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INVITED REVIEW

Capturing the Psychologic-Personal Perspective in Spinal Cord Injury

ABSTRACT

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Objective: The overall objective of this study was to illustrate a systematic approach for capturing the psychologic-personal perspective in International Classification of Functioning, Disability and Health–based comprehensive research on spinal cord injury (SCI) in terms of what and how to measure. The specific aims were to identify (1) relevant areas of research for capturing the psychologic-personal factors in a study that is planned and conceptualized according to the comprehensive context of the International Classification of Functioning, Disability and Health, using SCI as a case in point; (2) a set of domains relevant for SCI research from a psychologic-personal perspective; and (3) suitable measurement instruments that can be considered for the assessment of those identified domains based on a set of predefined guiding principles.

Design: The psychologic-personal factor structure was developed based on an item pool of 1246 entries from secondary analyses of available data from SCI studies. The domain set for psychologic-personal factors was identified through reviewing the scientific literature in PubMed and PsycInfo. The set of measurement instruments was collected using available measurement reviews, searches in the literature, instrument databases, and further sources and was selected using guiding principles.

Results: Forty specific psychologic-personal factors, subdivided into seven areas of research, were identified: (1) sociodemographic personal characteristics, (2) the position in the immediate social and physical context, (3) personal history and biography, (4) feelings, (5) thoughts and beliefs, (6) motives, and (7) patterns of experience and behavior. The psychologic-personal factors domain set contains both cross-cutting outcome domains, namely quality-of-life, life satisfaction, subjective well-being, and sociodemographic personal characteristics, life events, positive and negative affect, perceived stress, locus of control, self-efficacy, purpose in life, coping, lifestyle, and personality. For each of the identified domains, a pool of measurement instruments was listed, and the application of predefined guiding principles for measurement instrument selection was exemplified for self-efficacy. It resulted in the selection of the General Self-Efficacy Scale by Schwarzer and Jerusalem (*Measures in Health Psychology: A User's Portfolio. Causal and Control Beliefs*. pp. 35–37; 1995).

Conclusions: The results of the current article contributed to creating a transparent protocol for the Swiss Spinal Cord Injury Cohort study, coordinated by the Swiss Paraplegic Research in Nottwil, Switzerland. This article also stresses the relevance of the comprehensive approach to SCI and the consideration of the psychologic-personal perspective in this approach. The study, therefore, hopes to encourage scientists to use the International Classification of Functioning, Disability and Health and the psychologic-personal perspective as a frame of reference for their research. Furthermore, the research reported in this article can inform the World Health Organization's future development of the personal factors classification in the International Classification of Functioning, Disability and Health.

Key Words: Spinal Cord Injuries, Outcome Assessment, Quality-of-Life, Self-Efficacy, Epidemiologic Research Design, International Classification of Functioning, Disability and Health, Psychologic-Personal Factors

People with spinal cord injury (SCI) face serious challenges and special strains in their everyday lives.¹ SCI has many consequences—somatic, psychologic, social, and financial.² People sustaining SCI are individual human beings who differ from each other as persons. They differ in their individual background, life situation, and personal history; their ways of experiencing the consequences of the injury; and their reactions to their altered situation. In particular, they differ in their beliefs, attitudes, and expectations and behavioral strategies and coping styles.

The role of such psychologic-personal factors, their interactions with each other and their impact on outcomes such as secondary health conditions, participation, adaptation, and well-being are not yet fully understood. Specific findings about these factors in SCI have been summarized and show, for example, that sociodemographic personal characteristics and lifestyle are relevant for pressure ulcer prevention,³ that work status is related to satisfaction and quality-of-life,⁴ and that coping strategies, cognitions, psychosocial resources, and pre-injury factors like personality relate to adjustment and mental health after SCI.^{1,5}

Although some evidence has already been presented, the relative weight of specific psychologic-personal factors in functioning and disability in persons with SCI cannot be determined unless confounding variables are taken into account, that

is, unless lesion, body function, and aspects of the environment are adjusted for at the same time. Better understanding of the influence of those factors would provide a basis for enhanced services and would benefit persons with SCI, their significant others, and health professionals' practice. Therefore, comprehensive research is needed to better understand who would be at risk of unfavorable outcomes and why.

A comprehensive understanding and a holistic perspective are crucial in SCI and are key to the provision of rehabilitation services.⁶ The World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF)⁷ provides a conceptual framework and common language that corresponds to the many-faceted nature of SCI and to the complexity of comprehensive interdisciplinary rehabilitation. In principle, the ICF structures the whole universe of disability phenomena, which allows researchers to position their own results within the scope of a comprehensive picture, to identify research gaps, and to hypothesize about relationships among concepts and variables. Following the ICF's integrative biopsychosocial framework, it is possible to approach functioning and disability research from different standpoints at the same time, such as from a biomedical perspective, a social-environmental perspective, and from a psychologic-personal perspective as well.

However, the implementation of the ICF and its comprehensive approach in practical study design remains a challenge from the psychologic-personal perspective for three reasons:

First, the ICF contains a comprehensive classification of mental functions but not of personal factors. As a result, the psychologic-personal perspective that accounts for the differences between individuals regarding their background, experience, and styles of behavior is only partly addressed so far in the ICF.⁷⁻⁹

Second, a large number of conceptualizations and operationalizations that would fall within the scope of psychologic-personal factors, ranging from sociodemographic personal characteristics and coping styles to personality and lifestyle issues, exist.

Third, there are many measurement instruments that can be used to measure these psychologic factors, and selecting a set of appropriate measurement instruments remains a challenge to study design.

Therefore, the question that arises is how to identify what to measure and how to measure to address the psychologic-personal perspective in a

study that is planned and conceptualized according to the comprehensive context of the ICF.

The overall objective of this study was, therefore, to illustrate a systematic approach for capturing the psychologic-personal perspective in ICF-based comprehensive research on SCI in terms of what and how to measure. The specific aims are as follows:

1. to identify relevant areas of research for capturing the psychologic-personal factors in a study that is planned and conceptualized according to the comprehensive context of the ICF, using SCI as a case in point;
2. to identify a set of domains relevant for SCI research from a psychologic-personal perspective; and
3. to identify suitable measurement instruments that can be considered for the assessment of those identified domains based on a set of pre-defined guiding principles.

METHODS

Identifying Relevant Areas of Research

To identify relevant areas of research for capturing the psychologic-personal factors in a study planned and conceptualized according to the comprehensive context of the ICF using SCI as a case in point, an item pool of potential factors was created based on data from six sources. The item pool contained data that are relevant to many of the applications of the ICF: clinical, epidemiologic, health administration, and health surveys from both individual and population perspectives, from the point of view of health professionals and affected persons, and using quantitative or qualitative methods.

Three of the six data sources for the item pool were data collected from an international WHO collaborative project for the development of ICF Core Sets for SCI.⁸⁻¹⁰ The raw item pool consisted of 1948 items, which were concepts contained in different sources of information and which had been identified as psychologic-personal factors using the ICF linking method¹¹; (1) 201 concepts were contained in questionnaire items and outcomes from a systematic review of literature in SCI¹²; (2) 395 concepts were filtered from SCI patients' statements from focus groups conducted in five world regions¹³; (3) 329 concepts were identified from health professionals' statements in an international expert survey covering various disciplines¹⁴; (4) 58 concepts were identified in the variables from existing SCI registries and data

sets¹⁵⁻¹⁹; (5) 418 concepts were identified in a systematic literature review addressing SCI psychology²⁰; and (6) 548 concepts were identified in a categorization of personal factors created for use in social medical reports in Germany.²¹

The item pool was revised by extracting the key concepts using a process of abstraction and generalization. The revised item pool consisted of 1246 entries. These entries were grouped and listed under plausible research areas, and an item reduction exercise was performed to reduce redundancy to produce a final list of psychologic-personal factors under each research area.

Identifying an SCI Domain Set from the Psychologic-Personal Perspective

To identify a set of domains relevant for SCI research from a psychologic-personal perspective, the scientific literature was reviewed. PubMed and PsycInfo were searched for studies from the past 10 yrs using key words denoting SCI, in combination with search terms denoting global outcomes including *quality-of-life*, *satisfaction*, *well-being*, *psychologic adaptation*, *coping*, *adjustment*, *burden of illness*, and *distress*. Studies measuring these concepts quantitatively in at least ten persons with SCI were selected for further processing. Dependent and independent variables assessed were documented and grouped according to the components of the ICF. The variables assessing psychologic-personal factors were selected and sorted according to the suggested structure. This list represents a rough overview of the psychologic-personal factors currently measured in SCI in relation to broad, cross-cutting general outcomes (e.g., quality-of-life) and guides the identification of a domain set.

What can be measured from a psychologic-personal perspective in comprehensive SCI research were identified by choosing from among the variables found in the literature, taking into account the following criteria:

- the most frequently examined, top-ranking variables;
- variables that have strong explanatory value;
- variables that were not examined yet but might represent gaps in current SCI research to comprehensively cover the psychologic-personal perspective;
- variables that have not been examined frequently in SCI research but are the focus of current innovative research or current debate in and beyond the field of SCI (e.g., purpose in life); and
- variables that are relevant in the setting in which the study is conducted.

Identifying an SCI Measurement Instrument Set for Psychologic-Personal Factors

A pool of measurement instruments were identified and selected based on explicit criteria to assess the concepts from the domain set of psychologic-personal factors. To identify this pool reviews and recommendations,²²⁻²⁴ measurement instruments used in longitudinal and SCI cohort studies in different countries,^{19,25,26} measurement instruments listed in the review of the literature, information from online instrument databases (e.g., <http://www.proqolid.org/>, PSYNDEXplus with Testfinder), literature searches and reference cross-checks outside the area of SCI, and, finally, book resources on measurement instruments²⁷⁻²⁹ were consulted.

The suitability of a measurement instrument for use in any study depends not only on the content it covers and on intrinsic characteristics of the measurement instruments themselves (e.g., psychometric properties and feasibility) but also on external issues of the measurement context (e.g., purpose, patients, setting, and resources).³⁰⁻³² The overall internal criteria for the selection of measurement instruments and the more specific external criteria have been developed for comprehensive SCI research.³³ The criteria or guiding principles include validity and reliability, feasibility, comparability, level of detail of information, efficiency, and redundancy. For the final step of creating a pool of measurement instruments, these criteria can be used by ICF and methodologic experts who, mindful of study priorities and trade-offs, could precisely define which measurement instruments would be useful for a comprehensive assessment of psychologic-personal factors in the study.

RESULTS

Areas of Research for Capturing Psychologic-Personal Factors

Seven areas of research, subdivided into 40 specific psychologic-personal factors, were identified. These seven areas of research for capturing psychologic-personal factors are (1) sociodemographic personal characteristics, (2) the position in the immediate social and physical context, (3) personal history and biography, (4) feelings, (5) thoughts and beliefs, (6) motives, and (7) patterns of experience and behavior. These areas contain more specific items that were further grouped into three different parts. Part I or “Facts” refers to facts about the individual’s position in the physical, social, and temporal context; Part II or “Experience”

refers to the content of the individual’s experience, including contextual and situation-specific internal reactions; and Part III or “Patterns” refers to abstract concepts that describe generalized, context-independent, cross-situational, recurrent, and persistent patterns in the person’s experience and behavior.

Table 1 summarizes the parts, the areas, and the specific psychologic-personal factors that were selected, with provided examples of these factors.

The SCI Domain Set from the Psychologic-Personal Perspective

To select the membership of a domain set of psychologic-personal factors for use in comprehensive research in SCI, the scientific literature in the field was reviewed, focusing on studies with broad outcomes such as quality-of-life or subjective well-being. The search in PubMed and PsycInfo resulted in 103 publications, including 938 variables that had been measured. Of these, 239 came from 96 publications and could be grouped according to the seven areas of research and the psychologic-personal factors presented previously. The number of articles that contained the variables was also counted. These variables are usually what might be called “category specifications” of the psychologic-personal factors, that is, specific and concrete examples of each factor. For the rest of the article, we identified these as category specifications. The domain set from the psychologic-personal perspective was then a selection of potential category specifications. Table 2 gives an overview on the identified category specifications under each area.

The most frequent broad and cross-cutting category specifications documented in the literature review were life satisfaction ($n = 28$ studies), quality-of-life ($n = 24$ studies), and subjective well-being ($n = 11$ studies). There is some evidence that the quality-of-life, satisfaction, and well-being of persons with SCI seem to be diminished compared with those of the general population.^{34,35} However, in persons with SCI, quality-of-life seems to be directly related not with the severity of SCI^{35,36} but with other factors, particularly perceived health, participation, and integration, social support and relationships, as well as living circumstances, such as accessibility or income.^{34,36} Measuring subjective outcomes provides information about the health state of individuals beyond diagnosis, specifically information about the impact of a disease and its treatment on everyday life, and the health experience

TABLE 1 Overview of the areas of research for capturing psychologic-personal factors and specific psychologic-personal factors contained in them

Areas	Psychologic-Personal Factors	Examples
Part I. Facts: Facts about the individual's position in the physical, social, and temporal context		
Sociodemographic personal characteristics		
	Age	Years of age
	Sex	Male, female
	Nationality, citizenship, ethnicity	Country of birth
	Language	Mother tongue, multilingual
	Educational background	Highest degree
	Occupational background	Profession, position
	Economical background	Independent means
	Religious affiliation	Confession
Position in the immediate social and physical context		
	Family	Being a parent, being an identical twin
	Partnership and marriage	Being divorced
	Informal social network	Being in a gang
	Formal social network	Being member of a self-help group
	Housing	Being homeless
Personal history and biography		
	major life events	past diseases
	life course	upbringing, past exposures
Part II. Experience: Content of the individual's concurrent experience, including contextual and situation-specific internal reactions; characterized by "aboutness"		
Feelings		
	Emotions	Being happy
	Moods	Being in a high mood
Thoughts and beliefs		
	Knowledge/concepts	Knowledge about disease, self-concept
	Memories	Flashbacks
	Attitudes, beliefs	Attitude toward wheelchair drivers
	Expectations	Expectation about usefulness of medication
	Explanations/attributions	Seeing rehabilitation success as own achievement
	Values/norms	Having individualistic values
	Evaluations	Downward social comparisons
	Preferences	Treatment preferences
	Imagination, fantasy, dreams	Nightmares
Motives		
	Needs	Needs little sleep
	Interests/wishes	Interested in sports
	Goals/intentions	Life goals, wants to have children
Part III. Patterns: Abstract concepts describing generalized, context-independent, cross-situational, recurrent, and persistent patterns in the person's experience and behavior		
Patterns of experience and behavior		
	Patterns of feelings	Trait hostility
	Handling feeling	Anger management strategies
	Patterns of thoughts	Optimism
	Handling thoughts	Rationalization
	Patterns of motives	Ambitiousness
	Handling motives	Impulse control
	Habits	Nail biting
	Skills	Social skills
	Talents	Artistic talent
	Lifestyle	Active lifestyle
	Handling behavior	Self-management, coping strategies

of the affected persons from their own point of view.^{37,38}

In the area *sociodemographic personal characteristics*, specifications about the individual such as age, sex, nationality, ethnicity, language, educational background, and occupational background were identified. This basic information is frequently

considered in SCI research (with the exception of language) and was assessed in 52 studies as independent variables in relation to outcomes. Sociodemographic information is useful to position the person in relation to any reference population. For example, in the area of health and disability statistics, this kind of information is routinely considered

TABLE 2 Overview of the specifications of psychologic-personal factors assessed in the literature that are the basis for the domain set

Areas and Specifications	Number of Articles (N = 96)
Cross-cutting	
Life satisfaction (overall and domain specific)	28
Quality of life	24
Subjective well-being/ well-being	11
Adjustment/adaptation	5
Sociodemographic personal characteristics	52
Age/age at injury/aging	16
Occupational background	15
Sex	10
Ethnicity/race/country	6
Education	4
Income	1
Position in the immediate social and physical context	9
Marital status/relationship status	9
Personal history and biography	2
Previous traumatic events	2
Feelings	25
Anxiety	9
Emotional/affective distress	6
Negative affect	2
Anger	1
Sadness	1
Loneliness	1
Helplessness	1
Embarrassment	1
Discomfort	1
Boredom	1
Happiness	1
Thoughts and beliefs	85
Perceived stress	8
Locus of control	5
Self-efficacy	4
Acceptance	2
Attitudes (e.g., toward psychologic help-seeking)	2
Expectations (e.g., of independence)	2
Self-esteem	1
Self-concept (physical)	1
Conceptions of masculinity	1
Negative cognitions about the self	1
Pain beliefs	1
Readiness to change	1
Intention for physical activity	1
Social comparisons	1
Suicidal ideation	1
Awareness of death	1
Motives	2
Purpose in life	2
Patterns of experience and behavior	48
Coping (including pain coping)	19
Lifestyle (including physical activity, alcohol, tobacco, drug use, health practices)	14
Personality traits (including extroversion, solicitousness, vitality)	5
Control/life control	3
Sense of coherence	2
Problem-solving abilities (including social problem-solving)	2
Self-monitoring	1

and documented.³⁹⁻⁴² Sociodemographic variables need to be examined and considered to ensure the external validity of research and to identify possible existing biases or confounding variables.⁴³ In clin-

ical practice, information gained from inequalities in the prevalence of specific disease improves intervention by targeting specific populations at risk.⁴⁴ As an example, in SCI, the sociodemographic

variable age is related to secondary health and psychosocial conditions,⁴⁵ life satisfaction,⁴⁶ and rehabilitation outcomes.⁴⁷ In SCI, ethnicity seems to be related to participation and subjective well-being, and women report lower satisfaction with physical and mental health but higher satisfaction with interpersonal relations than do men.⁴⁸

The area *position in the immediate social and physical context* includes information about the individual's position in family, partnership, and informal or formal networks. The literature review showed that marital or relationship status is considered mainly within this domain ($n = 9$). Besides factual background information about the person, marital status, having children, and being a member of a self-help group or of a circle of friends are frequently used as proxy estimates for social support, social involvement, and responsibilities or of social circumstances to be dealt with by the affected person. For example, being married has indirect relationships with health outcomes mediated by depression and health habits and correlates with cardiovascular, endocrine, immune, neurosensory, and other physiologic indicators.⁴⁹ Mortality is reduced for individuals who are in a position of providing support to friends, relatives, and neighbors.⁵⁰ In people with SCI, the provision of social support is associated with reduced medical complications and better adjustment to disability.⁵¹ However, social support and social relations are features of the person's environment, not their inner psychologic state, and so were not included in the domain set.

In the area *personal history and biography*, factors such as major life events and biographical course are included. The relationship between major life events and health and well-being is well known and established.⁵² Spinal cord injury or other acute events that result in long-term disability can be assumed to be highly influential life events themselves. SCI as a major life event is related to an increased risk of developing depression,⁵ suicide,⁵³ anxiety disorder, or substance abuse.⁵ The review of the literature showed that, within this area, previous traumatic events are considered in SCI research, especially in relation to the development of posttraumatic stress disorder.^{54,55} However, life event research has also shown that not only negative occurrences (e.g., accidents or divorce) but also primarily positively valued events (e.g., birth of a child or marriage) can act as stressors and influence well-being. However, SCI should not solely be considered from a negative standpoint. For example, according to the con-

cept of posttraumatic growth, some persons can develop through challenging experiences and hardship and adopt a higher level of functioning compared with pretraumatic states.^{56,57} At different points in time following SCI, the full bandwidth of life events should be considered for measurement in the domain set; their occurrence, long-term development, and effect should all be investigated.

In the area *feelings*, the aspects of emotional experience and mood are considered. In the literature review, 25 articles were found that assessed aspects of emotional experience in SCI, with a strong focus on negative affect. For future research, positive feelings and affect balance should also be recognized and included in the domain set. Positive and negative effects are conceptually a part of subjective well-being⁵⁸ and also mirror the ICF's philosophy of a balanced and neutral view toward functioning and disability, including not only a deficit-oriented but also a resource-oriented perspective. Positive affect has been examined not only as a predictor but also as an outcome in a number of health conditions (e.g., cancer or limb amputation) in relation to stress, coping and adjustment, pain, and cardiovascular and immune functions, all of which are highly relevant to SCI as secondary conditions.^{52,59-63} Looking at positive and negative affect can thus be useful in a study to understand the relationships between functioning and the subjective experience of affected individuals.

In the area *thoughts and beliefs*, a wide variety of factors is covered, including knowledge, memories, attitudes, beliefs, expectations, attributions, values or norms, evaluations, appraisals, preferences, and imagination. The review of the literature showed that 85 studies considered category specifications that lay within the scope of this area. Perceived stress ($n = 8$), locus of control ($n = 5$), and self-efficacy ($n = 4$) were the top-ranking category specifications and should be included in the domain set. We know that 25% of people with SCI experience clinical-level stress⁶⁴ and that stress is positively related to pain,⁶⁵ depression, and anxiety,⁶⁶ and negatively related to life satisfaction and well-being^{66,67} in people with SCI.

An external health locus of control was related to posttraumatic stress disorder,^{54,68} health,⁶⁹ depression,⁷⁰ poorer adjustment to disability,⁷¹ lower well-being,^{69,72} and poorer sexual satisfaction⁷³ in people with SCI.

Self-efficacy⁷⁴ has been discussed as the prototypical example of an influential psychologic factor.^{20,75} People with SCI may experience low

self-efficacy,⁷⁶⁻⁷⁸ which correlates with a variety of consequences at the body, person, and society levels; physical and mental secondary health conditions; activity and participation areas; quality-of-life; and subjective well-being.⁷⁹⁻⁸⁸ However, as the balanced view of the ICF suggests, some of the persons with SCI retain or develop high levels of self-efficacy. Future research could focus on the trajectories of self-efficacy in longitudinal studies and on the factors that differentiate between those who have low and those who have high self-efficacy.

In the area *motives*, the needs, interests, and goals of the person are considered. In the literature review, only two studies that assessed aspects in this area were found, namely purpose in life in relation to well-being in SCI.^{89,90} Not only can purpose in life influence adjustment after SCI but also life goals, in particular, can influence motivation of persons with SCI to participate in and comply with treatment and prevention programs.⁹¹ Motivational factors are, in general, of high interest in rehabilitation needs assessment, in goal setting, and during the course of rehabilitation, and they seem to represent an understudied topic in SCI.^{92,93} Goal planning,^{94,95} goal attainment scaling,^{96,97} and motivational interviewing are fields of current rehabilitation research.⁹⁸ However,

Maslow's hierarchy of needs⁹⁹ or the concepts of intrinsic and extrinsic motivation^{74,100} could also be considered as category specifications to be studied within this area.

The final area addresses *patterns of experience* and behavior, which are general, context-independent, cross-situational, recurrent, and persistent. They contain trait-like personality characteristics, handling and management of feelings, thoughts and motives, habits, lifestyles, and talents. In the literature review, 48 studies have assessed category specifications that fall within the scope of this area. Among these domains, coping strategies ($n = 19$) and lifestyle (including physical activity, alcohol use, smoking, drug use, health practices; $n = 13$) and personality traits ($n = 5$) were found to be the most salient category specifications. Coping is a central topic^{2,101} and has been found to be related to quality-of-life, adjustment, participation, and mental health in SCI.^{1,4,5,102,103}

Lifestyle factors were found to be similarly relevant. Persons with SCI seem to be more likely to use and abuse alcohol and drugs (e.g., benzodiazepines),^{104,105} but the number of smokers among people with SCI was not higher than in the general population.¹⁰⁶ Previous alcohol abuse and smoking are risk factors for pressure sore

TABLE 3 Suggested specifications of the domain set from the psychologic-personal perspective

Areas	Specifications
Cross-cutting	Life satisfaction
Sociodemographic personal characteristics	Age Sex Nationality, citizenship, ethnicity Language Educational background Occupational background Economical background Religious affiliation
Position in the immediate social and physical context	Marital status/relationship status
Personal history and biography	Life events
Feelings	Positive and negative affect
Thoughts and beliefs	Perceived stress Locus of control Self-efficacy
Motives	Purpose in life
Patterns of experience and behavior	Coping Lifestyle (including physical activity, alcohol, tobacco, drug use) Personality traits (Big Five)

occurrence.^{107,108} Persons with more pack-years of smoking have a higher risk of obstructive lung diseases.¹⁰⁹ However, an active lifestyle and exercise buffers the effects of stress on well-being.⁶⁷ Persons doing exercise report less pain, depression, and stress; greater perceived quality-of-life; and better physical self-concepts.¹¹⁰

Finally, personality traits (e.g., conscientiousness, extroversion, neuroticism) have been shown to affect mortality risk in the general population.¹¹¹ They seem to relate to disability acceptance and coping, depression, anxiety, and psychopathologic symptoms,^{112–114} but also exercise behavior¹¹⁵ in SCI.

Table 3 provides a summary of the category specifications across the seven areas of research that have been identified as candidates for the domain set from the psychologic-personal perspective in SCI.

SCI Measurement Instrument Set for the Psychologic-Personal Factors Quality Of Life, Life Satisfaction, and Subjective Well-Being

For the measurement of quality-of-life, life satisfaction, and subjective well-being, an abundance of instruments exist. Several reviews summarized the application and metric properties of quality-of-life measurement instruments in SCI.^{24,35,116,117} Described measurement instruments included the Satisfaction with Life Scale,¹¹⁸ the Life Satisfaction Questionnaire–9,¹¹⁹ the Personal Well-Being Index,¹²⁰ and WHO Quality of Life Assessment instruments WHOQOL-BREF and WHOQOL-5.^{121–123} Measurement instruments such as the Medical Outcomes Study 36-Item Short-Form Health Survey,¹²⁴ the Sickness Impact Profile–68,^{125,126} and the Quality of Well-Being Scale¹²⁷ have all been discussed in the field of SCI. The Quality of Life Index SCI-Version III^{128,129} and the Spinal Cord Injury Quality of Life Questionnaire^{130,131} are two measurement instruments specifically developed for SCI. In the consulted reviews of quality-of-life measurement in SCI, the Satisfaction with Life Scale and Life Satisfaction Questionnaire were recommended. Recently, the WHOQOL-5 has been shown to be a cross-culturally comparable measurement instrument of quality-of-life and life satisfaction in SCI.¹²³

Sociodemographic Personal Characteristics and Position in the Immediate Social and Physical Context

In the assessment of sociodemographic personal characteristics, no standardized questionnaires exist; instead, researchers have developed

their own formulations and operationalizations of these variables. To measure these concepts, questions from population-based surveys, particularly from standardized measurement instruments assessing socioeconomic status¹³² could be considered. The information might be provided by the individuals themselves in an anamnestic interview or documented from patient health records. Standardized forms for capturing sociodemographic personal characteristics, like the International Spinal Cord Injury Data Sets,¹³³ could be developed in future.

Personal History and Biography

Assessment of major life events in SCI has, until now, relied mainly on subscales of questionnaires such as the Posttraumatic Stress Disorder Checklist¹³⁴ or the Purdue Posttraumatic Stress Disorder scale.¹³⁵ For life events research in various populations, a number of other measurement instruments have been developed. The most frequently applied measurement instrument is the Social Readjustment Rating Scale¹³⁶ and its numerous modifications. Other measurement instruments include the Impact of Event Scale,¹³⁷ the List of Threatening Experiences,¹³⁸ the Psychiatric Epidemiology Research Interview Life-Events Scale,¹³⁹ the Life Experiences Survey,¹⁴⁰ the Unpleasant Events Schedule¹⁴¹ or the Daily Hassles Scale.¹⁴² No measurement instruments that are specific to SCI have been found.

Feelings

Feelings have been considered distinct from psychiatrically relevant impairments of emotional functions (e.g., depression and anxiety disorders) and have been assessed in SCI research using, for example, the “role emotional” subscale of the Medical Outcomes Study 36-Item Short-Form Health Survey or the State-Trait Anxiety Inventory.¹⁴³ Affect and mood could also be captured using the Profile of Mood States,^{144,145} the Mood Adjective Checklist,¹⁴⁶ the 8-Item Affect Scale,¹⁴⁷ or the Positive and Negative Affect Schedule.¹⁴⁸ However, these scales need to be critically appraised for their appropriateness for certain application fields, such as because of unclear sensitivity to change, because of weaknesses of scale development, and others. Currently, techniques of momentary ecologic assessment are increasingly being used with affect scales^{149,150} and could be applied to persons with SCI.

Thoughts and Beliefs

The review of the literature showed that for the category specification of perceived stress, the Perceived Stress Scale¹⁵¹ was most frequently used

TABLE 4 Measurement instruments of self-efficacy and their performance according to the SwiSCI criteria 33—an example

Instrument	Validity	Reliability	Feasibility	Comparability	Level of Detail		
					of Information	Efficiency	Nonredundancy
General Self-Efficacy Scale ¹⁵³	–	X	X	X	–	–	X
Moorong Self-Efficacy Scale ¹⁵⁴	X	X	X	X	–	–	X
General Self-Efficacy Scale ¹⁵⁵	X	X	X	X	X	–	X
Self-Efficacy Questionnaire ¹⁵⁶	X	X	X	–	–	–	X
General Self-Efficacy Scale–12 ¹⁵⁷	X	–	X	–	–	–	X
New General Self-Efficacy Scale ¹⁵⁸	X	X	X	–	–	–	X
Generalized Self-Efficacy Scale ¹⁵⁹	–	X	X	–	–	–	X

SwiSCI, Swiss Spinal Cord Injury Cohort Study.

in SCI. Further measurement instruments that could be considered to assess this domain include the Impact of Event Scale¹³⁷ or the Depression, Anxiety and Stress Scales.¹⁵²

For the category specification of locus of control, the Multidimensional Health Locus of Control scale¹⁵³ and the Internality, Powerful Others, and Chance Scale¹⁵⁴ are among the most salient measurement instruments.

A number of different measurement instruments have been developed and applied in research to capture self-efficacy beliefs. In SCI, the General Self-Efficacy Scale (GSES)¹⁵⁵ and Moorong Self-Efficacy Scale¹⁵⁶ were most frequently applied. Other scales that could be considered for the Measurement Instrument Set include the General Self-Efficacy Scale,¹⁵⁷ the Self-Efficacy Questionnaire,¹⁵⁸ the GSES-12,¹⁵⁹ the New General Self-Efficacy Scale,¹⁶⁰ and the Generalized Self-Efficacy Scale.¹⁶¹ Table 4 illustrates the evaluation of various self-efficacy measurement instruments applying the Swiss Spinal Cord Injury Cohort Study criteria developed by Muff et al.³³ Using these criteria would help structure and make transparent the examination of the relative suitability of the different measurement instruments and guide researchers' deliberations when selecting an instrument for their study. Table 4 summarizes the finding that all identified measurement instruments of self-efficacy are short enough to be feasible and to measure a concept that is not already covered in other areas of the ICF. Reliability and validity have been reported and are acceptable in most of the instruments. The GSES by Sherer et al.,¹⁵⁵ the Moorong Self-Efficacy Scale, and the GSES by Schwarzer and Jerusalem¹⁵⁷ are

frequently used measurement instruments and can be used to compare findings from other studies and different population samples. The GSES by Schwarzer and Jerusalem¹⁵⁷ is the shortest measure and refers to overall self-efficacy, making it the measurement instrument with the most reasonable level of detail. Because all measurement instruments refer to one concept, namely self-efficacy, and use more than ten items to capture it, efficiency is not a special advantage of these scales.

Motives

For capturing the domain of life goals within the psychologic-personal perspective, only a few standardized measurement instruments exist, such as the Purpose in Life Test,¹⁶² which covers the existence and fulfillment of life goals. Qualitative and open-ended questions would be suitable to learn about the life goals of persons with SCI.

Patterns of Experience and Behavior

In the field of coping, not only are there a large range of conceptualizations¹⁶³ but also there is an abundance of measurement instruments. In SCI, the Ways of Coping Questionnaire,¹⁶⁴ the Coping Style Questionnaire,¹⁶⁵ and the Spinal Cord Lesion-related Coping Strategy Questionnaire¹⁶⁶ are among the most frequently used measurement instruments. Further measurement instruments to capture this key category specification within the psychologic-personal perspective include the Coping Orientation for Problem Experiences (COPE),^{167,168} the Coping Strategies Inventory,¹⁶⁹ the Multidimensional Coping Inventory,¹⁷⁰ the Adolescent Coping Orientation for Problem Experiences,¹⁷¹ the Illness Cognitions Questionnaire,¹⁷²

and the Coping Inventory of Stressful Situations.¹⁷⁰ Coping is viewed in different measurement instruments as a personality trait (e.g., as in the Coping Inventory of Stressful Situations), as a set of behavioral strategies (e.g., the COPE) or as a process outcome following adversity also including the idea of posttraumatic growth (e.g., Illness Cognitions Questionnaire). These views complement each other, so more than one of them could be included into the Measurement Instrument Set.

For lifestyle factors in contrast, few standardized questionnaires exist. Alcohol, tobacco, and drug use or physical activities are documented using anamnestic information or simple survey questions set up for the purposes of one study. In the case of alcohol, tobacco, and drug use, laboratory testing is sometimes conducted. An example for a standardized questionnaire would be the Michigan Alcoholism Screening Test.¹⁷³

Among the measurement instruments of personality traits, the Zuckerman-Kuhlman Personality Questionnaire,¹⁷⁴ the Eysenck Personality Questionnaire,¹⁷⁵ and the Neuroticism-Extroversion-Openness Personality Inventory¹⁷⁶ have been used in SCI. The latter is the most widely used questionnaire that captures the so-called Big Five traits, which are openness, conscientiousness, extraversion, agreeableness, and neuroticism. The Ten-Item Personality Inventory¹⁷⁷ has been currently developed as the shortest possible means to assess the Big Five traits and could be considered in survey research.

DISCUSSION

The current article illustrates the identification of relevant areas of research for capturing psychologic-personal factors according to the comprehensive context of the ICF, using SCI as a case in point. It shows how this structure can guide comprehensive research by indicating what to measure and how to measure in SCI from the psychologic-personal perspective. The stepwise approach of identifying areas of research, selecting relevant category specifications based on the literature, listing potential measurement instruments, and selecting among them according to predefined guiding principles, can be used in designing any study.

Areas of Research for Capturing the Psychologic-Personal Factors

The need to define areas of research for capturing the psychologic-personal perspective in any study corresponds to the obvious and fundamental fact that people are different as persons. These differences need to be taken into account in con-

sidering functioning, disability, and health. The provision of best care; respecting the individuality, autonomy, and dignity of the patient; and understanding and explaining the current health state of the person all require knowledge of the individual. Consumer-centered service delivery at all stages of the rehabilitation process,^{178,179} especially individualized tailored interventions and shared decision making, as well as epidemiologic research, health reporting, and administration, rely on this information.

The development of a personal factors classification is currently under consideration by the WHO. A number of challenges are associated with its development. The first is the conceptualization of personal factors, which has to be in line with the ICF and such as not to overlap with other ICF components. On the side of formal and methodologic issues, the classification structure itself needs to be developed to ensure the classification goals of mutually exclusive and jointly exhaustive categories. The classification needs to be backed up by a rigorous scientific development process, cross-cultural applicability testing, international agreement involving persons with disabilities and to adhere to WHO Family of International Classifications standards to be endorsed by the WHO.^{180,181} The identification of research areas and the definition of category specifications proceeding from the literature proposed in this article can contribute to the further development of a WHO classification of personal factors.

However, it is important to note that, when designing a study, neither a structure, as presented in this article, nor a classification can substitute for the necessary decision-making processes by researchers. Structures and classifications are simply supporting tools for researchers. Similarly, the ICF classification does not replace the professional jargon in the medical, psychologic, and health sciences but can support structuring, precisely defining, and analyzing complex phenomena and concepts. For measurement instrument selection, the ICF can help to define the content of the domains to be captured, but it does not automatically identify the best measurement instruments to use because the suitability of measurement instruments depends on further factors, such as those outlined in the guiding principles by Fekete et al.³³

The SCI Domain Set from the Psychologic-Personal Perspective

A set of domains was identified in this article, which are relevant for SCI research from the

psychologic-personal perspective. In this study, the seven defined areas of research effectively summarized the category specifications that are examined in SCI research. Various sociodemographic personal characteristics, thoughts, and beliefs, as well as patterns of experience and behavior, seem to be the major focus of past SCI research. On the other hand, there is little research dealing with feelings and motives in SCI, suggesting a research gap.

When selecting the category specifications to be measured from the psychologic-personal perspective, the difficulty frequently lies in the decision on whether well-known and frequently examined aspects should be involved (e.g., self-efficacy) or whether new and rarely examined hypotheses should be given priority (e.g., personality). Ideally, a balance between the assessment of the well-known and relevant factors and innovative questions should be achieved. We encourage researchers to always take into consideration cross-cutting outcomes such as quality-of-life, life satisfaction, and subjective well-being. The conceptual relation between these outcomes, the ICF, and the psychologic-personal factors is currently under debate;¹⁸² however, they can be considered cross-cutting category specifications because they may touch, depending on the exact operationalization and the specific instrument and a number of ICF components and categories at the same time.^{183,184}

In this study, the relevance of the category specifications was judged based on what has been found in the literature. However, expert knowledge might constitute another criterion for choosing assessment variables. Obviously, the objectives of the study, the theories used, and the research models used also determine the inclusion of variables.

SCI Measurement Instrument Set for Psychologic-Personal Factors

Suitable measurement instruments were identified and the application of a set of guiding principles for instrument selection has been exemplified. Measurement instrument selection should always follow an explicit, transparent, and comprehensive approach, similar to that outlined here.

In responding to the question “how to measure,” the application of certain criteria, such as efficiency and feasibility, was difficult because there is no consensus on guidelines to operationalize these criteria. The decisions in these cases have to be based on the reflection and discussion of the research team. Professional researchers are obliged to document such discussions and decisions to ensure transparency.

With certain measurement instruments, a problem of potential overlap between different components of the ICF model became apparent. For example, anxiety and depression could be assigned to the ICF component of health conditions (as clinical diagnoses), mental body functions (as impairments), or emotional experiences (as personal factors). Although conceptually, a differentiation might be possible, at the level of concrete operationalization—using versatile measurement instruments such as the Hospital Anxiety and Depression Scale, which could be seen as covering health conditions or body functions rather than psychologic-personal factors—the boundaries between the components become blurred. Therefore, for this example, it is especially important to use a measurement instrument from emotion research like the Positive and Negative Affect Schedule 149 in capturing the category specification of feelings, which clearly covers emotions.

Limitations

The current work is subject to several limitations. It relied on a review methodology in identifying the domain set, which was very simple and rudimentary. The results of this study should therefore be interpreted with caution because a more elaborate search strategy might have yielded more comprehensive results and a slightly different selection of category specifications. The collection of the pool of measurement instruments that corresponds to the identified psychologic-personal domains did not follow a rigorously systematic procedure but relied on available information and might therefore have gaps. The application of the guiding principles for the selection of measurement instruments is not a fully objective procedure or does not rely on strict decision algorithms but contains a certain subjective element, which might open the selection up for debate.

CONCLUSIONS

The step-by-step approach from identification of areas of research to identification of category specifications to the selection of measurement instruments as exemplified in this study can be used for designing any study in the medical, psychologic, and health sciences fields, not merely for studies involving SCI. The results of the current study contributed to creating a transparent protocol for the Swiss Spinal Cord Injury Cohort Study, coordinated by the Swiss Paraplegic Research in Nottwil, Switzerland.¹⁸⁵ The presentation of these results

also provides a starting point for further discussion and can therefore facilitate collaborative, comprehensive, and multidisciplinary research. This article stresses the relevance of the comprehensive approach to SCI and the consideration of the psychological-personal perspective in this approach. The study, therefore, hopes to encourage scientists to use the ICF and the psychological-personal perspective as a frame of reference for their research. Furthermore, the research reported in this article can inform the WHO's future development of the personal factors classification in the ICF.

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