meaningful interpretation for SCI or disability, the dimension "hope for recovery" was added to provide comprehensive information of the patients' psychological status in the context of QoL. The study concluded that hope for recovery and "the wide array of responses to questions on the severity, permanence, and extent to which there are treatments for SCI is a testament to individual differences in response to trauma."[51]

To assess patients' QoL Street *et al.* used the combination of the Short-Form 36 questionnaire (SF-36) and the Functional Independence Measure (FIM) within the scope of a SCI registry. The FIM measures patients' burden for regaining independence with regard to care on a seven-point rating scale, whereas the SF-36 measures eight different domains of health composed of a physical and a mental component summary. The authors realized that their "analysis failed to show an effect of acute care adverse events on [health-related QoL]," but do not link this result to the ability of any two assessments to measure what they were supposed to measure in the context of their study.[33]

Rognoni *et al.* also used the SF-36 in Italian patients with SCI to measure QoL and found the assessment to be insufficient." Although in rehabilitation medicine the SF-36 questionnaire has been widely used for patients with SCI, these current measures could be insufficient to represent their serious disability because many items were developed for use in the general population." However, the authors see the importance to measure QoL for estimating rehabilitation success.[56]

Table VI provides an overview of recommended assessments and its associated functioning information.[26, 27, 29-46, 48-52, 54-58] Table VII summarizes assessments that were not recommended to use in patients with acute/subacute SCI.[28, 47, 56]

Discussion

This review sought to present an update of the SCIRE project,[18] by investigating assessments' validation or their use in observational studies of acute and subacute SCI. Due to the inclusion criteria (*e.g.* time since injury, year of publication), this review does not provide a complete list of established assessments in SCI rehabilitation according to recommendations of the International Spinal Cord Society (ISCoS).[1] Tables VI and VII may inform health professionals about the evidence-based selection of outcome measures for assessing initial rehabilitation of patients with acute and subacute SCI. Out of the total of 26 assessments that were reviewed, 25 were recommended for use in patient populations covering some, but not all aspects of the bio-psycho-social model of functioning.[1] From the reviewed assessments, only the SCIPUS received negative recommendations for its use in initial SCI rehabilitation and research.[28, 47] During the reviewed publication period the assessment of patients' mental functions[27, 32, 34, 36, 37, 39] and QoL[33, 51, 56] were of most interest. The GRASSP was examined and recommended in five[31, 40, 42, 57, 58] and the WISCI II in three[41, 45, 46] studies.

Established checklists should be used to increase quality of systematic reviews and to promote evidence-informed health decision making.[64] Therefore depending on the study design, we applied the AMSTAR checklist for systematic reviews, the COSMIN tool for validation and the STROBE tool for observational studies and further developed the quality of SCIRE's research approach.[18] The quality of validation studies was generally fair, often hampered by low participant numbers, insufficient reporting of missing data and not following the COSMIN checklist.[21, 22] In general, the quality of these studies needs to be improved to increase validity of outcome measures in the SCI patient population despite the challenge of SCI being a rare condition and dealing with patients in a sensitive phase after injury. Observational studies showed better quality even though some did not use assessments specifically validated in the SCI population, but assessments adapted to the specific needs in SCI.[32, 51] For mental

TABLE VI.—*Functioning information (as proposed in the ICF) and assessments recommended by literature.*[26, 27, 29-46, 48-52, 54-58]

Functioning information	Assessment tool	N. of studies	Subgroup	Reference
Body functions	SAVES	2	tSCI	Glennie,[49] Street[33]
Mental functions	ADAPSS-SF	1		Eaton[38]
	Body Experience Questionnaire	1		van Diemen[37]
	FSS	2		Nooijen,[36] Anton[39]
	Interview for Prolonged Grief Disorder	1		Klyce[32]
	PHQ-9	2		Klyce,[32] Tate[34]
Sensory functions and pain	MAS	1		Akpinar[44]
	TAS	1		Akpinar[55]
	Self-reported pain locations	1		Zanca[27]
	Self-reported rating of pain intensity (0-10)	2		Tate,[34] Zanca[27]
Neuro-musculoskeletal functions	Classification algorithm for ISNCSCI	1		Walden[54]
	ISNCSCI	1	Tetraplegia	Kalsi-Ryan[31]
	MRI	1		Freund[30]
	S3 Pressure Sensation	1		Marino[29]
	SCATS	1		Akpinar[55]
Activity	FIM	1		Street[33]
	DHI	1		Misirlioglu[52]
	GRASSP	5	Tetraplegia	Kalsi-Ryan,[31, 40] Velstra,[42, 57] Marino[58]
	SCI-FI/AT	1		Jette[50]
	SCIM III-SR	1		Fekete[48]
	SCIM-III	1	Tetraplegia	Kalsi-Ryan[31]
	WISCI	3	iSCI	Ditunno,[45] Scivoletto,[41] Aigner[46]
Participation	WORQ-SELF	1		Bergamaschi[26]
Mobility	CB&M	1	iSCI	Chan[43]
	CUE-T	1	Tetraplegia	Marino[58]
	CUE-Q	1	Tetraplegia	Kalsi-Ryan[31]
	Propulsion tests (slalom, 6 m, 20 m)	1		Gagnon[35]
Quality of life	Illness Perception Questionnaire	1		Krause[51]
	SF-36	2		Street,[33] Rognoni[56]

SCI: spinal cord injury; iSCI: incomplete SCI; tSCI: traumatic SCI.
*Some studies examined assessments for specific subgroups of SCI in the acute and subacute phase. If applicable to the assessment, the subgroup will be listed.

TABLE VII.—*Functioning information (as proposed in the ICF) and assessments not recommended by literature in alphabetical order.*[28, 47, 56]

Functioning information	N. of studies	Assessment tool	Reason for negative recommendation	Reference
Quality of life	1	SF-36	"Although in rehabilitation medicine the SF-36 questionnaire has been widely used for patients with SCI, these current measures could be insufficient to represent their serious disability because many items were developed for use in the general population"	Rognoni[56]
Functions of the skin and related structures	2	SCIPUS	"The psychometric properties of the SCIPUS do not currently support its routine use as a measure of PU risk in individuals with spinal cord injury undergoing inpatient rehabilitation"	Delparte[47]
		SCIPUS	"The SCIPUS could predict PrU occurring within 2-3 days following administration during acute, but unable to predict over a longer term within acute or inpatient rehabilitation. Improved PrU risk assessment following SCI may be possible with modification to the SCIPUS"	Krishnan[28]

PU: pressure ulcer; PrU: risk for pressure ulceration.

functions and QoL, there was a need to adapt assessments specifically to the health condition as current ones seemed to not allow for any meaningful interpretation. Although, quality of observational studies was scored high according to STROBE, the choice to integrate not specifically validated assessments in research is a critical factor. This indicates that the topic is of relevance and needs to be examined and documented in clinical practice. However, the adapted assessment tool still needs to be validated with regard to its psychometric properties in a next step. The in-

tegration of adapted assessments in observational studies opens up the discussion about clinical relevance and face validity. Face validity refers to the ability of an assessment to measure the construct it was supposed to measure in a clinically relevant and accepted way.[21]

Patient-reported outcome measures (PROMs), such as questionnaires, were one example of increasingly used assessments coming from clinical practice. They reflect the tendency towards shared patient-health professional decision-making as a new quality indicator[65, 66] based on national legal requirements (Children and Adult Protection Law[67]). With the help of outcome measures taking the perspectives and priorities of patients into account, rehabilitation can be organized in a patient-centered way.[68]

The presented collection of literature is intended as an objective overview with regard to assessments' use in studies and their psychometric properties. It does not represent a comprehensive recommendation list based on clinical meaningfulness of the assessments. This evidence synthesis wants to provide a valuable basis for a subsequent consensus process, during which each of the assessments should be critically reflected and ranked in respect to their relevance and acceptance in daily practice. Depending on the cultural background and subjective viewpoints of the involved stakeholders, this consensus process might result in different recommendations.

Limitations and future perspectives

Most of the included literature was of moderate quality when considering the results of the checklist-based quality assessments. In particular, validation studies ranked using COSMIN were poor. However, the COSMIN research group published a revision of their checklist in early 2018 which addressed some of the deficits mentioned previously, *e.g.* implications for studies with small sample sizes like the ones in SCI.[21] In the presented review, one reviewer conducted basic data extraction and quality assessment of the eligible literature leaving room for bias (*e.g.* confirmation bias), but selection, synthesis and analysis of literature was done collaboratively. The search strategy did not reveal any specific reports in German language that could be included in this review. Most likely, SCI research in German-speaking countries frequently publishes in English language. A major problem in non-English speaking countries is that in particular questionnaires need to be translated to the local language and their psychometric properties need to be re-evaluated.

More high-quality validation studies are needed to support an evidence-based selection of outcome measures in SCI particular in respect to different phases after injury. Potential new research topics on assessments' development, validation and implementation are disclosed by this systematic review.

Conclusions

Since the last SCIRE review in 2013, a substantial amount of literature has been published on validation of new or established assessment instruments within the context of initial rehabilitation of patients after SCI. Identified assessments examine a wide range of the bio-psycho-social aspects of functioning and address the need for researchers and practitioners to continuously assess patients in all meaningful functioning domains. Additionally, several validated patient-reported outcome measures (PROMs) were identified which supports the importance of including patients' perspectives into the rehabilitation process and indicates the trend towards an expert-patient-shared-decision making model within the framework of the bio-psycho-social model of functioning. For development of clinical practice guidelines including recommendations for assessments in initial SCI rehabilitation not only the psychometric properties of outcome measures, but also their clinical relevance needs to be considered.

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