

ORIGINAL ARTICLE

Identification of the most common problems in functioning of individuals with spinal cord injury using the International Classification of Functioning, Disability and Health

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Study design: Cross-sectional, multicenter study.

Objectives: To identify the most common problems of individuals with spinal cord injury (SCI) in the early post-acute and the long-term context, respectively, using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference.

Setting: International.

Methods: The functional problems of individuals with SCI were recorded using the 264 ICF categories on the second level of the classification. Prevalence of impairment was reported along with their 95% confidence intervals. Data were stratified by context.

Results: Sixteen study centers in 14 countries collected data of 489 individuals with SCI in the early post-acute context and 559 in the long-term context, respectively. Impairments in thirteen ICF categories assigned to *Body functions* and *Body structures* were more frequently reported in the long-term context, whereas limitations/restrictions in 34 ICF categories assigned to *Activities and Participation* were more frequently found in the early post-acute context. Eleven ICF categories from the component *Environmental Factors* were more frequently regarded as barriers, facilitators or both by individuals with SCI in the early post-acute context as compared with individuals with SCI in the long-term context. Only two environmental factors were more relevant for people with SCI in the long-term context than in the early post-acute context.

Conclusion: The study identified a large variety of functional problems reflecting the complexity of SCI and indicated differences between the two contexts. The ICF has potential to provide a comprehensive framework for the description of functional health in individuals with SCI worldwide.

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Introduction

The unexpected occurrence of a spinal cord injury (SCI) may dramatically change the lives of injured people. Adaptation to the SCI requires coping with a wide range of health-

related problems. These problems may, apart from the paralysis, concern various body functions, such as bladder, bowel and sexual function, autonomic function and pain. Functional problems can lead to limitations in activities and participation restrictions typically related to mobility, self-care activities, difficulties in regaining work, maintaining social relationships, participating in leisure activities and being active members of the community.^{1,2} The participation restrictions are highly dependent on environmental factors, such as mobility equipment and transportation.³

The prevalence of many problems associated with SCI may vary within the phase of treatment and rehabilitation and

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the time after injury. It is reported that many newly injured people who met the diagnostic criteria for depression remit within 3 months of onset⁴ as is also the case with the orthostatic hypotension that is particularly evident in the early phase.⁵ On the other hand, odds ratios for pressure ulcers, autonomic dysreflexia, heterotopic ossification and need for help with activities of daily living increase over time after SCI.⁶

Numerous health status measures are used to assess the functional limitations associated with SCI. However, most of these measures cover only selected aspects of the whole SCI health experience and vary considerably regarding their content and psychometric characteristics.⁷ This degree of variation presents a number of disadvantages to workers who wish to compare or transfer data across successive phases of the continuum of care (emergency, medical, rehabilitative, outpatient and community clinical care). In addition, for comparability of outcome data across conditions and interventions, a common framework is needed.

With the approval of the International Classification of Functioning, Disability and Health (ICF)⁸ by the World Health Assembly, there is now a comprehensive and universally accepted framework to classify and describe the whole health experience, including environmental factors. The ICF is based on the integrative model of functioning and comprises four components: *Body Functions*, *Body Structures*, *Activities and Participation*, and *Environmental Factors*. Within these components, all items in the classification are arranged hierarchically. Categories are divided into chapters, which constitute the first level of precision. Categories on higher levels (for example, second, third or fourth level) are more detailed.

The objective of this cross-sectional study was to identify and describe the prevalence of problems in functioning experienced by individuals with SCI in the early post-acute and long-term context using the ICF.

Materials and methods

Study design

This cross-sectional, multicenter study was carried out within the international project 'Development of ICF Core Sets for Spinal Cord Injury' and was one of the four preparatory studies conducted in order to gather information about the relevance of functional problems in people with SCI.⁹ A large proportion of the data (71.4%) reported in this paper was used as an empirical basis for SCI experts to decide on the 'ICF Core Sets for Spinal Cord Injury'.^{10,11} Sixteen study centers in 14 countries participated in this study.

Individuals were included if they had sustained an SCI with an acute onset, if they were either in the early post-acute or in the long-term context, if they were at least 18 years old, if the purpose and reason of the study was understood and if an informed consent was signed. Individuals with significant traumatic brain injury or diagnosed mental disorders before SCI were excluded. Acute onset was defined as injury or disease with the development of SCI

within 14 days. The early post-acute context begins with active rehabilitation and ends with the completion of the first comprehensive rehabilitation after the acute SCI. The long-term context follows the early post-acute context. This working definition is based on a worldwide consensus of researchers involved in the data collection and was approved by the steering committee of the project.

The study was approved by the ethics committees in charge of the respective study centers involved and was carried out in accordance with the Declaration of Helsinki.

Measures and data collection

The participants' functional problems were recorded using a Case Record Form consisting of all 264 ICF categories on the second level of the classification. The presence of the problem was denoted for each category of the components *Body Functions*, *Body Structures*, and *Activities and Participation* using the qualifiers 0 for 'no impairment/limitation' and 1 for 'impairment/limitation'. The categories of the component *Environmental Factors* were graded with 0 for 'no facilitator and no barrier', +1 for 'facilitator but no barrier', -1 for 'barrier but no facilitator', and ± 1 for 'barrier and facilitator'. In addition, the qualifier '8' was used if the available information was not sufficient and '9' if the category was not applicable. Problems owing to a comorbidity not associated with the SCI were coded as described above and assigned as comorbidity (c).

The information regarding the ICF categories was collected by registered health professionals working in the clinical environment. The majority of information was obtained from individual interviews with persons with SCI—frequently performed with computer assistance. Clinical and demographic characteristics were retrieved from medical records. In addition, the individuals were asked to provide global ratings of their general health and well-being. The health professionals entered collected data in an electronic database.

Quality assurance

The health professionals were trained in a 2-day workshop in the principles and application of the ICF, in performing individual interviews and electronic data entry. Accuracy of data collection was assured by automatic error checks included in the database that helped to identify missing or implausible data without undue delay. The international project coordinator provided monitoring of the collected data.

Data analysis

Sample characteristics were analyzed using descriptive statistics. For the ICF categories assigned to the components *Body Functions*, *Body Structures*, and *Activities and Participation*, absolute frequencies and relative frequencies (prevalence) of impairment/limitation in the study sample are reported along with their 95% confidence intervals. For ICF categories representing *Environmental Factors*, absolute frequencies and relative frequencies (prevalence) of people who regarded a specific category as either barrier or facilitator or both are

reported. The sample size for the calculation of the prevalence differs for each ICF category, as only participants with SCI for whom health professionals could judge whether a problem is present or not were considered. To clarify, missing values, as well as the response options 'not applicable' 'not definable' and 'comorbidity' are not taken into account.

Results

The data were collected from June 2006 to January 2008 by the trained health professionals in the respective study centers. Most of the interviews were performed by physicians or physical therapists. In total, 1052 people with SCI participated in the study. Four individuals were excluded from the analysis because they did not fulfill the inclusion criteria.

The majority of data (30.2%) came from countries of the South-East Asian world region (Thailand, India, Vietnam and Malaysia). The European region (Denmark, Germany and Switzerland), Western Pacific region (New Zealand and Australia), Eastern Mediterranean region (Israel) and region of the Americas (USA, Canada and Brazil) were evenly represented with 14.1–19.2% of the data, whereas the African region (South Africa) contributed to 6.4% of the data (see Table 1).

Table 2 shows the sample characteristics. People with SCI in the early post-acute context significantly differed from the people in the long-term context regarding age, SCI severity, setting, time since SCI onset, American Spinal Injury Association (ASIA) Impairment Scale (AIS) grading, non-traumatic etiology and self-rating of general health and functioning. Tables 3–5 show the ICF categories in which problems were documented in >20% of the persons with SCI in the early post-acute or in the long-term context. Table 6 shows the ICF categories of the component *Environmental Factors* considered to be a barrier, a facilitator or both in >20% of the persons with SCI in the early post-acute or in the long-term context.

For the component *Body Functions*, 35 of the 79 ICF categories were reported with a frequency over 20% in both

Table 1 Number of observations stratified by country

Country	Early post-acute context	Long-term context
Australia	43	37
Brazil	6	36
Canada	40	40
Denmark	37	41
Germany	7	11
India	40	40
Israel	82	74
Malaysia	39	39
New Zealand	40	40
South Africa	26	41
Switzerland	13	39
Thailand	40	40
USA	40	39
Vietnam	36	42
Total	489	559

the early post-acute and the long-term context. The ICF categories *b126 Temperament and personality functions* and *b130 Energy and drive functions* had a frequency over 20% only in the early post-acute context. The ICF category *b126 Temperament and personality functions* was significantly more frequent in the early post-acute context, whereas problems in 11 ICF categories such as *b820 Repair functions of the skin* were significantly more common in the long-term context. The most common categories for both situations were *b730*

Table 2 Sample characteristics

	Early post-acute context (n = 489)	Long-term context (n = 559)
Age ^a in years	39.7 (18; 83.5)	41.4 (18.2; 80.5)
Gender		
Female	23.1 (19.5; 27)	21.6 (18.4; 25.3)
Years of education	12.0 (0.0; 24.0)	12.0 (0.0; 36.0)
SCI level		
Paraplegia	50.5 (46.1; 55)	56.9 (52.7; 61)
Tetraplegia	49.5 (45; 53.9)	43.1 (39; 47.3)
SCI severity		
Complete ^a	42.0 (37.7; 46.5)	52.1 (47.8; 56.3)
Incomplete ^a	50.9 (46.5; 55.4)	36.2 (32.2; 40.3)
Unknown	7.1 (5.1; 9.7)	11.7 (9.3; 14.8)
AIS		
A ^a	41.5 (37.2; 45.9)	50.4 (46.3; 54.6)
B	10.6 (8.2; 13.7)	11.8 (9.4; 14.7)
C ^a	20.0 (16.7; 23.8)	12.5 (10; 15.5)
D ^a	20.0 (16.7; 23.8)	10.7 (8.4; 13.6)
Unknown ^a	7.8 (5.7; 10.5)	14.5 (11.8; 17.7)
Time since the onset of SCI in months ^b	3.10 (0.1; 41.2)	85.90 (1.1; 722.3)
Setting		
Outpatient ^a	6.2 (4.4; 8.8)	69.5 (65.4; 73.2)
In-patient ^a	92.5 (89.8; 94.5)	30.3 (26.6; 34.4)
Day clinic	1.2 (0.6; 2.7)	0.2 (0; 1.1)
Etiology		
Sports and leisure activities	8.4 (6.3; 11.2)	6.6 (4.8; 9.0)
Assaults	6.3 (4.4; 8.8)	7.1 (5.2; 9.6)
Transport activities	37.3 (33.1; 41.7)	46 (41.8; 50.2)
Falls	20.8 (17.4; 24.7)	21.5 (18.2; 25.2)
Other traumatic causes	11.3 (8.7; 14.4)	9.9 (7.7; 12.7)
Non-traumatic causes ^a	14.8 (11.9; 18.2)	8 (6; 10.7)
Unknown	1 (0.4; 2.4)	0.6 (0.2; 1.6)
Self-rating general health ^{c,d}	4 (0.0; 10.0)	3 (0.0; 10.0)
Self-rating functioning ^{b,c}	6 (0.0; 10.0)	5 (0.0; 10.0)

Abbreviations: AIS, American Spinal Injury Association (ASIA) Impairment Scale; SCI, spinal cord injury.

Median and minimum/maximum are given for numerical variables; percentage and 95% confidence intervals are given for nominal variables.

^aSignificant difference between early post-acute and long-term group ($P < 0.05$, Wilcoxon test or confidence interval).

^bSignificant difference between early post-acute and long-term group ($P < 0.001$, Wilcoxon test).

^cSelf-rating scales range from 0 = no problem with functioning/excellent health to 10 = complete problem with functioning/poor health.

^dSignificant difference between early post-acute and long-term group ($P < 0.01$, Wilcoxon test).

Table 3 Prevalence (95% CI) of impairment in the ICF categories of the component 'body functions'

ICF category		Early post-acute context (n = 489)		Long-term context (n = 559)	
Code	Title	n	% (95% CI)	n	% (95% CI)
<i>Chapter 1: Mental functions</i>					
b126 ^a	Temperament and personality functions	111	23.4 (19.8; 27.4)	85	16.1 (13.2; 19.4)
b130	Energy and drive functions	100	21.6 (18.1; 25.6)	93	17.6 (14.6; 21.1)
b134	Sleep functions	141	30.8 (26.7; 35.2)	139	27.9 (24.2; 32.0)
<i>Chapter 2: Sensory functions and pain</i>					
b260	Proprioceptive function	361	75.1 (71.0; 78.7)	413	77.2 (73.5; 80.6)
b265	Touch function	401	83.4 (79.8; 86.4)	448	83.6 (80.2; 86.5)
b270	Sensory functions related to temperature and other stimuli	414	86.1 (82.7; 88.9)	469	87.7 (84.6; 90.2)
b280	Sensation of pain	417	86.7 (83.4; 89.4)	468	87.3 (84.2; 89.9)
<i>Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory systems</i>					
b420	Blood pressure functions	98	22.3 (18.7; 26.4)	113	23.1 (19.5; 27.0)
b445	Respiratory muscle functions	175	37.0 (32.8; 41.4)	225	42.7 (38.5; 47.0)
b450	Additional respiratory functions	171	36.0 (31.8; 40.4)	216	41.0 (36.9; 45.2)
b455	Exercise tolerance functions	183	44.4 (39.7; 49.2)	225	44.0 (39.8; 48.4)
<i>Chapter 5: Functions of the digestive, metabolic and endocrine systems</i>					
b525	Defecation functions	407	84.8 (81.3; 87.7)	451	84.9 (81.6; 87.7)
b530	Weight maintenance functions	100	22.9 (19.2; 27.0)	150	29.2 (25.5; 33.3)
b535 ^a	Sensations associated with the digestive system	125	26.8 (23.0; 31.0)	182	35.1 (31.1; 39.3)
b550 ^a	Thermoregulatory functions	182	38.0 (33.8; 42.4)	253	47.5 (43.3; 51.7)
<i>Chapter 6: Genitourinary and reproductive functions</i>					
b620	Urination functions	411	85.6 (82.2; 88.5)	484	90.3 (87.5; 92.5)
b630	Sensations associated with urinary functions	349	72.6 (68.4; 76.4)	427	79.7 (76.1; 82.9)
b640 ^a	Sexual functions	302	83.2 (79.0; 86.7)	442	89.7 (86.7; 92.0)
b650	Menstruation functions	26	35.6 (25.6; 47.1)	25	26.0 (18.3; 35.6)
b660	Procreation functions	30	50.0 (37.7; 62.3)	105	64.8 (57.2; 71.7)
b670	Sensations associated with genital and reproductive functions	301	81.8 (77.5; 85.4)	415	86.8 (83.5; 89.6)
<i>Chapter 7: Neuromusculoskeletal and movement-related functions</i>					
b710	Mobility of joint functions	268	59.3 (54.7; 63.7)	348	66.5 (62.4; 70.4)
b715	Stability of joint functions	245	53.5 (48.9; 58.0)	274	52.5 (48.2; 56.7)
b720	Mobility of bone functions	230	49.6 (45.0; 54.1)	263	49.9 (45.7; 54.2)
b730	Muscle power functions	471	97.9 (96.2; 98.9)	530	99.1 (97.8; 99.6)
b735 ^a	Muscle tone functions	414	86.1 (82.7; 88.9)	499	93.4 (91.0; 95.2)
b740	Muscle endurance functions	450	94.1 (91.7; 95.9)	498	93.4 (91.0; 95.2)
b750 ^a	Motor reflex functions	369	77.5 (73.6; 81.0)	486	91.2 (88.5; 93.3)
b755 ^a	Involuntary movement reaction functions	342	71.7 (67.5; 75.6)	459	86.3 (83.1; 88.9)
b760 ^a	Control of voluntary movement functions	367	76.5 (72.5; 80.0)	458	85.6 (82.4; 88.3)
b765 ^a	Involuntary movement functions	333	70.1 (65.8; 74.0)	434	81.3 (77.7; 84.4)
b770	Gait pattern functions	420	97.2 (95.2; 98.4)	429	97.9 (96.1; 98.9)
b780	Sensations related to muscles and movement functions	394	82.1 (78.4; 85.3)	468	87.3 (84.2; 89.9)
<i>Chapter 8: Functions of the skin and related structures</i>					
b810	Protective functions of the skin	166	35.1 (30.9; 39.5)	223	42.0 (37.9; 46.2)
b820 ^a	Repair functions of the skin	109	23.1 (19.6; 27.2)	203	38.6 (34.5; 42.8)
b830 ^a	Other functions of the skin	131	27.6 (23.8; 31.8)	210	39.7 (35.6; 43.9)
b840 ^a	Sensation related to the skin	301	62.8 (58.4; 67.0)	394	73.8 (69.9; 77.3)

Abbreviations: CI, confidence interval; ICF, International Classification of Functioning, Disability and Health

Only categories with prevalence above 20% in the early post-acute or long-term context are presented.

^aSignificant different problem frequency in early post-acute versus long-term context (no overlap of CIs).

Muscle power functions, b735 Muscle tone functions, b740 Muscle endurance functions and b770 Gait pattern functions showing a prevalence exceeding 93%.

For the component *Body Structures*, 12 of the 40 ICF categories reflected the common problems experienced by individuals in both contexts. The highest prevalence was

reached by the categories s120 *Spinal cord and related structures*, s760 *Structure of trunk* and s810 *Structure of areas of skin* in both contexts. Three categories were significantly more common in the long-term context.

For the component *Activities and Participation*, 47 of the 81 ICF categories reflected the common problems experienced

Table 4 Prevalence (95% CI) of impairment in the ICF categories of the component 'body structures'

ICF category		Early post-acute context (n = 489)		Long-term context (n = 559)	
Code	Title	n	% (95% CI)	n	% (95% CI)
<i>Chapter 1: Structures of the nervous system</i>					
s120	Spinal cord and related structures	478	99.4 (98.2; 99.8)	529	99.2 (98.1; 99.7)
s130	Structure of meninges	152	32.2 (28.1; 36.5)	155	29.4 (25.6; 33.4)
s140	Structure of sympathetic nervous system	124	26.7 (22.9; 30.9)	182	34.5 (30.6; 38.7)
s150	Structure of parasympathetic nervous system	149	32.0 (27.9; 36.3)	197	37.5 (33.4; 41.7)
<i>Chapter 6: Structures related to the genitourinary and reproductive systems</i>					
s610 ^a	Structure of urinary system	111	24.1 (20.4; 28.2)	214	41.4 (37.2; 45.7)
<i>Chapter 7: Structures related to movement</i>					
s710	Structure of head and neck region	199	42.0 (37.6; 46.5)	200	37.8 (33.8; 42.0)
s720	Structure of shoulder region	87	19.2 (15.8; 23.0)	113	22.2 (18.8; 26.0)
s730	Structure of upper extremity	96	21.6 (18.0; 25.7)	120	23.6 (20.1; 27.5)
s740 ^a	Structure of pelvic region	96	20.6 (17.1; 24.5)	151	29.0 (25.3; 33.1)
s750	Structure of lower extremity	141	30.4 (26.4; 34.7)	193	38.0 (33.9; 42.3)
s760 ^a	Structure of trunk	180	38.6 (34.3; 43.1)	264	50.0 (45.8; 54.2)
s770	Additional musculoskeletal structures related to movement	144	31.0 (26.9; 35.3)	184	35.0 (31.0; 39.2)
<i>Chapter 8: Skin and related structures</i>					
s810	Structure of areas of skin	215	46.6 (42.1; 51.2)	263	51.1 (46.8; 55.4)

Abbreviations: CI, confidence interval; ICF, International Classification of Functioning, Disability and Health.

Only categories with prevalence above 20% in the early post-acute or long-term context are presented.

^aSignificant different problem frequency in early post-acute versus long-term context (no overlap of CIs).

by individuals in both contexts. The most common categories for both situations were *d435 Moving objects with lower extremities*, *d450 Walking*, *d455 Moving around* and *d460 Moving around in different locations*. Four of the 81 ICF categories had a frequency over 20% only in the early post-acute context and one only in the long-term context. Thirty-four categories were significantly more common in the early post-acute context, whereas only *d940 Human rights* was reported significantly more frequently in the long-term context.

For the component *Environmental Factors*, all of the 64 ICF categories were commonly reported as either a barrier, a facilitator or both in the early post-acute and the long-term contexts. The highest prevalence of >90% were reached by the categories *e310 Immediate family*, *e355 Health professionals* and *e580 Health services, systems and policies* in both contexts and *e450 Individual attitudes of health professionals* in the early post-acute context. Eleven categories were significantly more common in the early post-acute context, whereas the ICF categories *e210 Physical geography* and *e225 Climate* were reported significantly more frequently in the long-term context.

Discussion

The spectrum and prevalence of problems experienced by individuals with SCI worldwide were examined in this study. The ICF was used as reference as it provides a comprehensive framework and common language. The most common problems identified highlight the diversity of problems

associated with a SCI and the relevance of environmental factors. Furthermore, the results indicate potential differences between the prevalence of problems in the early post-acute versus the long-term context.

The high prevalence of typical impairments in *Body functions*, such as pain, defecation, urination and movement-related functions, supports previous findings in the SCI literature.¹² When interpreting the high prevalence of pain (87%) in our sample, it must be taken into account that any problem regarding pain is included in this second-level ICF category *b280 Sensation of pain* irrespective of the intensity, duration, location or nature of the pain. To provide a more detailed description of pain problems when applying the ICF, the specific third- and fourth-level ICF categories would be more appropriate. The SCI experts involved in the decision-making and consensus process, which led to the first version of the Comprehensive ICF Core Sets for SCI, also identified this need and included a number of third- and fourth-level ICF categories in the ICF Core Set allowing a detailed description of the participants' pain problems.^{10,11}

Some impaired body functions, such as sensations associated with the digestive system, thermoregulatory functions, sexual functions and skin-related functions, were found to be more prevalent in the long-term context. The more frequently impaired thermoregulatory functions in people in the long-term context may be due to the higher proportion of in-patients among the early post-acute sample who may experience a more constant environmental temperature and thus are not challenged by managing variations in temperature.¹³ The higher prevalence of

Table 5 Prevalence (95% confidence interval (CI)) of impairment in the ICF categories of the component 'activities and participation'

ICF category		Early post-acute context (n = 489)		Long-term context (n = 559)	
Code	Title	n	% (95% CI)	n	% (95% CI)
<i>Chapter 1: Learning and applying knowledge</i>					
d120	Other purposeful sensing	102	21.4 (17.9; 25.3)	100	18.7 (15.6; 22.2)
d170	Writing	169	37.6 (33.3; 42.2)	152	29.5 (25.7; 33.5)
<i>Chapter 2: General tasks and demands</i>					
d210	Undertaking a single task	101	21.4 (18.0; 25.4)	108	20.3 (17.1; 24.0)
d220 ^a	Undertaking multiple tasks	189	41.4 (37.0; 46.0)	162	30.9 (27.1; 35.0)
d230 ^a	Carrying out daily routine	188	40.8 (36.4; 45.3)	153	28.8 (25.1; 32.8)
d240 ^a	Handling stress and other psychological demands	141	30.4 (26.4; 34.7)	111	21.1 (17.8; 24.7)
<i>Chapter 3: Communication</i>					
d335	Producing nonverbal messages	106	22.5 (18.9; 26.4)	82	15.6 (12.8; 19.0)
d345	Writing messages	187	41.7 (37.3; 46.4)	171	33.5 (29.5; 37.7)
d360 ^a	Using communication devices and techniques	153	33.6 (29.4; 38.1)	112	21.7 (18.4; 25.5)
<i>Chapter 4: Mobility</i>					
d410 ^a	Changing basic body position	392	85.0 (81.5; 88.0)	378	71.7 (67.7; 75.4)
d415 ^a	Maintaining a body position	369	77.7 (73.7; 81.2)	368	68.8 (64.7; 72.6)
d420 ^a	Transferring oneself	401	85.7 (82.2; 88.6)	373	69.9 (65.8; 73.6)
d430	Lifting and carrying objects	400	86.0 (82.6; 88.9)	423	80.4 (76.8; 83.6)
d435	Moving objects with lower extremities	437	94.8 (92.4; 96.5)	508	96.6 (94.7; 97.8)
d440	Fine hand use	231	49.5 (45.0; 54.0)	234	44.4 (40.2; 48.7)
d445	Hand and arm use	229	49.0 (44.5; 53.6)	238	45.2 (41.0; 49.5)
d450	Walking	433	96.7 (94.5; 98.0)	484	97.8 (96.1; 98.8)
d455	Moving around	439	97.6 (95.7; 98.6)	498	96.7 (94.8; 97.9)
d460	Moving around in different locations	438	96.3 (94.1; 97.7)	488	94.2 (91.9; 95.9)
d465 ^a	Moving around using equipment	396	85.7 (82.2; 88.6)	345	64.8 (60.7; 68.8)
d470 ^a	Using transportation	339	84.3 (80.5; 87.6)	375	73.0 (69.0; 76.6)
d475 ^a	Driving	278	89.1 (85.2; 92.1)	317	70.3 (65.9; 74.3)
d480	Riding animals for transportation	118	96.7 (91.9; 98.7)	126	88.1 (81.8; 92.4)
<i>Chapter 5: Self-care</i>					
d510 ^a	Washing oneself	386	82.7 (79.0; 85.8)	323	60.7 (56.5; 64.8)
d520 ^a	Caring for body parts	355	75.1 (71.0; 78.7)	318	59.8 (55.6; 63.9)
d530 ^a	Toileting	385	83.7 (80.0; 86.8)	352	66.4 (62.3; 70.3)
d540 ^a	Dressing	398	84.7 (81.1; 87.7)	342	64.2 (60.0; 68.1)
d550 ^a	Eating	201	42.5 (38.1; 47.0)	173	32.4 (28.6; 36.5)
d560	Drinking	177	37.4 (33.2; 41.9)	158	29.6 (25.9; 33.6)
d570 ^a	Looking after one's health	251	55.0 (50.5; 59.5)	219	41.3 (37.2; 45.6)
<i>Chapter 6: Domestic life</i>					
d610 ^a	Acquiring a place to live	183	60.4 (54.8; 65.7)	195	44.5 (39.9; 49.2)
d620 ^a	Acquisition of goods and services	267	70.6 (65.9; 75.0)	284	54.6 (50.3; 58.8)
d630 ^a	Preparing meals	306	82.7 (78.5; 86.2)	337	65.4 (61.2; 69.4)
d640 ^a	Doing housework	315	88.0 (84.2; 91.0)	411	80.0 (76.3; 83.2)
d650 ^a	Caring for household objects	310	86.1 (82.2; 89.3)	395	76.3 (72.4; 79.7)
d660 ^a	Assisting others	284	74.9 (70.3; 79.0)	328	64.2 (59.9; 68.2)
<i>Chapter 7: Interpersonal interactions and relationships</i>					
d770	Intimate relationships	142	39.7 (34.7; 44.8)	184	40.5 (36.1; 45.1)
<i>Chapter 8: Major life areas</i>					
d810 ^a	Informal education	57	26.3 (20.9; 32.5)	53	14.0 (10.9; 17.8)
d820	School education	37	39.8 (30.4; 49.9)	44	25.3 (19.4; 32.2)
d825	Vocational training	56	37.1 (29.8; 45.0)	83	29.5 (24.5; 35.1)
d830	Higher education	52	46.4 (37.5; 55.6)	72	32.6 (26.7; 39.0)
d840 ^a	Apprenticeship (work preparation)	118	72.8 (65.5; 79.1)	134	51.3 (45.3; 57.3)
d845 ^a	Acquiring, keeping and terminating a job	171	67.9 (61.9; 73.3)	223	56.6 (51.7; 61.4)
d850 ^a	Remunerative employment	194	71.3 (65.7; 76.4)	247	60.4 (55.6; 65.0)
d855 ^a	Non-remunerative employment	151	60.6 (54.5; 66.5)	168	42.3 (37.6; 47.2)
d860 ^a	Basic economic transactions	153	37.6 (33.0; 42.4)	109	21.1 (17.8; 24.8)
d865 ^a	Complex economic transactions	155	45.1 (39.9; 50.3)	152	31.5 (27.5; 35.7)
d870 ^a	Economic self-sufficiency	201	52.9 (47.9; 57.9)	194	38.2 (34.1; 42.5)
<i>Chapter 9: Community, social and civic life</i>					
d910 ^a	Community life	217	58.2 (53.1; 63.1)	225	44.4 (40.1; 48.7)
d920 ^a	Recreation and leisure	293	75.3 (70.8; 79.3)	300	58.5 (54.2; 62.7)

Table 5 Continued

ICF category		Early post-acute context (n = 489)		Long-term context (n = 559)	
Code	Title	n	% (95% CI)	n	% (95% CI)
d930 ^a	Religion and spirituality	90	27.9 (23.3; 33.0)	77	18.6 (15.1; 22.6)
d940 ^a	Human rights	63	18.6 (14.8; 23.1)	126	27.9 (23.9; 32.2)

Abbreviations: CI, confidence interval; ICF, International Classification of Functioning, Disability and Health.

Only categories with prevalence above 20% in the early post-acute or long-term context are presented.

^aSignificant different problem frequency in early post-acute versus long-term context (no overlap of CIs).

problems regarding skin functions in the long-term context is supported by several studies reporting an increasing prevalence of pressure sores with time after injury.¹⁴ Information on sexual functions was not available for >20% of the participants in the early post-acute context in our study. Again it should be taken into account that most of these individuals were in-patients and it could be expected that they become more aware of these problems when they are back home with their families and partners. Therefore, it might not be surprising that the prevalence was higher for the long-term context. The finding that sensations associated with the digestive system were more frequent in the long-term group is supported by studies reporting an increase of bowel problems and a change of the pattern of colorectal dysfunction with time since SCI.¹⁵ The fact that several movement-related functions were more prevalent in the long-term context may be related to the higher number of people with AIS A and a fewer with AIS D. The only body functions that were found to be impaired more frequently in people with SCI in the early post-acute context were temperament and personality functions. This finding is supported by studies that reported an association between time since injury and a decreasing risk of psychopathology and depression.¹⁶

This study found a considerable prevalence for a number of *Body Structures*—beside the spinal cord itself—which are typically impaired in SCI, for example, structures of the trunk, pelvis, urinary system and skin. It is important to mention that the structure of areas of skin was the second most common reported structural problem with a prevalence around 50%. This finding is in line with the studies which found pressure ulcers to be the most frequent secondary medical complication with an increasing prevalence after injury and which observed a trend toward an increasing prevalence in the recent years.^{17,18}

Regarding the ICF component *Activities and Participation* high prevalence was found specifically regarding mobility and self-care. As expected, all restrictions regarding this domain were more common in people with SCI in the early post-acute context. However, about 70% of the people in the long-term context still experience limitations regarding mobility, such as maintaining or changing a body position, or transferring oneself, and about 60% have limitations in self-care activities. Several studies have also reported that the need for help in activities of daily living, specifically bathing, dressing and transfers, increases over the years.¹⁹

All of the second-level ICF categories from the component *Environmental factors* were found to be relevant for >20% of

the sample either as a facilitator or a barrier or both. These results highlight the need to consider environmental factors when assessing functional problems and disability in people with SCI, especially when planning the transition from the facility to the community.²⁰ Our results also indicate that support from others is a crucial factor for people with SCI. The finding that support and attitudes of others were more frequently regarded as relevant aspects in the early post-acute context may be related to an initial high need for support and an unstable self-perception that may be easily disturbed by other persons' attitudes on the one hand and a growing level of independence and adaptive coping over time on the other hand.

The main objective of this study was to examine the prevalence of functional problems in people with SCI in order to get an empirical basis for the decision process on the ICF Core Sets for SCI. Thus, this paper only reports about the basic findings. Further analyses, including subgroup analysis for clinical, demographic and country-specific characteristics, as well as statistical models that allow a closer look at the association between functional problems and environmental factors, could be most interesting.

The limitations of this study relate to the comparison of prevalence detected in the early post-acute versus long-term context. As the prevalence was not adjusted for confounding variables, the differences found may be biased and should be interpreted with caution. Furthermore, countries were not equally represented in the sample. Industrialized countries were overrepresented, and consequently, the external validity of our results may be limited. In addition, the ICF was applied in a restricted way in this study. First, only second-level ICF categories were applied, which brought about a description of functional problems on a relatively low level of specification. Second, the qualifiers, which denote the magnitude of a problem and originally consist of a five-step scale, were transformed to a dichotomous scale indicating only the presence or absence of a problem.

In conclusion, the results of this study indicate that the ICF has potential to be developed as a useful framework to comprehensively describe functional health and disability in people with SCI, but still requires further study and exploration. The most common second-level ICF categories for individuals with SCI were identified in this study and made up the basis for the decision of the ICF Core Sets for SCI, which will facilitate further exploration of the application of the ICF framework in SCI clinical practice and SCI research in future.

Table 6 Prevalence (95% CI) of a barrier, facilitator or both in the ICF categories of the component 'environmental factors'

<i>ICF category</i>		<i>Early post-acute context (n = 489)</i>		<i>Long-term context (n = 559)</i>	
<i>Code</i>	<i>Title</i>	<i>n</i>	<i>% (95% CI)</i>	<i>n</i>	<i>% (95% CI)</i>
<i>Chapter 1: Products and Technology</i>					
e110	Products or substances for personal consumption	341	74.6 (70.4; 78.4)	376	72.9 (68.9; 76.5)
e115	Products and technology for personal use in daily living	390	85.5 (82.0; 88.5)	437	83.6 (80.1; 86.5)
e120	Products and technology for personal indoor and outdoor mobility and transportation	392	89.7 (86.5; 92.2)	467	88.8 (85.8; 91.2)
e125	Products and technology for communication	385	84.4 (80.8; 87.5)	413	79.1 (75.4; 82.4)
e130	Products and technology for education	156	67.0 (60.7; 72.7)	272	70.5 (65.7; 74.8)
e135	Products and technology for employment	164	71.0 (64.8; 76.5)	274	75.5 (70.8; 79.6)
e140	Products and technology for culture, recreation and sport	264	75.4 (70.7; 79.6)	354	76.0 (71.9; 79.6)
e145	Products and technology for the practice of religion and spirituality	137	48.9 (43.1; 54.8)	189	49.2 (44.3; 54.2)
e150	Design, construction and building products and technology of buildings for public use	354	90.3 (87.0; 92.9)	452	87.8 (84.7; 90.3)
e155	Design, construction and building products and technology of buildings for private use	324	88.0 (84.3; 91.0)	450	88.1 (85.0; 90.6)
e160	Products and technology of land development	275	81.6 (77.1; 85.4)	367	80.3 (76.4; 83.7)
e165 ^a	Assets	361	86.2 (82.5; 89.1)	392	78.1 (74.3; 81.5)
<i>Chapter 2: Natural environment and human-made changes to environment</i>					
e210 ^a	Physical geography	211	54.5 (49.5; 59.4)	320	64.0 (59.7; 68.1)
e215	Population	199	50.5 (45.6; 55.4)	275	53.9 (49.6; 58.2)
e220	Flora and fauna	160	41.7 (36.8; 46.7)	233	47.0 (42.6; 51.4)
e225 ^a	Climate	276	65.7 (61.1; 70.1)	393	75.1 (71.3; 78.7)
e230	Natural events	186	65.0 (59.3; 70.3)	277	69.4 (64.7; 73.7)
e235	Human-caused events	197	65.9 (60.3; 71.0)	271	70.0 (65.3; 74.4)
e240	Light	210	50.2 (45.5; 55.0)	254	51.2 (46.8; 55.6)
e245	Time-related changes	157	38.1 (33.5; 42.9)	178	36.4 (32.3; 40.8)
e250	Sound	189	44.8 (40.1; 49.6)	225	44.2 (39.9; 48.5)
e255	Vibration	160	39.7 (35.0; 44.6)	212	43.7 (39.4; 48.2)
e260	Air quality	203	48.3 (43.6; 53.1)	278	54.8 (50.5; 59.1)
<i>Chapter 3: Support and relationships</i>					
e310 ^a	Immediate family	448	94.9 (92.5; 96.6)	475	90.1 (87.3; 92.4)
e315 ^a	Extended family	417	90.8 (87.9; 93.2)	421	81.6 (78.0; 84.7)
e320	Friends	436	92.2 (89.4; 94.3)	462	86.8 (83.7; 89.5)
e325	Acquaintances, peers, colleagues, neighbours and community members	378	85.7 (82.1; 88.7)	455	85.2 (81.9; 88.0)
e330	People in positions of authority	339	86.7 (83.0; 89.7)	388	80.2 (76.4; 83.5)
e335	People in subordinate positions	208	81.6 (76.4; 85.8)	273	79.6 (75.0; 83.5)
e340 ^a	Personal care providers and personal assistants	324	94.7 (91.8; 96.6)	374	88.6 (85.2; 91.3)
e345	Strangers	268	63.5 (58.8; 68.0)	332	64.1 (59.9; 68.1)
e350	Domesticated animals	206	62.6 (57.3; 67.7)	262	60.5 (55.8; 65.0)
e355 ^a	Health professionals	457	96.4 (94.3; 97.7)	491	91.9 (89.3; 94.0)
e360	Other professionals	373	83.8 (80.1; 87.0)	403	77.5 (73.7; 80.9)
<i>Chapter 4: Attitudes</i>					
e410	Individual attitudes of immediate family members	434	92.5 (89.8; 94.6)	457	87.0 (83.9; 89.7)
e415 ^a	Individual attitudes of extended family members	402	88.4 (85.1; 91.0)	411	80.6 (76.9; 83.8)
e420	Individual attitudes of friends	415	88.7 (85.5; 91.2)	450	84.7 (81.4; 87.6)
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	367	85.3 (81.7; 88.4)	426	80.5 (76.9; 83.7)
e430	Individual attitudes of people in positions of authority	317	83.6 (79.6; 87.0)	388	80.7 (76.9; 83.9)
e435	Individual attitudes of people in subordinate positions	210	81.4 (76.2; 85.7)	269	79.1 (74.5; 83.1)
e440 ^a	Individual attitudes of personal care providers and personal assistants	315	91.6 (88.2; 94.1)	349	83.5 (79.6; 86.7)
e445	Individual attitudes of strangers	286	67.1 (62.5; 71.4)	346	66.3 (62.1; 70.2)
e450 ^a	Individual attitudes of health professionals	451	95.1 (92.8; 96.7)	464	87.4 (84.3; 89.9)
e455 ^a	Individual attitudes of health-related professionals	380	84.8 (81.2; 87.8)	396	76.4 (72.6; 79.9)
e460	Societal attitudes	311	82.1 (77.9; 85.6)	394	77.7 (73.9; 81.1)
e465	Social norms, practices and ideologies	267	74.2 (69.4; 78.4)	374	75.6 (71.6; 79.1)
<i>Chapter 5: Services, systems and policies</i>					
e510	Services, systems and policies for the production of consumer goods	226	64.0 (58.9; 68.9)	322	62.9 (58.6; 67.0)
e515	Architecture and construction services, systems and policies	284	82.8 (78.4; 86.4)	427	85.1 (81.7; 87.9)
e520	Open space planning services, systems and policies	244	79.0 (74.1; 83.1)	402	82.4 (78.7; 85.5)
e525	Housing services, systems and policies	243	80.7 (75.9; 84.8)	363	78.4 (74.4; 81.9)

Table 6 Continued

Code	Title	ICF category		Early post-acute context (n = 489)		Long-term context (n = 559)	
				n	% (95% CI)	n	% (95% CI)
e530	Utilities services, systems and policies			281	82.2 (77.8; 85.9)	400	78.6 (74.8; 81.9)
e535	Communication services, systems and policies			294	81.7 (77.3; 85.3)	402	77.9 (74.1; 81.3)
e540	Transportation services, systems and policies			322	87.7 (84.0; 90.7)	442	87.7 (84.5; 90.3)
e545	Civil protection services, systems and policies			220	68.3 (63.1; 73.2)	344	72.1 (67.9; 76.0)
e550	Legal services, systems and policies			234	74.5 (69.4; 79.0)	366	77.5 (73.6; 81.1)
e555	Associations and organizational services, systems and policies			213	75.0 (69.7; 79.7)	341	76.1 (72.0; 79.8)
e560	Media services, systems and policies			278	75.7 (71.1; 79.9)	377	74.2 (70.2; 77.8)
e565	Economic services, systems and policies			231	70.6 (65.5; 75.3)	344	69.6 (65.4; 73.5)
e570	Social security services, systems and policies			328	88.6 (85.0; 91.5)	427	89.1 (86.0; 91.6)
e575	General social support services, systems and policies			292	83.2 (78.9; 86.7)	425	88.2 (85.0; 90.8)
e580	Health services, systems and policies			426	95.1 (92.7; 96.7)	498	94.9 (92.6; 96.4)
e585	Education and training services, systems and policies			161	75.6 (69.4; 80.9)	285	75.4 (70.8; 79.5)
e590	Labour and employment services, systems and policies			198	78.9 (73.4; 83.5)	319	81.6 (77.4; 85.1)
e595	Political services, systems and policies			169	63.3 (57.4; 68.9)	282	67.5 (62.8; 71.8)

Abbreviations: CI, confidence interval; ICF, International Classification of Functioning, Disability and Health.

*Significant different problem frequency in early post-acute versus long-term context (no overlap of CIs).

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