

## ORIGINAL ARTICLE

# The individual experience of functioning and disability in Switzerland—patient perspective and person-centeredness in spinal cord injury

H Lüthi<sup>1</sup>, S Geyh<sup>2,3,4</sup>, ME Baumberger<sup>5</sup>, P Dokladal<sup>6</sup>, M Scheuringer<sup>3</sup>, M Mäder<sup>1</sup> and A Cieza<sup>2,3</sup>

<sup>1</sup>REHAB Basel, Swiss Paraplegic Centre, Basel, Switzerland; <sup>2</sup>Swiss Paraplegic Research (SPF), Nottwil, Switzerland; <sup>3</sup>ICF Research Branch in cooperation with the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI), Nottwil, Switzerland; <sup>4</sup>Department of Health Sciences and Health Policy, University of Lucerne and SPF, Nottwil, Switzerland; <sup>5</sup>Swiss Paraplegic Centre, Nottwil, Switzerland and <sup>6</sup>Spinal Cord Injury Centre, Zurich, Switzerland

**Study design:** Qualitative, multi-center study.

**Objectives:** The objective of this study is to explore the aspects of functioning and disability that are relevant to individuals with spinal cord injury (SCI), using a comprehensive approach based on the International Classification of Functioning, Disability and Health (ICF).

**Methods:** Forty-nine people with SCI from early post-acute and long-term rehabilitation settings participated in nine focus groups. Five open-ended questions based on the ICF were used to initiate discussion about relevant Body Functions and Structures, Activities and Participation, Environmental and Personal Factors. The focus groups were audiotaped and the recording was transcribed verbatim. Qualitative analyses included the identification, extraction and coding of meaningful concepts from the transcribed dialogue. Concepts were coded according to established rules using ICF categories and were summarized semi-quantitatively.

**Results:** In the analysis, 1582 different concepts were identified. For coding one concept, an average of 1.4 ICF categories was used. This resulted in 2235 concept-ICF category links, 1068 in the early post-acute and 1167 in the long-term context, respectively. For the coding, 274 out of the 1454 categories contained in the ICF were used.

**Conclusion:** The ICF coding showed the broad range of relevant aspects in the functioning experience of persons with SCI. Besides body limitations (especially paralysis and pain), the most relevant concepts covered mainly barriers in physical environment, assistive devices and social support, as well as the impact on everyday life regarding leisure and work. The resulting list of ICF categories can be helpful in facilitating person-centered clinical care and research.

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**Keywords:** spinal cord injury; qualitative study; patient perspective; focus groups; ICF; patient-centered care

## Introduction

Person-centered rehabilitation has currently gained in importance.<sup>1</sup> Person-centeredness represents a key aspect of best practice in health care, not only from the viewpoint of professional conduct and ethics, but also for the quality and efficacy of rehabilitation.<sup>2</sup> Person-centeredness implies that for optimal health care, it is necessary to consider the patients' insider perspective, the individual perception of functioning and the affected persons' own perception of individual needs and goals. This information can make an essential contribution to assessment, goal setting and assign-

ment of interventions, and to evaluation and documentation in rehabilitation. For the clinical quality manager, the patients' perspective is an important source of information for analyzing and improving clinical processes. Moreover, health economists also ask about the impact of consumer-driven health care on financial indicators. For the affected individuals themselves, person-centeredness is connected to empowerment and individual responsibility.

The importance of person-centeredness has been emphasized in spinal cord injury (SCI) research.<sup>3,4</sup> The patients' perspective is traditionally addressed in research, using qualitative methodology.<sup>5</sup> In SCI, qualitative research has focused, for example, on the narratives of quality of life, subjective handicap,<sup>6</sup> gender-specific perspectives and the impact of aging,<sup>7</sup> or has dealt with educational interests or

Correspondence: H Lüthi, REHAB Basel, Swiss Paraplegic Centre, Im Burgfelderhof 40, CH-4055 Basel, Switzerland.  
E-mail: hj.luethi@rehab.ch  
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sexuality.<sup>8</sup> SCI is a multifaceted condition that is associated with various somatic, psychological and social consequences. Unfortunately, qualitative studies to date have not systematically considered all aspects of functioning and disability relevant to individuals with SCI, nor examined these functioning and disability from the affected person's own perspective.

The International Classification of Functioning, Disability and Health (ICF) offers a universal framework and a common taxonomy that describes all aspects of functioning comprehensively.<sup>9</sup> It can also integrate different viewpoints including that of the patient and has already been used in qualitative studies for this purpose.<sup>10,11</sup> Therefore, it seems suitable that the ICF serves as a basis for a systematic and comprehensive exploration of the persons' perspective in SCI.

The objective of this study is to explore the aspects of functioning and disability that are relevant to individuals with SCI, using a comprehensive ICF-based approach. The specific aims are (1) to identify the problems in functioning that are most frequently reported by people with SCI and (2) to explore differences between problems in functioning, reported by people with SCI in the early post-acute context and those reported by people with SCI in the long-term care context.

## Methods

A multi-center qualitative study was conducted with individuals with SCI in three Swiss paraplegic centers (Swiss Paraplegic Centre, Nottwil; Spinal Cord Injury Centre, Zurich; Swiss Paraplegic Centre, Basel), using a focus group methodology.<sup>12</sup> This study also contributed to the development of the 'ICF Core Sets for Spinal Cord Injury'.<sup>13</sup>

Patients were eligible to participate in the study when they signed an informed consent form, were older than 18 years, had sustained traumatic or non-traumatic SCI with an acute onset, were graded AIS A–D<sup>14</sup> and were in the early post-acute or in the long-term context. Exclusion criteria included ventilator-dependent high tetraplegia, psychiatric disorders or cognitive impairments (for example, depression and traumatic brain injury).

Focus groups were conducted with four to seven people. Five open-ended questions about functioning based on the ICF were used to initiate the discussion about problems within five components of health, functioning and disability, namely Body Structures, Body Functions, Activities and Participation, Environmental and Personal Factor.

The five questions to initiate the discussion were:

If you think about your body and mind, what does not work the way it is supposed to?

If you think about your body, in which parts are your problems?

If you think about your daily life, what are your problems?

If you think about your environment and your living conditions:

What do you find helpful or supportive?

What barriers do you experience?

If you think about yourself, what is important about you and the way you handle your injury?

Each focus group was audiotaped and the recording was transcribed verbatim. The qualitative data analysis of the transcribed text followed three steps. First, the text was divided into 'meaning units', that is, units of text, words or sentences with a common theme. Second, the information about functioning, that is, the concepts contained in the meaning units, was extracted. Third, every concept was coded using ICF categories according to established rules.<sup>15</sup>

The ICF contains 1454 categories that are structured in a stem/branch/leaf scheme. Each of the four major components (Body Functions, Body Structures, Activity and Participation, Environmental Factors) consists of chapters (categories at the first level); each chapter consists of second level categories, which can be broken down further into third or fourth level categories. For example:

b5 Chapter 5—Functions of the digestive, metabolic and endocrine systems.

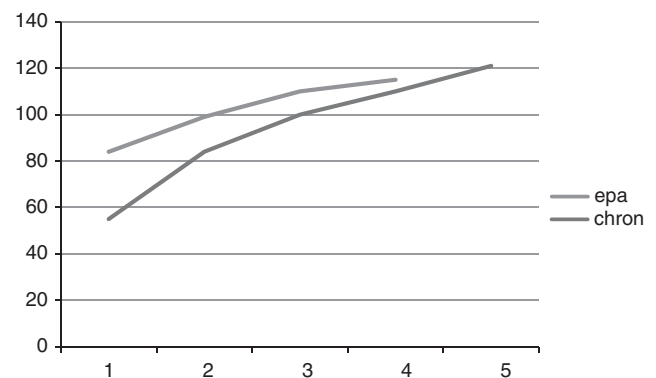
b510 Ingestion functions.

b5105 Swallowing.

b51050 Oral swallowing.

Concepts that refer to a health condition or diagnoses were coded using 'hc—health condition'. Personal Factors were coded using 'pf—personal factors'. If concepts were not specific enough to be denoted by an ICF code, they were labeled as 'nd—not definable'. If they addressed content beyond the scope of the ICF, they were coded as 'nc—not covered'. The coding of the concepts in the long-term context was performed separately by two health professionals, and subsequently, the resulting codes were compared. To quantify the agreement between the two coding versions, the percentage of agreement was calculated. Disagreements were resolved by discussing them and finding a consensus.

The qualitative analyses were conducted after each focus group session. Additional focus group sessions were held until saturation of the data was reached. Saturation was defined as the point during data collection when the coding of two consecutive focus groups revealed less than 10% new second-level ICF categories (Figure 1).



**Figure 1** Saturation of data: number of ICF categories across focus group sessions.

The study design, materials and procedures were approved by the Ethics Committees of the Cantons Lucerne, Basel and Zurich.

## Results

Forty-nine people participated in nine focus groups. Table 1 shows their socio-demographic and SCI-related characteristics. Four focus group sessions were conducted for the early post-acute context (21 participants) and five group sessions were conducted for the long-term context (28 participants).

In the 855 min of transcribed dialogue, 1582 different concepts were identified. For coding one concept, an average of 1.4 ICF categories was used. This resulted in 2235 concept-ICF category links, 1068 in the early post-acute and 1167 in the long-term context, respectively. For the coding, 274 out of the 1454 categories contained in the ICF were used. For the early post-acute setting, 208 ICF categories were used: 71 Body Functions, 10 Body Structures, 80 Activities and Participation, and 47 Environmental Factors. For the long-term context, 209 ICF categories were used: 57 Body Functions, 13 Body Structures, 78 Activities and Participa-

tion, and 61 Environmental Factors. The two health professionals, who coded independently, agreed on 981 concepts out of 1167, corresponding to 84.1% agreement.

Table 2 provides a summary of the quantitative results of the extraction of concepts and the coding. Detailed results of the coding are shown in Tables 3–5.

The three most frequently used ICF categories in the component of Body Functions were b735 Muscle tone functions ( $n_{\text{concepts}}=96$ ), d730 Muscle power functions ( $n_{\text{concepts}}=62$ ) and b280 Sensation of pain ( $n_{\text{concepts}}=48$ ). These categories were used to code statements such as the following:

‘Having to stay seated for a long time makes me tense up and stiff; the legs get pulled in.’

‘I can hardly move my arm at all, my hands are completely paralysed.’

‘These backpains, they just don’t stop.’

Considering Body Structures, the most frequently used ICF category was s810 Structure of areas of skin ( $n_{\text{concepts}}=22$ ).

‘Once the bedsore was so big I had to have an operation.’

In the component Activities and Participation, d920 Recreation and leisure ( $n=73$  concepts), d530 Toileting

**Table 1** Socio-demographic and spinal cord injury related patient characteristics

	Total	Early post-acute context	Long-term context
Participants (n)	49	21	28
Years of age Mean (s.d.)	45.1 (15.5)	42.1 (17.4)	47.3 (13.8)
Gender % male (n)	75.5 (37)	76.2 (16)	75.0 (21)
Marital status % Never married (n)	40.8 (20)	38.1 (8)	42.6 (12)
% Currently married or cohabiting (n)	38.8 (19)	38.1 (8)	39.3 (11)
% Separated, divorced, widowed (n)	20.4 (10)	23.8 (6)	17.9 (5)
Years of education Mean (s.d.)	13.4 (3.1)	13.7 (2.4)	13.3 (3.6)
Etiology % Sport (n)	20.4 (10)	28.6 (6)	14.3 (4)
% Assault (n)	4.1 (2)	0 (0)	7.1 (2)
% Transport (n)	38.8 (19)	38.1 (8)	39.3 (11)
% Fall (n)	18.4 (9)	14.3 (3)	21.4 (6)
% Other traumatic (n)	10.2 (5)	9.5 (2)	10.7 (3)
% Non-traumatic (n)	4.1 (2)	4.8 (1)	3.6 (1)
% Unspecific (n)	4.1 (2)	4.8 (1)	3.6 (1)
Level of injury % Paraplegia (n)	67.3 (33)	66.7 (14)	67.9 (19)
Completeness of injury % AIS A (n)	59.2 (29)	52.4 (11)	64.3 (18)
% AIS B (n)	12.2 (6)	14.3 (3)	10.7 (3)
% AIS C (n)	16.3 (8)	14.3 (3)	17.9 (5)
% AIS D (n)	12.2 (6)	19.0 (4)	7.1 (2)
Time since onset of SCI (months) Mean (s.d.)	110.7 (154.6)	5.1 (2.8)	190.0 (165.2)
Median (IQR)	43.4 (146.5)	4.5 (2.9)	122.0 (253.3)

Abbreviations: AIS, ASIA Impairment Scale; SCI, spinal cord injury.

**Table 2** Summary of the results of the data extraction

Concepts and ICF Codes	Total (n)	Early post-acute context		Long-term context	
		n	% (n = 1068)	n	% (n = 1167)
Number of identified unique concepts (n)	1582				
Average number of ICF categories used to code one concept	1.4				
Number of concept-category links	2235	1068		1167	
<i>Per ICF component</i>					
Body functions (b)	620	322	30.1	298	25.5
Body structures (s)	53	23	2.2	30	2.6
Activity and participation (d)	669	364	34.1	305	26.1
Environmental factors (e)	660	265	24.8	395	33.8
Personal factors (pf)	156	60	5.6	96	8.2
Not definable (nd)	55	25	2.3	30	2.6
Not covered (nc)	5	2	0.2	3	0.3
Health conditions (hc)	17	7	0.7	10	0.9
<i>Per level of the ICF hierarchy</i>					
Component level <sup>a</sup>	234	94	8.8	140	12.0
Chapter level	135	59	5.5	76	6.5
Second level categories	1104	513	48.0	591	50.6
Third level categories	736	387	36.2	349	29.9
Fourth level categories	26	15	1.4	11	0.9
<i>Number of different ICF categories (n)</i>					
Body functions (b)	274	208		209	
Body structures (s)	84	71		57	
Activity and participation (d)	18	10		13	
Environmental factors (e)	105	80		78	
	67	47		61	

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

<sup>a</sup>Component level includes personal factors (pf), not definable (nd), not covered (nc) and health condition (hc).

( $n = 47$  concepts), and d850 Remunerative employment ( $n = 40$  concepts) emerged as the most frequently used ICF categories.

'The thing I miss is playing football.'

'The thing which bothers me most is how I have to depend on others when I go to the WC.'

'I used to be a builder. Now I can't build walls any more, I can't manage any physically demanding work...'

Regarding Environmental Factors, categories in chapter e1 Products and technology were most frequently used, specifically, e150 Design, construction and building products and technology of buildings for public use ( $n = 93$ ), e155 Design, construction... for private use ( $n = 65$ ), e120 Products and technology for personal indoor and outdoor mobility and transportation ( $n = 79$ ).

'How am I supposed to get to this local government office; it is on the first floor, and of course there's no elevator.'

'At my house, one door to the bathroom was too narrow, and the bathroom was just too small.'

'For example, I can't get on the tram without someone helping me.'

Several ICF categories were addressed in all focus groups. In Body Functions, the categories d280 Sensation of pain, b525 Defecation, b610 Urinary excretory functions and b620 Urination functions, b730 Muscle power and b735 Muscle tone functions were mentioned in all focus groups. In Activities and Participation, the categories d230 Carrying out daily routine, d530 Toileting, d850 Remunerative

employment and d920 Recreation and leisure were addressed in all groups. All focus groups referred to the Environmental Factors e115 Products and technology for personal use in daily living and e120 Products and technology for personal indoor and outdoor mobility and transportation, e150 Design, construction and building products and technology of buildings for public use and e155 Design, construction ... for private use as well as e580 Health services, systems and policies.

Differences between the focus groups of the early post-acute versus the long-term context were found. The ICF categories b180 Experience of self and time functions (including Body Image), b710 Mobility of joint functions and d910 Community life were not addressed at all in the long-term context, but were mentioned in more than 50% of the focus groups of the early post-acute context. In contrast, the ICF category d660 Assisting others was identified in the long-term context only, but not mentioned at all in the early post-acute context.

## Discussion

In the current study, we illustrate the whole range of functioning and disability relevant for people with SCI from their own 'insider' perspective. Body Functions, Activities and Participation, as well as Environmental Factors, seemed to be equally relevant; however, Body Structures appeared to

**Table 3** List of ICF categories from the components of Body Functions and Structures, which have been used to code the concepts named in the focus groups

Code Title	Focus groups			Concepts		
	Total (n = 9)	Early post-acute context (n = 4)	Long-term context (n = 5)	Total (n = 2235)	Early post-acute context (n = 1068)	Long-term context (n = 1167)
<i>b1 Mental functions</i>						
b126 Temperament and personality functions	4	1	3	6	2	4
b130 Energy and drive functions	5	3	2	10	8	2
b134 Sleep functions	2	1	1	7	5	2
b152 Emotional functions	4	1	3	11	1	10
b180 Experience of self and time functions	<sup>a</sup> 3	3	0	3	3	0
<i>b2 Sensory functions and pain</i>						
b260 Proprioceptive function	<sup>a</sup> 1	1	0	2	2	0
b265 Touch function	<sup>b</sup> 7	4	3	43	20	23
b270 Sensory functions related to temperature and other stimuli	<sup>b</sup> 8	4	4	43	19	24
b280 Sensation of pain	<sup>c</sup> 9	4	5	48	21	27
<i>b4 Functions of the cardiovascular, hematological, immunological and respiratory systems</i>						
b415 Blood vessel functions	<sup>a</sup> 2	0	2	4	0	4
b440 Respiration functions	2	1	1	7	6	1
b455 Exercise tolerance functions	4	1	3	10	4	6
<i>b5 Functions of the digestive, metabolic and endocrine systems</i>						
b510 Ingestion functions	2	1	1	3	2	1
b515 Digestive functions	7	3	4	14	5	9
b525 Defecation functions	<sup>c</sup> 9	4	5	41	25	16
b530 Weight maintenance functions	4	1	3	9	3	6
b550 Thermoregulatory functions	3	1	2	6	3	3
<i>b6 Genitourinary and reproductive functions</i>						
b610 Urinary excretory functions	<sup>c</sup> 9	4	5	22	9	13
b620 Urination functions	<sup>c</sup> 9	4	5	53	26	27
b630 Sensations associated with urinary functions	2	1	1	4	3	1
b640 Sexual functions	7	3	4	21	7	14
b670 Sensations associated with genital and reproductive functions	<sup>a</sup> 2	0	2	3	0	3
<i>b7 Neuro-musculoskeletal and movement-related functions</i>						
b710 Mobility of joint functions	<sup>a</sup> 3	3	0	9	9	0
b730 Muscle power functions	<sup>c</sup> 9	4	5	62	39	23
b735 Muscle tone functions	<sup>c</sup> 9	4	5	96	52	44
b755 Involuntary movement reaction functions	5	3	2	8	6	2
b760 Control of voluntary movement functions	4	3	1	5	4	1
b770 Gait pattern functions	2	1	1	2	1	1
b780 Sensations related to muscles and movement functions	2	1	1	4	3	1
<i>b8 Functions of the skin and its related structures</i>						
b810 Protective functions of the skin	7	3	4	28	11	17
b830 Other functions of the skin	3	1	2	4	1	3
<i>s1 Structures of the nervous system</i>						
s120 Spinal cord and related structures	5	2	3	15	7	8
<i>s7 Structures related to movement</i>						
s720 Structure of shoulder region	3	1	2	4	2	2
s730 Structure of upper extremity	2	1	1	3	2	1
s750 Structure of lower extremity	3	1	2	3	1	2
s760 Structure of trunk	4	3	1	5	4	1
<i>s8 Skin and related structures</i>						
s810 Structure of areas of skin	7	3	4	22	7	15

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

Categories are only shown if they were used to code concepts in more than one focus group.

The results are summarized at the second level of the ICF classification.

<sup>a</sup>Reported in only one situation.

<sup>b</sup>Reported in all focus groups of one situation.

<sup>c</sup>Reported in all focus groups.

**Table 4** List of ICF categories from the component Activity and Participation, which have been used to code the concepts named in the focus groups

Code Title	Focus groups			Concepts		
	Total (n = 9)	Early post-acute context (n = 4)	Long-term context (n = 5)	Total (n = 2235)	Early post-acute context (n = 1068)	Long-term context (n = 1167)
<i>d1 Learning and applying knowledge</i>						
d155 Acquiring skills	3	2	1	3	2	1
<i>d2 General tasks and demands</i>						
d220 Undertaking multiple tasks	a 8	4	4	35	19	16
d230 Carrying out daily routine	b 9	4	5	19	10	9
d240 Handling stress and other psychological demands	a 8	4	4	35	17	18
<i>d3 Communication</i>						
d335 Producing non-verbal messages	2	1	1	2	1	1
<i>d4 Mobility</i>						
d410 Changing basic body position	a 8	4	4	22	16	6
d415 Maintaining a body position	6	3	3	22	13	9
d420 Transferring oneself	4	3	1	18	17	1
d430 Lifting and carrying objects	5	3	2	9	5	4
d440 Fine hand use	7	3	4	34	20	14
d445 Hand and arm use	6	3	3	30	20	10
d450 Walking	a 8	4	4	39	13	26
d455 Moving around	a 7	2	5	15	3	12
d460 Moving around in different locations	3	1	2	5	1	4
d465 Moving around using equipment	6	1	5	11	3	8
d470 Using transportation	4	2	2	7	3	4
d475 Driving	5	3	2	19	12	7
<i>d5 Self-care</i>						
d510 Washing oneself	4	3	1	6	5	1
d520 Caring for body parts	3	2	1	8	7	1
d530 Toileting	b 9	4	5	47	28	19
d540 Dressing	a 6	4	2	18	14	4
d550 Eating	a 6	4	2	9	7	2
d570 Looking after one's health	4	2	2	8	5	3
<i>d6 Domestic life</i>						
d620 Acquisition of goods and services	6	2	4	7	2	5
d630 Preparing meals	4	3	1	6	5	1
d640 Doing housework	4	2	2	11	4	7
d650 Caring for household objects	6	3	3	9	6	3
d660 Assisting others	c 3	0	3	7	0	7
<i>d7 Interpersonal interactions and relationships</i>						
d710 Basic interpersonal interactions	2	1	1	4	2	2
d720 Complex interpersonal interactions	4	2	2	5	3	2
d750 Informal social relationships	4	2	2	5	3	2
d770 Intimate relationships	7	3	4	14	6	8
<i>d8 Major life areas</i>						
d825 Vocational training	3	1	2	4	1	3
d845 Acquiring, keeping and terminating a job	2	1	1	3	2	1
d850 Remunerative employment	b 9	4	5	40	19	21
<i>d9 Community, social and civic life</i>						
d910 Community life	c 2	2	0	3	3	0
d920 Recreation and leisure	b 9	4	5	73	41	32
d950 Political life and citizenship	2	1	1	3	1	2

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

Categories are only shown if they were used to code concepts in more than one focus group.

The results are summarized at the second level of the ICF classification.

<sup>a</sup>Reported in all focus groups of one situation.

<sup>b</sup>Reported in all focus groups.

<sup>c</sup>Reported in only one situation.

**Table 5** List of ICF categories from the component Environmental Factors, which have been used to code the concepts named in the focus groups

Code Title	Focus groups			Concepts		
	Total (n = 9)	Early post-acute context (n = 4)	Long-term context (n = 5)	Total (n = 2235)	Early post-acute context (n = 1068)	Long-term context (n = 1167)
<i>e1 Products and technology</i>						
e110 Products or substances for personal consumption	<sup>a</sup> 8	4	4	21	10	11
e115 Products and technology for personal use in daily living	<sup>b</sup> 9	4	5	55	34	21
e120 Products and technology for personal indoor and outdoor mobility and transportation	<sup>b</sup> 9	4	5	79	29	50
e125 Products and technology for communication	<sup>a</sup> 7	2	5	12	4	8
e135 Products and technology for employment	3	1	2	4	1	3
e140 Products and technology for culture, recreation and sport	3	2	1	6	3	3
e150 Design, construction and building products and technology of buildings for public use	<sup>b</sup> 9	4	5	93	36	57
e155 Design, construction and building products and technology of buildings for private use	<sup>b</sup> 9	4	5	65	26	39
e160 Products and technology of land development	6	2	4	15	4	11
<i>e2 Natural environment and human-made changes to environment</i>						
e210 Physical geography	3	2	1	4	2	2
e225 Climate	<sup>a</sup> 6	1	5	15	1	14
e240 Light	<sup>c</sup> 2	0	2	2	0	2
<i>e3 Support and relationships</i>						
e310 Immediate family	<sup>a</sup> 8	4	4	27	18	9
e320 Friends	5	1	4	7	3	4
e325 Acquaintances, peers, colleagues, neighbors and community members	6	2	4	12	8	4
e330 People in positions of authority	3	1	2	5	2	3
e340 Personal care providers and personal assistants	2	1	1	5	1	4
e345 Strangers	5	2	3	10	3	7
e350 Domesticated animals	<sup>c</sup> 1	1	0	1	1	0
e355 Health professionals	<sup>a</sup> 6	4	2	19	16	3
<i>e4 Attitudes</i>						
e410 Individual attitudes of immediate family members	2	1	1	3	2	1
e420 Individual attitudes of friends	2	1	1	2	1	1
e445 Individual attitudes of strangers	2	1	1	2	1	1
e450 Individual attitudes of health professionals	2	1	1	3	1	2
e455 Individual attitudes of health-related professionals	3	1	2	3	1	2
e460 Societal attitudes	2	1	1	9	1	8
<i>e5 Services, systems and policies</i>						
e515 Architecture and construction services, systems and policies	<sup>a</sup> 7	2	5	16	4	12
e540 Transportation services, systems and policies	5	2	3	9	4	5
e545 Civil protection services, systems and policies	<sup>c</sup> 2	0	2	2	0	2
e555 Associations and organizational services, systems and policies	<sup>c</sup> 2	0	2	2	0	2
e565 Economic services, systems and policies	<sup>c</sup> 1	0	1	2	0	2
e570 Social security services, systems and policies	7	3	4	22	5	17
e580 Health services, systems and policies	<sup>b</sup> 9	4	5	35	12	23
e590 Labor and employment services, systems and policies	4	1	3	6	1	5

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

Categories are only shown if they were used to code concepts in more than one focus group.

The results are summarized at the second level of the ICF classification.

<sup>a</sup>Reported in all focus groups of one situation.

<sup>b</sup>Reported in all focus groups.

<sup>c</sup>Reported in only one situation.

be of less importance. The patients were mainly concerned with movement-related impairments of Body Function, leisure-time Activities and Participation, and with the features of public buildings and transportation as barriers in their everyday environment. Patients in the early post-acute context tended more often to report problems in Body Functions, and Activity and Participation as a consequence

of the paralysis, whereas patients in the chronic context more often referred to barriers in the environment.

In line with the literature, the whole spectrum of expected SCI-related bodily problems was identified, such as muscle tone and power, in relation to paralysis, sensory functions and pain, urinary and defecation functions, as well as skin functions related to pressure sores.<sup>16,17</sup>

As discussed in the literature at length, the most relevant categories of the component Activities and Participation reflect the limitations in activities of daily living, as well as in occupation and working. However, these categories also highlight the significance of leisure activities. Interestingly, the participants often expressed issues of dependency in activities of daily living in terms of autonomy ('I cannot do this the way I want to'). The concept of autonomy is increasingly addressed in discussions about the operationalization of Activity and Participation,<sup>18</sup> and instruments, for example, the Impact on Participation and Autonomy questionnaire,<sup>19</sup> that have been developed accordingly. Thereby, current outcome research seems to have taken up the concerns of the patients.

One of the main findings of this study is that five of the six most frequently reported categories represent Environmental Factors. From a traditional biomedical perspective of disability, healthcare focuses on problems at the body level. However, in today's understanding of comprehensive rehabilitation, the larger context has taken center stage, extending to the participation and community integration of people with SCI.<sup>20</sup> The comprehensive view of disability and rehabilitation, which emphasizes the relevance of the context, corresponds with the perception of affected people about their own situation, as shown in our study.

Considering the differences between the early post-acute and the chronic contexts, our findings are in agreement with the clinical experience that impairments of Body Functions are more strongly emphasized in the early period after injury and during the first stage of rehabilitation than in the long-term. In contrast, for patients whose injury occurred long-ago and who have been living in the community, Environmental Factors have a greater role, and therefore, addressed with a higher degree of differentiation than in the early post-injury phase. We hypothesize that the patient's focus changes from body to environment in the course of time after injury. However, longitudinal studies are required to support this hypothesis.

The current study is subject to several limitations. First, the focus groups consisted of a convenience sample of people with SCI living in the German-speaking part of Switzerland and excluded people with high tetraplegia. Thus, the generalizability of the results may be questioned. Second, differences between the early post-acute and the chronic situations could not be tested statistically due to the small number of focus groups conducted. As the focus groups were mixed in terms of lesion level and severity (complete versus incomplete), no conclusions could be made regarding individual participants or subgroups of the study population.

Third, the linking process based on the ICF can lead to a reduction of detail and depth, compared with the original statements. Finally, problems of functioning were identified and listed; however, the rating of these problems was not explicitly requested from the focus group participants. Thus, our assumption that frequently reported ICF categories are relevant has to be taken with caution.

The advantage of the study lies in its broad focus towards the 'insider' perspective of functioning and disability in SCI, guided by a comprehensive ICF-based approach. Using the

ICF's standardized coding scheme allows a structured, straightforward and efficient communication of information about functioning between different stakeholders, and facilitates comparability with the results of other ICF-based studies.

## Conclusion

The main output of this study is a list of ICF categories that reflects those areas of functioning and disability that are relevant to patients. Therefore, this list may serve as a rough criterion of person-centeredness for clinicians and researchers who would like to check if the assessments, interventions and research priorities cover the patients' perspective. For patient-centered assessment, instruments should cover those aspects of functioning and disability that have been identified as relevant from the insider perspective. For patient-centered rehabilitation, goal setting and interventions should focus on those problems perceived as important by the patients themselves. For patient-centered research, research priorities should be set not only by scientists or by funding agencies, but also involve affected individuals, and address those issues that are seen as important by them.

## Conflict of interest

The authors declare no conflict of interest.

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