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INVITED REVIEW

Category Specification and Measurement Instruments in Large Spinal Cord Injury Studies

A Comparison Using the International Classification of Functioning, Disability, and Health as a Reference

ABSTRACT

Eriks-Hoogland I, Cieza A, Post M, Hilfiker R, van Hedel H, Cripps R, Chen Y, Boldt C, Stucki G: Category specification and measurement instruments in large spinal cord injury studies: A comparison using the international classification of functioning, disability, and health as a reference. Am J Phys Med Rehabil 2011; 90(suppl):S39–S49.

The objective of this paper was to examine whether large longitudinal studies have comprehensively covered the functioning of persons with spinal cord injuries (SCI), using the International Classification of Functioning, Disability and Health (ICF) as reference framework. First, the literature was reviewed to select relevant studies. Second, category specifications measured in the included studies were linked to the ICF and compared with the Brief ICF Core Sets for postacute and chronic situations. Finally, all measurement instruments used to assess these category specifications were listed according to the corresponding ICF category. Four studies were included: the National SCI Database in the United States, the Australian SCI Register, the European Multicenter Study about SCI, and the Dutch research program "Restoration of mobility in SCI rehabilitation." All measures could be linked to the ICF Core Sets. However, all studies only partly covered (range, 14–27) the 49 categories of the Brief ICF Core Sets. Least well covered were categories of body structures and environmental factors. Besides the International Standards for Neurological Classification of SCI (American Spinal Injury Association Impairment Scale), the areas of functioning were measured using the same measurement instruments in all studies. None of the included longitudinal studies comprehensively cover functioning. There is the need to develop truly comprehensive longitudinal studies in SCI.

Key Words: Spinal Cord Injuries, Rehabilitation, Cohort Studies, ICF, ICF Core Set, Measurement Instruments

Spinal cord injury (SCI) affects all body systems and the corresponding structures below the level of the neurological lesion[1] and is also related to posttraumatic stress disorder and depression.[2] As a consequence, SCI affects not only mobility[3] but also, for example, intimate relationships,[4] work, and other participation domains.[5] These impairments do not, however, completely determine the lived experience of disability in persons with SCI because that depends on background contextual factors, both environmental (such as availability of transportation) and personal.[6,7] Therefore, to fully understand the lived experience of persons living with SCI, a comprehensive research approach is needed, going beyond the biomedical parameters and also covering activities, participation, and contextual factors.[8]

Ensuring the comparability among data in SCI studies using the same outcome parameters and measurement instruments would be preferable. This need for comparability has been recognized by the International Spinal Cord Society and the American Spinal Injury Association and has led to the initiative of the International SCI Data Sets in 2006.[9] Besides the International Spinal Cord Injury Core Data Sets,[10] data sets on urinary function,[11–13] bowel function,[14,15] autonomic function,[16] female and male sexual and reproductive function,[17] pain,[18,19] cardiovascular function,[20] and quality-of-life (www.iscos.org.uk) have been finalized, and the development of new data sets is an ongoing endeavor.

Studies focusing on persons with SCI that use a longitudinal design, involving repeated observations of the same items during longer periods of time, are a crucial source of knowledge on the long-term consequences of SCI. Longitudinal designs allow us by virtue of being able to exclude time-invariant unobserved individual differences and by virtue of observing the temporal order of events to detect causal relationships. Ideally, these longitudinal studies include subjects early after SCI, follow them throughout the rehabilitation and chronic phase, and address the full range of relevant category specifications that encompass the lived experience of persons with SCI.

An in-depth understanding of the domains covered and the use of category specifications of previous and current longitudinal cohort studies is of utmost importance for the planning of new studies aiming for a comprehensive understanding of functioning. Currently, we do not know which aspects of functioning are covered by previous and current longitudinal studies in SCI. Furthermore, we do not know how comparable these studies are with respect to their outcomes defined and measurement instruments used. The recent development of the ICF Core Sets for SCI[10] enables us to compare previous and current longitudinal studies using the universally accepted framework of functioning of the ICF[21] on the study category specifications chosen and the measurement instruments used and, thereby, to identify areas of overlap and gaps between studies. Based on the ICF Core Sets for SCI, it is also possible to examine how comprehensively individual studies have covered functioning. If a study comprehensively covers functioning of persons with SCI, it can be expected that the study category specifications broadly cover the ICF categories included in the ICF Core Sets for SCI.

The objective of this study, therefore, is to examine how previous and current longitudinal studies have covered the functioning of persons with SCI using the ICF as reference framework.

The specific aims were as follows:

1. to examine how selected longitudinal studies have covered functioning using the ICF Core Sets for SCI as reference, and
2. to identify the category specifications and measurement instruments used in the different studies to cover functioning aspects and to describe commonalities and differences.

METHODS

Study Design

The study was performed in three steps: first, literature was screened to select relevant studies. Second, category specifications of the data sets of the included studies were linked to the ICF, and all measurement instruments used to assess the category specifications of the studies were listed according to the specific ICF category. Third, the category specifications of the included studies were compared with the contents of the Brief and Comprehensive ICF Core Sets to conclude on comprehensiveness and comparability, and the measurement instruments used were listed according to the corresponding ICF category to compare the measurement instruments used for a certain category specification in different studies.

Reference Framework

The ICF[21] is structured hierarchically in chapters and categories of different levels. To give an example, the fourth-level ICF category, b28014 Pain in upper limb, is one element of the third-level

category b2801 Pain in body part, which is, in turn, an element of the second level category b280 Pain, which is, in turn, an element of the chapter b2 Sensory functions and pain, which is, in turn, an element of the ICF component b Body Functions. ICF Core Sets for SCI were developed for the early postacute context[22] and the long-term context,[23] covering the first comprehensive rehabilitation after SCI and the subsequent time period, respectively. The Brief ICF Core Sets capture the essence of the experience of persons with a specific health condition or in a specific setting. They therefore serve as the starting point for condition-specific research and basic clinical documentation. The Comprehensive ICF Core Sets serve as a reference pool of potentially relevant categories of functioning and determinants of functioning that can be drawn upon to describe specific issues of functioning in the population under study.

Literature Review

Search Strategy and Inclusion Criteria

We aimed to identify large ($N > 200$) longitudinal studies, starting in the acute or postacute phase, which have been performed in SCI during the last 10 yrs, through a literature search in PubMed. The key words used were *spinal cord injuries*, *cohort*, *longitudinal*, *prospective*, *follow-up*, and *outcomes*. Only publications on adults and those written in English, Dutch, or German were selected.

The principal investigators of selected studies were asked to provide the list of category specifications studied and the measurement instruments used.

Linking Procedure of Category Specifications and Measurement Instruments

All category specifications were linked to the ICF using an established methodology.[24] The linking was independently performed by two researchers (I. Eriks-Hoogland, R. Hilfiker). The results of the linking of both researchers were compared. In case of a disagreement, a third researcher (C. Boldt) was involved, and, based on an informed discussion, agreement was reached. A table was developed, including the ICF categories contained in the Comprehensive ICF Core Sets for SCI and the ICF categories identified in the selected studies. For readability reasons, we linked all category specifications to second-level ICF categories.

In a final step, the measurement instruments used in the studied data sets were also linked to the ICF, and a second table was created in which the instruments covering the ICF categories of the ICF Core Sets are listed.

Analysis

A comparison of the category specifications and measurement instruments used in the included studies was made using the second level of the ICF Core Sets as a reference to conclude on comprehensiveness and comparability. The categories of the Brief ICF Core Sets for SCI were displayed in bold in the tables.

RESULTS

Literature Search

Of 1583 publications retrieved, we found four studies meeting our inclusion criteria; the National SCI Database in the United States (https://www.nscisc.uab.edu/), the Australian Spinal Cord Injury Register (www.nisu.flinders.edu.au), the European Multicenter Study about Spinal Cord Injury (https://www.emsci.org), and the Dutch research program "Restoration of mobility in SCI rehabilitation" (https://www.scionn.nl). The principal investigators of the selected longitudinal studies were contacted and have sent us their data sets with category specifications measured and the list of measurement instruments used to assess the different category specifications.

National SCI Database in the United States

Since its inception, the Spinal Cord Injury Model Systems program began in 1970 with funding from the National Institute on Disability and Rehabilitation Research of the US Department of Education to improve care and outcomes for individuals with SCI.[25] Each Spinal Cord Injury Model Systems center contributes data to the National SCI Database and follows registered SCI cases on a regular basis. A total of 26 Spinal Cord Injury Model Systems centers have contributed data to the database, which captures data from approximately 13% of new SCI cases in the United States every year and which monitors trends on new injuries and tracks the long-term consequences of SCI. As of October 2009, the database contained information on 26,852 persons with SCI and 120,568 follow-up records with the longest follow-up time of 35 yrs postinjury (National Spinal Cord Injury Statistical Center, 2009). For our comparison, we have used the category specifications and measurement instruments used in the 2006–2011 project period.

TABLE 1 Representation of second level of the ICF core sets for SCI

ICF Code	Description	NSCISC	SCI-MS	EMSCI	DRM-SCI	ASCIR
Body structures						
s120	**Structure of the spinal cord and related structures**	**X**		**X**	**X**	**X**
s430	**Structure of respiratory system**					
s610	**Structure of urinary system**			**X**		
s710	Structure of head and neck region					
s720	Structure of shoulder region					
s730	Structure of upper limb					
s740	Structure of pelvic region					
s750	Structure of lower limb					
s760	Structure of trunk					X
s810	**Structure of areas of skin**			**X**	**X**	
Body functions						
b126	Temperament and personality functions					
b130	Energy and drive functions				X	
b134	Sleep functions			X		
b152	**Emotional functions**	**X**		**X**	**X**	
b260	Proprioceptive function					
b265	Touch function	X		X	X	X
b270	Sensory functions related to temperature and other stimuli					
b280	**Sensation of pain**	**X**		**X**	**X**	**X**
b310	Voice functions					
b410	Heart functions				X	
b415	Blood vessel functions					
b420	Blood pressure functions				X	
b430	Hematologic system functions				X	
b440	**Respiration functions**				**X**	
b445	Respiratory muscle functions					
b455	Exercise tolerance functions				X	
b510	Ingestion functions					
b515	Digestive functions					
b525	**Defecation functions**	**X**		**X**	**X**	**X**
b530	Weight maintenance functions	X			X	
b550	Thermoregulatory functions					
b610	Urinary excretory functions			X		
b620	**Urination functions**	**X**		**X**	**X**	**X**
b630	Sensations associated with urinary functions					
b640	**Sexual functions**					
b660	Procreation functions					
b670	Sensations associated with genital and reproductive functions					
b710	**Mobility of joint functions**				**X**	
b715	Stability of joint functions					
b720	Mobility of bone functions					
b730	**Muscle power functions**	**X**		**X**	**X**	**X**
b735	**Muscle tone functions**			**X**	**X**	
b740	Muscle endurance functions				X	
b750	Motor reflex functions			X		
b755	Involuntary movement reaction functions					
b760	Control of voluntary movement functions					
b765	Involuntary movement functions					
b770	Gait pattern functions					
b780	Sensations related to muscles and movement functions			X	X	
b810	**Protective functions of the skin**			**X**	**X**	
b820	Repair functions of the skin				X	
b830	Other functions of the skin					
b840	Sensation related to the skin					
Activities and participation						
d155	Acquiring skills					
d230	**Carrying out daily routine**					
d240	**Handling stress and other psychologic demands**					
d360	Using communication devices and techniques					
d345	Writing messages					

(Continued on next page)

TABLE 1 (Continued)

ICF Code	Description	NSCISC SCI-MS	EMSCI	DRM-SCI	ASCIR
d410	**Changing basic body position**		**X**		
d415	Maintaining a body position				
d420	**Transferring oneself**	**X**	**X**	**X**	**X**
d430	Lifting and carrying objects				
d435	Moving objects with lower limbs				
d440	Fine hand use			X	
d445	**Arm and hand use**			**X**	
d450	**Walking**	**X**	**X**	**X**	**X**
d455	**Moving around**	**X**	**X**	**X**	**X**
d460	Moving around in different locations		X		
d465	**Moving around using equipment**	**X**	X	X	X
d470	**Using transportation**	**X**			
d475	Driving	X			
d510	**Washing oneself**	**X**	**X**	**X**	**X**
d520	**Caring for body parts**	**X**	**X**	**X**	**X**
d530	**Toileting**	**X**	**X**	**X**	
d540	**Dressing**	**X**	**X**	**X**	**X**
d550	**Eating**	**X**	**X**	**X**	**X**
d560	**Drinking**	**X**	**X**	**X**	**X**
d570	Looking after one's health				
d610	Acquiring a place to live				
d620	Acquisition of goods and services				
d630	Preparing meals	X			
d640	Doing housework	X		X	
d650	Caring for household objects	X		X	
d660	Assisting others				
d720	Complex interpersonal interactions				
d750	Informal relationships	X		X	
d760	Family relationships	X		X	
d770	Intimate relationships	X		X	
d810	Informal education	X		X	
d820	School education	X		X	
d825	Vocational training	X		X	
d830	Higher education	X		X	
d840	Apprenticeship (work preparation)				
d845	Acquiring, keeping, and terminating a job			X	
d850	Remunerative employment	X		X	X
d870	Economic self-sufficiency				
d910	Community life	X		X	
d920	Recreation and leisure	X		X	
d930	Religion and spirituality				
d940	Human rights				
Environmental factors					
e110	**Products or substances for personal consumption**	**X**	**X**	**X**	
e115	**Products and technology for personal use in daily living**	**X**	**X**	**X**	
e120	**Products and technology for personal indoor and outdoor mobility and transportation**	**X**		**X**	
e125	Products and technology for communication				
e130	Products and technology for education				
e135	Products and technology for employment				
e140	Products and technology for culture, recreation, and sport				
e150	**Design, construction, and building products and technology of buildings for public use**				
e155	**Design, construction and building products and technology of buildings for private use**				
e160	Products and technology of land development				
e165	Assets				
e310	**Immediate family**	**X**		**X**	
e315	Extended family	X		X	
e320	Friends	X		X	
e325	**Acquaintances, peers, colleagues, neighbors, and community members**	**X**		**X**	

(Continued on next page)

TABLE 1 (Continued)

ICF Code	Description	NSCISC	SCI-MS	EMSCI	DRM-SCI	ASCIR
e330	People in positions of authority					
e340	**Personal care providers and personal assistants**					
e355	Health professionals					
e360	Other professionals					
e410	Individual attitudes of immediate family members					
e415	Individual attitudes of extended family members					
e420	Individual attitudes of friends					
e425	Individual attitudes of acquaintances, peers, colleagues neighbors and community members					
e440	Individual attitudes of personal care providers and personal assistants					
e450	Individual attitudes of health professionals					
e455	Individual attitudes of health-related professionals					
e460	Societal attitudes					
e465	Social norms, practices, and ideologies					
e510	Services, systems, and policies for the production of consumer goods					
e515	Architecture and construction services, systems, and policies					
e525	Housing services, systems, and policies					
e530	Utilities services, systems, and policies					
e535	Communication services, systems, and policies					
e540	Transportation services, systems, and policies					
e550	Legal services, systems, and policies					
e555	Associations and organizational services, systems, and policies					
e570	Social security services, systems, and policies			X		
e575	General social support services, systems, and policies					
e580	**Health services, systems, and policies**					
e585	Education and training services, systems, and policies					
e590	Labor and employment services, systems, and policies					

The items of the brief ICF core sets are boldfaced.

SCI, spinal cord injuries; ICF, International Classification of Functioning, Disability and Health; NSCISC, National SCI Database in the United States; EMSCI, European Multicenter Study about Spinal Cord Injury; DRM-SCI, Dutch research program "Restoration of mobility in SCI rehabilitation: The Umbrella Project"; ASCIR, Australian Spinal Cord Injury Register.

European Multicenter Study About Spinal Cord Injury

The European Multicenter Study About Spinal Cord Injury study started in 2001. The objective of the European Multicenter Study About Spinal Cord Injury study group is to establish a multicenter basis for future therapeutic interventions in human spinal cord injury.[26] The group has detailed information on neurologic recovery in acute traumatic SCI patients that has been clinically followed up through repeated neurologic assessments extending for 1 yr after injury. Since its inception, 18 European SCI centers have contributed data to the database, which currently includes over 1,900 patients (April 2010).

Dutch Research Program "Restoration of Mobility in SCI Rehabilitation: The Umbrella Project"

The Dutch Research Program "Restoration of Mobility in SCI Rehabilitation: The Umbrella Project" started its inclusion in 1999. This multicenter study, executed in eight rehabilitation centers with specialized SCI departments, included 225 individuals with new SCI during primary rehabilitation between 2000 and 2003. The objective of this study was to analyze the restoration of mobility at the level of impairments, disability, and handicap with a combination of clinical tests, diagnostic tests, and self-report measurement instruments. For our comparison, we have used the category specifications that were assessed at the start of inpatient rehabilitation.[27]

Australian Spinal Cord Injury Register

The Australian Spinal Cord Injury Register covers all new cases of SCI arising from trauma in persons 15 yrs and older in Australia.[28] The ASCIR focuses on a small set of core surveillance data items specified in a data dictionary. To maximize the potential for international comparisons, data

items and classifications were selected, as much as possible, based on international standards.

Linking of Category Specifications to the ICF

The date of birth, age, sex, weight, height, racial or ethnic group, dominance of hand, marital status, highest education level attained, and employment status before SCI were considered to be personal factors. The date of admission, date of examination, date of discharge, place of discharge, and cause of injury were not covered and classified as such. The use of alcohol, tobacco, or drugs was also classified as a personal factor, assuming that they are part of habits or lifestyle. All of the other category specifications of the data sets that we examined could be linked to the ICF.

Table 1 presents all second-level categories of the ICF Core Sets for SCI and which of them were addressed by the considered data sets. Some aspects of functioning are covered across the studies. All data sets assess the following Body Functions and Structures: s120 Structure of the spinal cord, b265 Touch function, b280 Sensation of pain, b525 Defecation functions, b620 Urination functions, and b730 Muscle power functions. The following activities and participation ICF categories were also addressed in all data sets: d420 Transferring oneself, d450 Walking, d455 Moving around, d465 Moving around using equipment, d510 Washing oneself, d520 Carrying for body parts, d540 Dressing, d550 Eating, and d560 Drinking. Most aspects were covered by some but not all studies.

Some aspects of functioning considered relevant in the ICF Core Sets for SCI were not covered by any study. They include s430 Structures of the respiratory system and, on the level of Body Function, b640 Sexual functions.

On the level of activities and participation, the ICF categories d230 Carrying out daily routine and d240 Handling stress and other psychologic demands, which are among those included in the Brief Core Sets for SCI, are not covered in any of the included data sets; at the level of the Environmental factors, e 155 Design, construction, and building products and technology of buildings for private use; e340 Personal care providers and personal assistants; e355 Health professionals; and e580 Health services, systems, and policies are not covered in any data set.

Table 2 presents an overview of the chapters of the ICF Brief Core Set for SCI and how many were covered by the selected studies, specified for Body Structures, Body Functions, and Activities and Participation. The studies cover between 14 and 27 categories of the Brief Core Sets for SCI.

Measurement Instruments Used in the Data Sets

Table 3 presents all second-level categories of the ICF Core Sets for SCI and the corresponding measurement instruments used in the data sets. Only the categories that were represented in the data sets are listed in Table 3.

Table 3 gives an overview of the measurement instruments used in the data sets. It shows that, besides the International Standards for Neurological and Functional Classification of Spinal Cord Injury (American Spinal Injury Association Impairment scale),[29] no areas of functioning were measured by the same measurement instrument in different studies. For example, the ICF category d455 Moving around is assessed using the Functional Independence Measure[30] and the Spinal Cord Independence Measure.[31]

DISCUSSION

The categories of the Brief ICF Core Sets for SCI are the minimum number of categories to understand functioning in SCI. Through a linking of

TABLE 2 Overview of the chapters of the ICF brief core set for SCI and how many were covered by the selected studies, specified for body structures, body functions, activities and participation, and environmental factors

Brief Core Set for SCI	NSCISC	EMSCI	DRM-SCI	ASCIR
Body structures (n = 4)	1	3	2	1
Body functions (n = 10)	5	7	9	4
Activities and participation (n = 15)	10	10	11	9
Environmental factors (n = 10)	5	2	5	0
Total (n = 49)	21	22	27	14

ICF, International Classification of Functioning, Disability, and Health; NSCISC, National SCI Database in the United States; EMSCI, European Multicenter Study about Spinal Cord Injury; DRM-SCI, Dutch research program "Restoration of mobility in SCI rehabilitation: The Umbrella Project"; ASCIR, Australian Spinal Cord Injury Register.

TABLE 3 Measurement instruments of the selected data sets linked to second level of the ICF categories of the ICF core sets for SCI

ICF Code	Description	NSCISC	EMSCI	DRM-SCI	ASCIR
Body structure					
s120	**Structure of the spinal cord and related structures**	Diagn	Diagn	Diagn	Diagn
s610	**Structure of urinary system**	Diagn	Diagn		
s760	**Structure of trunk**				Diagn
s810	**Structure of areas of skin**		Diagn	Diagn	
Body function					
b134	Sleep functions	PHQ			
b152	**Emotional functions**	PHQ	HDS	SF-36	
b265	Touch function	AIS	AIS	AIS	AIS
b280	**Sensation of pain**	AIS	AIS, pain question	AIS, pain question	AIS
b410	Heart functions			CA/ECG	
b420	Blood pressure functions			CA /ECG	
b430	Haematologic system functions			Clinical test	
b440	**Respiration functions**			Spiro, ME	
b445	Respiratory muscle functions			Spiro	
b455	Exercise tolerance functions			ME	
b525	**Defecation functions**	FIM	SCIM II	FIM	FIM
b530	Weight maintenance functions	CA		CA	
b620	**Urination functions**	FIM	SCIM II	FIM, QIF	FIM
b630	Sensations associated with urinary functions		UD		
b710	**Mobility of joint functions**			CA	
b730	**Muscle power functions**	AIS	AIS	AIS	AIS
b735	**Muscle tone functions**		NP	Burchiel	
b740	Muscle endurance functions			ME	
b750	Motor reflex functions		NP	Burchiel	
b810	**Protective functions of the skin**		PSP	PSP	
Activities and participation					
d410	**Changing basic body position**		SCIM II	QIF	
d420	**Transferring oneself**	FIM	SCIM II	FIM, QIF	FIM
d440	Fine hand use			VLT, GRT QIF	
d445	**Arm and hand use**			VLT, GRT QIF	
d450	**Walking**	FIM	SCIMII, 10MWT, 6MWT	FIM, WST	FIM
d455	**Moving around**	FIM	SCIM II	FIM	FIM
d460	Moving around in different locations		SCIM II		
d465	**Moving around using equipment**	FIM	SCIM II	FIM, WST	FIM
d510	**Washing oneself**	FIM	SCIM II	FIM, QIF	FIM
d520	**Caring for body parts**	FIM	SCIM II	FIM	FIM
d530	**Toileting**	FIM	SCIM II	FIM, QIF	FIM
d540	**Dressing**	FIM	SCIM II	FIM	FIM
d550	**Eating**	FIM	SCIM II	FIM	FIM
d560	**Drinking**	FIM	SCIM II	FIM	FIM
d630	Preparing meals	CHART		UAL	
d640	Doing housework	CHART		UAL	
d650	Caring for household objects	CHART		UAL	
d750	Informal relationships	CHART		UAL	
d760	Family relationships	CHART		UAL	
d770	Intimate relationships	CHART			
d810	Informal education			UAL	
d820	School education			UAL	
d825	Vocational training			UAL	
d830	Higher education			UAL	
d850	Remunerative employment			UAL	
d910	Community life	CHART		UAL	
d920	Recreation and leisure	CHART		UAL, HB	

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TABLE 3 (Continued)

ICF Code	Description	NSCISC	EMSCI	DRM-SCI	ASCIR
Environmental factors					
e120	**Products and technology for personal indoor and outdoor mobility and transportation**	FIM	SCIM II	FIM	FIM
e310	**Immediate family**			SSL12	
e315	Extended family	CHART		SSL12	
e320	**Friends**	CHART		SSL12	
e325	Acquaintances, peers, colleagues, neighbors and community members	CHART		SSL12	

The items of the brief ICF core sets are boldfaced.

ICF, International Classification of Functioning, Disability and Health; NSCISC, National SCI Database in the United States; EMSCI, European Multicenter Study about Spinal Cord Injury; DRM-SCI, Dutch research program "Restoration of mobility in SCI rehabilitation: The Umbrella Project"; ASCIR, Australian Spinal Cord Injury Register; AIS, American Spinal Injury Association Impairment Scale as defined by the International Standards for Neurological Classification of SCI, Burchiel, spasticity assessment by Burchiel; CA, clinical assessment, not specified; CHART, The Craig Handicap Assessment and Reporting Technique; Diagn, diagnostic measures not specified; ECG, electrocardiogram; PSP, pressure sore prevalence; FIM, Functional Independence Measure; GRT, Grasp Release Test; HB, Handbike Use (Handbike Questionnaire); HDS, Hamilton Depression scale; ME, Maximal Exercise testing; NP, neurophysiologic measurement; PHQ, Patient Health Questionnaire (brief version); QIF, Quadriplegia Index of Functioning; SF-36, Short-Form Health Survey; SCIM II, Spinal Cord Injury Independence Measure version II; Spiro, Spirometry; SSL 12, Social Support List; UD, Urodynamics; VLT, Van Lieshout Test; UAL, Utrecht Activity Questionnaire (Utrechtse Activiteiten Lijst); WST, Wheelchair Skills test; 10MWT, 10-m walking test; 6MWT, 6-min walking test.

the concepts measured in four large longitudinal SCI studies to the ICF Core Sets for SCI, it became clear that none of these studies cover all categories of the Brief ICF Core Sets and that some aspects (e.g., b640 Sexual function) are not described in any of the studies. We realize that these studies do not intend to comprehensively study functioning in persons with SCI according to the ICF and are therefore not to blame for not assessing all aspects of functioning as described in the Brief ICF Core Sets for SCI. Nevertheless, important gaps were shown, indicating the need for comprehensive studies, including at least the items of the Brief ICF Core Sets for SCI. A challenge then is to find an appropriate balance of width (comprehensive), depth (providing sufficient detail and using validated measurement instruments), costs, and subject burden. A possible solution to this challenge is the application of a modular approach, which has been introduced in the Swiss Spinal Cord Injury Study, whose questionnaire will be composed of a main questionnaire in combination with random assignment to one of five different modules, together providing the desired comprehensive approach.[32] In addition, the possibility of nested and joint projects might be a solution to provide sufficient depth. In the Swiss Spinal Cord Injury Study, nested projects will be based on the main Swiss Spinal Cord Injury Study database and allow an efficient use of the available study data. For example, in-depth surveys can be conducted in smaller subsamples of the study population, such as in a specific age group or in persons with SCI who are currently employed.[32]

Because personal factors are not classified in the ICF yet, category specifications referring to demographic and additional personal characteristics, such as coping strategies and lifestyles, could not be included in the comparison and are not presented in the table. However, personal factors are an important consideration in patient care and research and are taken into account in the included data sets to some extent. The need to systematically capture personal factors has led to the development of a structure and definition of a domain set to capture personal factors.[33]

This study also shows that, besides the International Standards for Neurological and Functional Classification of Spinal Cord Injury,[29] no areas of functioning were measured using the same instrument in all studies. For example, the ICF category d455 Moving around is assessed using the Functional Independence Measure [30] and the Spinal Cord Independence Measure.[31] Although there might be a good rationale for choosing a specific measurement instrument (e.g., because of the use for reimbursement or lack of well-validated measurement instruments), the various measurement instruments used show a need for measurement standardization that would facilitate comparing results between studies. Knowledge of which measurement instruments used for which ICF categories may contribute to their future operationalization.

The International Spinal Cord Society has developed for SCI research the so-called international data sets. The purpose of these data sets is to standardize the collection and reporting of a minimal

amount of information necessary to evaluate and to compare the results of published studies.[10] The development of the data sets is rapidly expanding, not only covering the biomedical aspect of persons with SCI but also other aspects of functioning (like in the pain data set, where also the influence of pain on activities and participation is asked for). The comparison presented in this paper could also be used to inform the process followed by the International Spinal Cord Society when developing additional data sets.

This study informs experts working in the field of SCI on the focus of current research in longitudinal studies, which is a basis for our current understanding of the lived experience of persons living with SCI. Because the ICF Core Sets for SCI contain the necessary categories of functioning for persons with SCI, comparing these core sets with the data sets of longitudinal studies sheds light on areas of functioning that are not taken into account but are essential to understand the experience of persons with SCI.

Limitations

This investigation has limitations. First, only longitudinal studies with more than 200 persons with SCI were included, with the consequence that studies with fewer included persons that might have been relevant were excluded. We have chosen the current selection of studies because they represent larger and well-established studies within SCI research. Having shown that it is possible to use the ICF as a reference, the same could be done for smaller studies.[34] Second, the linking procedure always entails loss of information. For example, because personal factors are not classified yet, all category specifications referring to demographic and additional personal characteristics, such as coping strategies and lifestyle, could not be included in the comparison and are not presented in the matrix. Third, the matrix is presented at the second level of the ICF classification, which does not reflect the large variation in detail of the category specifications found in the data sets.

CONCLUSIONS

None of the studies used in our comparison included longitudinal studies that comprehensively cover functioning. Studies in SCI should at least cover the items of the Brief ICF Core Sets for SCI to capture the minimal amount of categories found to be important to describe functioning in SCI. Considering the wide variability of category specifications and measurement instruments used to measure functioning, the comparability of studies is difficult. There is the need to develop truly comprehensive longitudinal studies in SCI. The standardization of outcome parameters and measurement instruments in future studies is of major relevance to be able to compare study outcomes and should rely as much as possible on the category specifications recommended by relevant scientific bodies, including the International Spinal Cord Society.

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