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ORIGINAL ARTICLE

ICF Core Sets for individuals with spinal cord injury in the long-term context

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Study design: A formal decision-making and consensus process integrating evidence gathered from preparatory studies was followed.
Objectives: The objective of the study was to report on the results of the consensus process to develop the first version of a Comprehensive International Classification of Functioning, Disability and Health (ICF) Core Set, and a Brief ICF Core Set for individuals with spinal cord injury (SCI) in the long-term context.
Setting: The consensus conference took place in Switzerland. Preparatory studies were performed worldwide.
Methods: Preparatory studies included an expert survey, a systematic literature review, a qualitative study and empirical data collection involving people with SCI. Relevant ICF categories were identified in a formal consensus process by international experts from different backgrounds.
Results: The preparatory studies identified a set of 595 ICF categories at the second, third or fourth level. A total of 34 experts from 31 countries attended the consensus conference (12 physicians, 6 physical therapists, 5 occupational therapists, 6 nurses, 3 psychologists and 2 social workers). Altogether, 168 second-, third- or fourth-level categories were included in the Comprehensive ICF Core with 44 categories from body functions, 19 from body structures, 64 from activities and participation and 41 from environmental factors. The Brief Core Set included a total of 33 second-level categories with 9 on body functions, 4 on body structures, 11 on activities and participation and 9 on environmental factors.
Conclusion: A formal consensus process integrating evidence and expert opinion based on the ICF led to the definition of the ICF Core Sets for individuals with SCI in the long-term context. Further validation of this first version is needed.
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Keywords: spinal cord injury; ICF; ICF Core Set; rehabilitation

Introduction

For most of the affected people, a spinal cord injury (SCI) has long-term consequences. Following an extended period of hospitalization with acute care and early post-acute rehabilitation, community reintegration is the main goal of rehabilitation.[1] Successful community reintegration depends not only on a person's physical functioning, but also on many interrelated facilitators and barriers in the social and physical environment. Rehabilitation teams therefore need to consider aspects such as employment, mobility and transportation, family support and physical accessibility in the community when planning transition to the community.

Another challenge associated with the long-term care of people with SCI is the changing range of functional problems with increasing duration of injury. Studies report that the prevalence of pressure ulcers, autonomic dysreflexia, heterotopic ossification and need for help with activities of daily living increases per years after injury.[2]

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Therefore, long-term care of people with SCI requires an in-depth understanding of the broad range and interaction of these functional problems that people may experience. The International Classification of Functioning, Disability and Health (ICF)[3] provides a comprehensive and universally accepted framework to classify and describe functioning, disability and health in people with all kinds of diseases or conditions, including SCI. According to the ICF, the problems associated with a disease may involve Body Functions and Body Structures and the Activities and Participation in life situations. Health states and the development of disability are modified by contextual factors such as environmental and personal factors.[3] Additional information on the ICF model can be found on the 'Spinal Cord' website. The ICF is structured hierarchically. Categories are divided into chapters, which constitute the first level of precision. Categories on higher levels (for example, third or fourth level) are more detailed. To give an example, the third-level ICF category, *d5400 Putting on clothes,* is one element of the second-level category, *d540 Dressing*. The second-level category, *d540 Dressing,* is an element of the chapter *d5 Self-Care*. Finally, the chapter *d5 Self-Care* is part of the ICF component *d Activities and Participation*. Further details can found on the website World Health Organization (http://apps.who.int/classifications/icfbrowser/).

As the ICF can serve as the basis for a comprehensive and detailed understanding of the functioning and disability, it is essential in the first step to identify what aspects of functioning and disability in people with SCI should be defined. This process is consistent with the approach that has been followed in other health conditions. Selections of ICF categories relevant for people with a specific health condition, the so-called 'ICF Core Sets', have already been developed for a number of health conditions.[4] However, in SCI different contexts have to be taken into account.

As 'ICF Core Sets for Neurological Conditions in the Acute Context' were already developed[5] and are currently validated for SCI, the project aimed at developing ICF Core Sets for SCI for the early post-acute context and for the long-term context.[6] The early post-acute context covers the first comprehensive rehabilitation after the acute SCI. The long-term situation follows the early post-acute situation. This definition was regarded as being applicable throughout the world, irrespective of the different health systems.

The development process of the ICF Core Sets for SCI is divided in a preparatory phase in which information was gathered from different studies and from a final consensus conference.[6] The objective of this paper is to report the results of the consensus process, integrating evidence from preparatory studies to develop the Comprehensive ICF Core Set for SCI in the long-term context and the Brief ICF Core Set for SCI in the long-term context.

Methods

A formal decision-making and consensus process integrating evidence gathered from preparatory studies and expert opinion was followed.

Preparatory studies

The conference was based on the data available as on 1 October 2007. The preparatory studies included an empiric data collection applying the second-level ICF categories in 387 people with chronic SCI from 14 countries, an Internet-based expert survey including 144 SCI health professionals worldwide, a systematic literature review on outcomes used in 281 SCI clinical trials and a qualitative study including 23 focus groups with people with SCI from six countries. On the basis of these preparatory studies, a pre-selection of ICF categories was performed using the modified scree test.[7] The ICF categories most frequently named in all four preparatory studies made up the starting point of the decision-making and consensus process. Details of the preparatory studies are described in the reference publications.[8–11]

Recruitment of conference participants

Health professionals who have expressed their interest in the project in advance as well as people who were suggested by the project steering committee built up a pool of potential participants. A total of 154 people (58 physicians, 24 physical therapists, 27 occupational therapists, 23 nurses, 12 psychologists and 10 social workers from 38 countries) made up this pool. Participants were selected randomly after consideration of the profession and the country of origin to assure a balanced representation of all important health professions and all world regions.

Training and information exchange

During the conference, the first meeting consisted of a 3-h training, in which all participants were familiarized with the ICF framework and classification.[4] In a series of successive meetings described elsewhere, the decision process of the ICF Core Sets for SCI in the early post-acute context took place,[12] followed by the presentation of the evidence from the preparatory studies of the ICF Core Sets for the long-term context. Thus, the participants were very aware of the decision process to be followed for the ICF Core Sets for SCI in the long-term context. Participants received the summary sheets containing both the pre-selected ICF categories and the results of the preparatory studies during this presentation (see Table 1).

Iterative decision-making process

The ICF Core Set categories were identified in an iterative decision-making process with discussions and voting in working groups and plenary sessions. The process was guided by a member of the ICF Research Branch. In the process, ICF categories that were either clearly relevant or irrelevant according to preset decision rules were excluded from further discussion. The focusing on the remaining controversial categories was thereby facilitated. The decision-making process consisted of two major activities.

In the first activity, the participants were asked to select ICF categories to be included in the Comprehensive ICF Core Set, that is, a list of ICF categories long enough to describe the prototypical spectrum of limitations in the functioning and health of individuals with SCI in the long-term context,

Table 1 Fraction of the list including the results of the preparatory studies for each ICF category as presented to the participants of the consensus conference

ICF code			ICF title	Empir. study	Expert survey	Review	Focus groups
Second level	Third level	Fourth level		n = 387 %	n = 144 %	n = 281 %	n = 23 %
+b130[a]			*Energy and drive functions*	14[b]	8[c]	5[d]	x[e]
b130			Energy and drive functions	14		1	x
	b1300		Energy level		1	3	x
	b1301		Motivation		3	1	x
	b1302		Appetite		3	1	
	b1303		Craving		2		
+b134[a]			*Sleep functions*	24	7	7	x
b134			Sleep functions	24	7	5	x
	b1340		Amount of sleep			1	x
	b1341		Onset of sleep			1	
	b1342		Maintenance of sleep			2	x
	b1343		Quality of sleep			1	

Abbreviations: Empir., empirical; ICF, International Classification of Functioning, Disability and Health.
[a]Combines results from second and higher-level categories.
[b]In 14% of 387 people, this problem was reported.
[c]Of 144 experts, 8% reported this problem.
[d]In 5% of 281 empirical studies, this problem was reported.
[e]This problem was identified by at least one of the focus groups.

but at the same time short enough to be practical in comprehensive, multidisciplinary assessments.

In the second activity, the participants were requested to select the Brief ICF Core Set from the list of ICF categories included in the Comprehensive ICF Core Set by means of a two-round ranking exercise and a final vote. The Brief ICF Core Set is a list of ICF categories long enough to describe the prototypical spectrum of limitations in the functioning and health of people with SCI in the long-term context, but at the same time short enough to be practical in clinical studies.

The data resulting from the voting and ranking processes were continuously entered in MS Excel 2003 throughout the conference.

Results

Preparatory studies

In the empirical study, 258 second-level categories were identified. The qualitative study, the expert survey and the systematic review revealed 344, 392 and 424 second-, third- and fourth-level categories, respectively. In total, a list of 262 different second-level categories resulted from the preparatory studies. Using modified scree test, the 198 most frequently reported categories were selected.[7] The list of ICF categories finally presented at the conference to the participants included 595 ICF categories at the second, third or fourth level (164 on *Body Functions*, 89 on *Body Structures*, 212 on *Activities and Participation* and 130 on *Environmental Factors*).

ICF consensus conference

The consensus process took place from 15 November to 18 November 2007 at the Swiss Paraplegic Research, Nottwil, Switzerland. Although 33 health professionals participated in the development of the ICF Core Sets for the early post-acute context, an additional health professional was recruited during the process to develop the ICF Core Sets for the long-term context. In total, 12 physicians with various sub-specializations, 6 physical therapists, 5 occupational therapists, 6 nurses, 3 psychologists and 2 social workers from 31 different countries attended the consensus process for SCI in the long-term context.

The decision-making process involved five working groups with 6–7 health professionals in each. The process was facilitated by the moderator of the plenary sessions and the five working-group leaders.

Comprehensive ICF Core Set

Tables 2–5 show the ICF categories included in the Comprehensive ICF Core Set. The number of second-, third- and fourth-level categories in the Comprehensive ICF Core Set is 168, with 116 categories on the second level, 41 categories on the third level and 11 categories on the fourth level. The 52 third- and fourth-level categories are a further specification of 11 categories on the second level. The 168 categories of the Comprehensive ICF Core Set are made up of 44 (26.2%) categories from the component *Body Functions*, 19 (11.3%) from the component *Body Structures*, 64 (38.1%) from the component *Activities and Participation* and 41 (24.4%) from the component *Environmental Factors*.

All chapters of the component *Body Functions* and *Activities and Participation* are represented in the Comprehensive ICF Core Set. From the component *Body Structures*, chapter 2 *The eye, ear and related structures*, chapter 3 *Structures involved in voice and speech* and chapter 5 *Structures related to the digestive, metabolic and endocrine systems* are not represented in the Comprehensive ICF Core Set. From the *Environmental Factors*, all chapters are represented in the Comprehensive ICF Core

Table 2 ICF categories of the component body functions included in the Comprehensive ICF Core Set for spinal cord injury in the long-term context

ICF code			*Title*
Second level	*Third level*	*Fourth level*	
b126			Temperament and personality functions
b130			Energy and drive functions
b134			Sleep functions
b152			Emotional functions
b260			Proprioceptive function
b265			Touch function
b270			Sensory functions related to temperature and other stimuli
		b28010	Pain in head and neck
		b28011	Pain in chest
		b28012	Pain in stomach or abdomen
		b28013	Pain in back
		b28014	Pain in upper limb
		b28015	Pain in lower limb
		b28016	Pain in joints
	b2803		Radiating pain in a dermatome
	b2804		Radiating pain in a segment or region
b420			Blood pressure functions
b440			Respiration functions
b445			Respiratory muscle functions
b455			Exercise tolerance functions
b525			Defecation functions
b530			Weight maintenance functions
b550			Thermoregulatory functions
b610			Urinary excretory functions
	b6200		Urination
	b6201		Frequency of urination
	b6202		Urinary continence
b640			Sexual functions
b660			Procreation functions
b670			Sensations associated with genital and reproductive functions
b710			Mobility of joint functions
b715			Stability of joint functions
b720			Mobility of bone functions
b730			Muscle power functions
b735			Muscle tone functions
b740			Muscle endurance functions
b750			Motor reflex functions
b760			Control of voluntary movement functions
b770			Gait pattern functions
b780			Sensations related to muscles and movement functions
b810			Protective functions of the skin
b820			Repair functions of the skin
b830			Other functions of the skin
b840			Sensation related to the skin

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

Set except chapter 2 *Natural environment and human-made changes of environment*.

Brief ICF core set

Table 6 shows the second-level ICF categories ordered by rank that were selected for the Brief ICF Core Set. The Brief ICF Core Set includes a total of 33 second-level categories that represents 28.4% of all second-level categories that were selected for the Comprehensive Core Set. In total, nine categories were chosen from the component *Body Functions* (representing 28.1% of selected second-level categories in the Comprehensive Core Set), four from *Body Structures* (representing 100% of selected second-level categories in the Comprehensive Core Set), 11 from *Activities and Participation* (representing 28.2% of selected second level-categories in the Comprehensive Core Set) and nine from *Environmental Factors* (representing 22.0% of selected second-level categories in the Comprehensive Core Set).

Table 3 ICF categories of the component body structures included in the Comprehensive ICF Core Set for spinal cord injury in the long-term context

ICF code			*Title*
Second level	*Third level*	*Fourth level*	
		s12000	Cervical spinal cord
		s12001	Thoracic spinal cord
		s12002	Lumbosacral spinal cord
		s12003	Cauda equina
	s1201		Spinal nerves
s430			Structure of respiratory system
s610			Structure of urinary system
s720			Structure of shoulder region
	s7300		Structure of upper arm
	s7301		Structure of forearm
	s7302		Structure of hand
	s7500		Structure of thigh
	s7501		Structure of lower leg

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

Discussion

The formal consensus process integrating evidence from preparatory studies and expert knowledge at the ICF Core Set conference for SCI led to the definition of a Comprehensive ICF Core Set for SCI in the long-term context for multidisciplinary assessment and a Brief ICF Core Set for SCI in the long-term context for clinical studies.

The 168 categories (116 second-level categories) that were included in the Comprehensive Core Set reflect the numerous functional changes that occur in people with SCI in the long-term context. As the Core Set should be applied for all levels of spinal cord lesions, a wide range of functional problems was included in the Comprehensive Core Set. Despite keeping in mind that the Comprehensive ICF Core Set should include as many categories as necessary to comprehensively describe functioning in patients with SCI, but as few as possible to be practical, the participants frequently felt that a specific description of a problem is necessary. Thus, they included many third and even fourth-level categories that provide specifications of second-level categories, such as *b280 Pain*, *s120 Spinal cord and related structures* or *d445 Hand and arm use*.

With respect to the four main components of the ICF, the following issues were raised:

Table 4 ICF categories of the component activities and participation included in the Comprehensive ICF Core Set for spinal cord injury in the long-term context

ICF code		*Title*
Second level	*Third level*	
d155		Acquiring skills
d230		Carrying out daily routine
d240		Handling stress and other psychological demands
d345		Writing messages
d360		Using communication devices and techniques
	d4100	Lying down
	d4102	Kneeling
	d4103	Sitting
	d4104	Standing
	d4105	Bending
	d4106	Shifting the body's center of gravity
d415		Maintaining a body position
d420		Transferring oneself
d430		Lifting and carrying objects
	d4400	Picking up
	d4401	Grasping
	d4402	Manipulating
	d4403	Releasing
	d4450	Pulling
	d4451	Pushing
	d4452	Reaching
	d4453	Turning or twisting the hands or arms
	d4454	Throwing
	d4500	Walking short distances
	d4501	Walking long distances
	d4502	Walking on different surfaces
	d4503	Walking around obstacles
d455		Moving around
	d4600	Moving around within the home
	d4601	Moving around within buildings other than home
	d4602	Moving around outside the home and other buildings
d465		Moving around using equipment
d470		Using transportation
d475		Driving
d510		Washing oneself
d520		Caring for body parts
	d5300	Regulating urination
	d5301	Regulating defecation
	d5302	Menstrual care
d540		Dressing
d550		Eating
d560		Drinking
d570		Looking after one's health
d610		Acquiring a place to live
d620		Acquisition of goods and services
d630		Preparing meals
d640		Doing housework
d650		Caring for household objects
d660		Assisting others
d720		Complex interpersonal interactions
d750		Informal social relationships
d760		Family relationships
d770		Intimate relationships
d810		Informal education
d820		School education
d825		Vocational training
d830		Higher education
d840		Apprenticeship (work preparation)
d845		Acquiring, keeping and terminating a job
d850		Remunerative employment
d870		Economic self-sufficiency
d910		Community life
d920		Recreation and leisure
d940		Human rights

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

Table 5 ICF categories of the component environmental factors included in the Comprehensive ICF Core Set for spinal cord injury in the long-term context

ICF code	*Title*
Second level	
e110	Products or substances for personal consumption
e115	Products and technology for personal use in daily living
e120	Products and technology for personal indoor and outdoor mobility and transportation
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
e315	Extended family
e320	Friends
e325	Acquaintances, peers, colleagues, neighbors and community members
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
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

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

Approximately one-third of the second-level ICF categories of the component *Body functions* were included in the first vote with a high agreement among the participants. These categories include functions typically problematic in people with SCI in the long-term context, such as procreation functions and weight maintenance functions.[13,14]

The inclusion of the category *b164 Higher level cognitive functions* was discussed and found to be related primarily to co-morbid traumatic brain injury, which was not the focus of the SCI Core Sets.

Table 6 ICF categories included in the Brief ICF Core Set for spinal cord injury in the long-term context

ICF component	*Rank*	*ICF code*	*Title*
Body functions	1	b730	Muscle power functions
	2	b620	Urination functions
	3	b280	Sensation of pain
	4	b525	Defecation functions
	5	b640	Sexual functions
	6	b810	Protective functions of the skin
	7	b735	Muscle tone functions
	8	b710	Mobility of joint functions
	9	b152	Emotional functions
Body structures	1	s120	Spinal cord and related structures
	2	s610	Structure of urinary system
	3	s810	Structure of areas of skin
	4	s430	Structure of respiratory system
Activities and participation	1	d530	Toileting
	2	d420	Transferring oneself
	3	d230	Carrying out daily routine
	4	d465	Moving around using equipment
	5	d410	Changing basic body position
	6	d445	Hand and arm use
	7	d470	Using transportation
	8	d455	Moving around
	9	d520	Caring for body parts
	10	d550	Eating
	11	d240	Handling stress and other psychological demands
Environmental factors	1	e310	Immediate family
	2	e120	Products and technology for personal indoor and outdoor mobility and transportation
	3	e115	Products and technology for personal use in daily living
	4	e150	Design, construction and building products and technology of buildings for public use
	5	e155	Design, construction and building products and technology of buildings for private use
	6	e110	Products or substances for personal consumption
	7	e355	Health professionals
	8	e340	Personal care providers and personal assistants
	9	e580	Health services, systems and policies

Abbreviation: ICF, International Classification of Functioning, Disability and Health.

It was not clear for the participants whether problems with depression and anxiety are covered by *b126 Temperament and personality functions* or *b152 Emotional functions*. Finally, they agreed that these important aspects may be covered by *b152 Emotional functions* and should be included in the Core Set.[15]

In addition, the inclusion of *b180 Experience of self and time functions* was discussed controversially. The participants who recognized that this category includes problems related to alteration of the body image of a person stressed its importance. However, the majority of participants voted for an exclusion of this category.

b310 Voice functions was excluded after discussion; 41% of the participants who wanted to include the category pointed out that persons with high spinal cord lesions frequently have problems with voice functions in the long-term phase.[16]

Some participants wanted to include *b535 Sensations associated with the digestive system* to cover abdominal distension that is frequent in persons with SCI.[17] However, in the final vote the majority of the participants voted against an inclusion of this category.

Regarding neuromusculoskeletal functions, all candidate second-level categories were included except two categories addressing involuntary movement functions.

The selection of all four candidate ICF categories related to functions of skin underlines the importance of impaired skin function in patients with SCI in the long-term context.[18]

In the selection process of *Body Structures,* several categories were included in the first voting round with a high agreement. Besides the structures of the spinal cord and urinary system, categories were selected that include trunk, upper extremities and shoulder region that address problems typically found in persons with SCI in the long-term situation.[19] In addition, the high prevalence of pressure sores in the chronic phase was taken into consideration by selecting four third-level categories that refer to structural alterations of specific areas of the skin.[18] The structures of the sympathetic and parasympathetic nervous system were finally excluded as the functional problems associated with these systems seemed to be more important than the structural impairments.

A broad range of categories of the ICF component *Activities and Participation* was selected by the participants, reflecting the diversity of problems associated with SCI. The inclusion of many third-level categories of chapter *4 Mobility* highlights the need for a detailed description of mobility problems by health professionals.

The discussion of the inclusion of *d480, Riding animals for transportation,* clearly showed cultural differences regarding the relevance of single ICF categories. Although the participants from India and Nepal pointed out that this category represents an important aspect of mobility in their countries, the majority finally decided not to include this ICF category in the Core Set.

It stands out that all candidate categories addressing education as well as work and employment were included in the Core Set. This decision reflects the essential role employment has in long-term adaptation to the injury and participation within a community. It is supported by the results of several studies reporting relatively low employment rates in people with SCI and identifying a number of facilitators and barriers that are associated with returning to work.[20]

A large number of *Environmental Factors* was included in the Comprehensive ICF Core Set, which is consistent with studies reporting on the importance of environmental factors for the adjustment of people with SCI.[21] Systems, services and policies available for people with SCI within their country were regarded as major facilitators or barriers by the participants. Thus, most of the ICF categories of the component *Environmental factors* included in the Comprehensive ICF Core Set pertain to this chapter 5.

Furthermore, products and technology for different uses, including mobility, daily living or employment, were regarded as important. Consequently, all candidate categories of chapter 1 *Products and Technology*, except products and technology for the practice of religion and spirituality, were included in the Comprehensive ICF Core Set. The remaining categories that were included in the Comprehensive ICF Core Set address the support specifically provided by the family, friends and care providers as well as their attitudes.

The Brief ICF Core Set includes 33 second-level categories that were selected out of the second-level categories of the Comprehensive ICF Core Set, using a two-step ranking procedure and a final cutoff decision. The reduction in the number of categories, however, brought about the loss of presentation of several chapters. Depending on the component, up to five chapters per component are not represented in the Brief ICF Core Set.

The component *Activities and Participation* is represented by a considerable number of categories that predominantly pertain to the chapters *4 Mobility* and *5 Self-Care*. In contrast to the ICF Core Set for SCI in the early post-acute context, the category *d465 Moving around using equipment*, which refers to wheelchair driving, is included.[12] It is also interesting that the Brief ICF Core Set for SCI in the long-term context has nearly twice the number of categories assigned to the component environmental factors compared with the Core Set for the early post-acute context. Again, this emphasizes the importance that the environment gains when people are being prepared to go back to the community life.

Validation studies will show whether specific subsets of people, for example, those with paraplegia versus tetraplegia or complete versus incomplete lesions will differ. Besides validation, strategies for the implementation of the ICF Core Sets for SCI in clinical practice are currently being developed. Using case studies of individuals with SCI, the application of the ICF Core Sets for SCI in rehabilitation practice is presented on an Internet website (http://www.ICF-casestudies.org). In addition, a handbook for users will be developed. Finally, as the ICF Core Sets for SCI indicate which areas of functioning should be measured but not how they should be measured, an operationalization of the ICF categories included in the ICF Core Sets for SCI would be useful. The International SCI Data Sets may complement the ICF Core Sets for SCI on this point because they provide specific information about how the relevant information could be assessed.[22]

In conclusion, a formal consensus process integrating evidence and expert opinion based on the ICF framework and classification led to the definition of ICF Core Sets for SCI in the long-term context. Both the Comprehensive Core Set for multi-disciplinary, comprehensive assessment and the Brief Core Set for research and clinical practice are preliminary and need to be tested and validated in the coming years with the ultimate goal of finally defining a universal, valid and accepted tool for clinical practice, clinical studies and health reporting.

Postscript

Professor Haim Ring (Julio Ring), our friend and colleague and author of this paper died on 15 September 2008. Haim always supported and motivated the process of developing ICF Core Sets. He built bridges among disciplines and health professions. He also brought world regions and countries to work together. We will always be endlessly thankful of having the opportunity of being close to this inspiring spirit.

Conflict of interest

The authors declare no conflict of interest.

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Supplementary Information accompanies the paper on the Spinal Cord website (http://www.nature.com/sc)