

## ORIGINAL ARTICLE

# Functioning and disability in spinal cord injury from the consumer perspective: an international qualitative study using focus groups and the ICF

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

**Objectives:** To examine the lived experiences of persons with spinal cord injury (SCI) in both the early post-acute and the long-term context using the International Classification of Functioning, Disability and Health (ICF) as a frame of reference.

**Setting:** International study sites representing the six World Health Organization world regions.

**Methods:** A qualitative study using focus groups methodology was conducted. Sample size was determined by saturation. The focus groups were digitally recorded and transcribed verbatim. The meaning condensation procedure was used for the data analysis. The resulting meaningful concepts were linked to ICF categories according to established linking rules.

**Results:** Forty-nine focus groups with 230 participants were performed. Saturation was reached in four out of the six world regions. A total of 3122 and 4423 relevant concepts were identified in the focus groups for the early post-acute and the long-term context, respectively, and linked to a total of 171 and 188 second-level categories. All chapters of the ICF components *Body functions*, *Activities and participation* and *Environmental factors* were represented by the linked ICF categories. In all, 36 and 113 concepts, respectively, are not classified by the ICF and 306 and 444, respectively, could be assigned to the ICF component *Personal Factors*, which is not yet classified.

**Conclusion:** A broad range of the individual experiences of persons with SCI is covered by the ICF. A large number of experiences were related to *Personal Factors*.

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## Introduction

A spinal cord injury (SCI) is associated with a wide range of impairments of functioning and health that may lead to limitations in activity and restrictions in participation. An important basis for the optimal management of SCI is an in-depth understanding of the effect of SCI on health and activities of daily living. To achieve greater understanding, the experiences of people with the health problem are increasingly examined.<sup>1</sup>

Studies aimed at the exploration of this ‘patient perspective’—in this case called ‘consumer perspective’—frequently apply qualitative methods, which are increasingly accepted in health research and health-related sciences.<sup>2</sup> A number of qualitative studies examining the experiences of people with SCI are available so far. These studies either had a focus on specific body functions, for example, fatigue,<sup>3</sup> neuropathic pain<sup>4</sup> and spasticity<sup>5</sup> or have addressed specific aspects of activities and participation including leisure participation,<sup>6</sup> physical activities,<sup>7</sup> personal relationships<sup>8</sup> and parenting.<sup>9</sup> Other studies have focused on personal factors and examined the individuals’ experiences of hope<sup>10</sup> and post-traumatic growth<sup>11</sup> or have studied the experiences of specific subgroups such as women<sup>12</sup> or adolescents.<sup>13</sup> In

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addition, some studies have investigated different aspects of treatment and care of people with SCI using qualitative methods.<sup>14,15</sup>

However, each of these studies addresses only a specific area of experiences and is limited to people with SCI in a single country. Consequently, a qualitative study investigating the entire scope of lived experiences of people with SCI from an international perspective is missing.

A comprehensive and systematic description of the experience of persons with a determined disease requires a general model or framework. With the approval of the International Classification of Functioning, Disability and Health (ICF)<sup>16</sup> by the World Health Assembly there is now a universally accepted framework to classify and describe functioning from both the patient perspective and that of the health professionals. 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 or third level) are more detailed. Several studies have already shown that the ICF facilitates the analysis of qualitative data derived from individual interviews over focus groups.<sup>17–20</sup>

The experiences of people with a health problem are frequently examined using the focus group inquiry. Focus groups are a series of discussions designed to obtain perceptions in a defined area of interest, in a permissive, non-threatening environment. They are especially useful for studies involving complex issues that entail many levels of feeling and experience. The idea behind this technique is that the group process helps people to examine and clarify their views. The non-directive nature of focus groups allows participants to comment, explain and disagree while sharing experiences and attitudes.<sup>21</sup> It is commonly assumed that focus groups reveal a larger number of ideas and statements in comparison with individual interviews. However, only a few studies compared focus groups and individual interviews in a structured way. Although Thomas *et al.*<sup>22</sup> reported that certain concepts were more likely to occur in focus groups than in individual interviews and no difference was found between the two methods in the depth of data generated, a marketing research study reported that individual interviews generated significantly more ideas and a significantly higher quality of ideas than focus groups.<sup>23</sup> Focus groups as well as individual interviews were applied in a project of the ICF Research Branch Munich to examine the spectrum of functional problems associated with rheumatoid arthritis using the ICF as a framework of reference.<sup>19,20</sup> A comparison between the two methods revealed a larger number of ideas from the focus groups in comparison with individual interviews. Consequently, the focus group approach seems well suited to capture the comprehensiveness and complexity of the experiences of people with SCI when using the ICF as a framework of reference and applying similar methods as in the study performed by Coenen *et al.*<sup>19</sup>

Thus, the objective of this study was to examine the lived experiences of persons with SCI from six countries of

different world regions. The specific aim was to identify the aspects of functioning and disability important to persons with SCI in both the early post-acute context and the long-term context, using the ICF as a framework and applying focus group methodology.

## Methods

### *Design*

We conducted an international multi-center qualitative focus group inquiry. The specific methodology for identifying aspects of functioning using the ICF as a reference was developed within the validation of the ICF Core Sets for rheumatoid arthritis from the patient perspective.<sup>19</sup> Our study was part of the international co-operation project 'Development of ICF Core Sets for SCI'.<sup>24</sup> A large proportion of the data reported in this paper was used as a basis for SCI experts to decide on the 'ICF Core Sets for SCI'.<sup>25,26</sup> Ten study centers in six countries from all six world regions as defined by the World Health Organization were involved in this study. Each center gained ethics committee approval.

### *Participants*

Participants were included if they had sustained a SCI with an acute onset, if they were either in the early post-acute context 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. Participants with traumatic brain injury or diagnosed mental disorders before SCI were excluded. Acute onset was defined as a trauma or non-traumatic event resulting in spinal cord dysfunction within 14 days of onset. The early post-acute context begins with active rehabilitation and ends with the completion of the first comprehensive rehabilitation after the acute SCI, which varies from country to country. 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.

According to previous studies,<sup>17,19</sup> the focus group size was set at a maximum of seven people to represent different opinions and facilitate interactions.

All eligible individuals in a study center meeting the inclusion criteria were identified. Up to seven individuals were selected according to a maximum variation strategy based on age, gender, level of SCI and American Spinal Injury Association Impairment Scale. Selected individuals were informed regarding the nature and course of the study and invited to participate. In case a person refused to participate another person was selected and asked to participate. Persons who agreed gave written consent. Finally, they were informed regarding time and location of the focus group discussion.

### *Sample size*

The sample size in each country was determined by saturation.<sup>27</sup> Saturation refers to the point at which an investigator has obtained sufficient information from the

**Table 1** Questions applied in the focus group

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?
If you think about your environment and your living conditions, what barriers do you experience?
If you think about yourself, what is important about you and the way you handle your disease?

field. In this study, it was defined as the point during data collection and analysis when the linking of the concepts of two consecutive focus groups revealed not more than 10% new second-level categories.

### Materials

An established topic guide with guidelines describing how to prepare and perform the focus group sessions as well as open-ended questions was applied. The six open-ended questions used are shown in Table 1.

### Data collection

Each focus group in a country was conducted by the same moderator and one group assistant. The moderators were physicians or physical therapists experienced in facilitating group processes, were familiar with the problems associated with SCI and had a good knowledge of the ICF. All moderators attended a 2-day training workshop held by members of the ICF Research Branch Munich to become familiar with the focus group process and the data analysis in which they were also involved.

The focus groups were conducted between January 2007 and March 2008. They took place in a quiet room in the study center. At the beginning of each focus group, the procedure of the session was explained, and the concept of the ICF was presented in lay terms to all participants. The open-ended questions and the titles of the ICF components were presented visually to the participants by a Power-Point presentation.

The assistants observed the process within the group. In addition, they filled in descriptive field notes according to a standardized coding schema. The focus groups were digitally recorded and transcribed verbatim.

### Data analysis

**Qualitative analysis.** The meaning condensation procedure<sup>27</sup> was used for the qualitative analysis of the data. This involved an initial read through to get an overview of the content. Second, the data were divided into units of meaning, and the theme that dominated a meaning unit was determined. A meaning unit was defined as a specific unit of text either a few words or a few sentences with a common theme.<sup>28</sup> Therefore, a meaning unit division did not follow linguistic grammatical rules. Rather, the text was divided in which the researcher discerned a shift in meaning. Next, the

concepts contained in the meaning units were identified. A meaning unit could contain more than one concept.

**Linking to the ICF.** The identified concepts were linked to the categories of the ICF based on established linking rules.<sup>29</sup> According to these linking rules, researchers trained in the ICF are advised to link each concept to the ICF category representing this concept most precisely. One concept could be linked to one or more ICF categories, depending on the number of themes contained in the concept. A detailed example of this linking process can be found on the 'Spinal Cord' website.

**Quality assurance.** In each country at least two professionals were involved in the data analysis. At least one of them (commonly the moderator of the focus groups) received 2-day training from members of the ICF Research Branch Munich. On the basis of the 'train-the-trainers principle', these professionals trained the colleagues in their respective country. Monitoring was provided by the International Project Coordinator (MS, IK). A computerized system was used for the linking process and the entry of demographic patient data.

**Accuracy of the analysis.** To ensure the accuracy of data analysis the following two strategies were conducted:

**Multiple coding:** In each study center, the qualitative analysis and the linking to the ICF of the first focus group were performed by two researchers to achieve agreement concerning the implementation of the linking rules. Agreements, specifications and special cases of the linking rules were documented. After this adjustment process, the subsequent focus groups were analyzed by one researcher.

**Peer review:** A peer review was performed for all focus groups with the exception of the first one. Random samples consisting of 15% of the transcribed text and 15% of the concepts identified by the first researcher were analyzed and were linked by the second one. The degree of agreement was calculated by the Kappa statistic with 95%-bootstrapped confidence intervals.<sup>30,31</sup> The values of the Kappa coefficient generally range from 0 to 1, whereas 1 indicates perfect agreement and 0 indicates no additional agreement beyond what is expected by chance alone. The data analysis was performed using SAS for windows V9.1.

## Results

### Description of the focus groups

A total of 230 participants were included in 22 focus groups for the early post-acute context and 27 for the long-term context (see Table 2). Participants' characteristics are summarized in Table 3. Table 4 shows the distribution of SCI level and severity as well as the American Spinal Injury Association Impairment Scale (AIS) grading. A comparison between the countries using the 95% confidence intervals shows significant differences regarding the focus groups for the early post-acute context performed in the United States. In these groups, no participants with paraplegia were

**Table 2** Characteristics of the focus groups and agreement between peers regarding the linking of identified meaningful concepts to ICF categories

Country	Early post-acute context				Long-term context			
	Focus groups (n)	Participants (n)	Saturation reached?	Kappa coefficient (boots-traped confidence interval)	Focus groups (n)	Participants (n)	Saturation reached?	Kappa coefficient (boots-traped confidence interval)
Israel	5	24	Yes	—	5	25	Yes	—
New Zealand	5	22	Yes	0.75 (0.63–0.89)	5	22	Yes	0.60 (0.55–0.66)
South Africa	2	8	No	—	2	13	No	—
Switzerland	4	20	Yes	0.52 (0.47–0.57)	5	28	Yes	0.46 (0.35–0.56)
Thailand	4	17	Yes	0.76 (0.72–0.82)	5	24	Yes	0.73 (0.61–0.87)
USA	2	7	No	0.39 (0.29–0.51)	5	20	Yes	0.58 (0.55–0.62)
Total	22	98			27	132		

**Table 3** Characteristics of participants

	Early post-acute context (n = 98)	Long-term context (n = 132)
Age in years	43.5 (18.9;81.0)	44.9 (19.9;74.1)
Gender		
Female	18.4 (11.9;27.2)	22.7 (16.4;30.6)
Male	81.6 (72.8;86.9)	77.3 (69.7;82.8)
Years of education	12 (0;19)	12 (1;25)
Time since onset of SCI in months	3.3 (0.2;16.3)	101.8 (0.7;608.6)
Setting		
Outpatient	4.1 (1.6;10.0)	84.1 (76.9;89.4)
Inpatient	95.9 (90.0;98.4)	15.9 (10.6;23.1)
Etiology		
Sports and leisure activities	13.3 (7.9;21.4)	9.9 (5.9;16.2)
Assaults	7.1 (3.5;14.0)	7.6 (4.2;13.5)
Transport activities	38.8 (29.7;48.7)	46.6 (38.2;55.1)
Falls	23.5 (16.2;32.8)	22.1 (15.9;30)
Other traumatic causes	5.1 (2.2;11.4)	9.2 (5.3;15.3)
Non-traumatic causes	12.2 (7.1;20.2)	3.8 (1.6;8.6)
Unknown	—	0.8 (0.1;4.2)

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

included and the percentage of people with tetraplegia was significantly higher than in Switzerland, South Africa and Israel. Although no significant differences between the countries regarding AIS grades were detected, the early post-acute focus groups from United States did not include participants with AIS grades B and D. No differences could be identified for the long-term focus groups except a non-representation of people with AIS grade B in Israel, New Zealand and South Africa.

Saturation of data were generally reached after conducting four or five focus groups in each country (see Table 2). In

South Africa and United States, not enough focus groups could be performed to reach saturation because of a lack of available researchers who could manage recruitment and perform the group sessions.

#### Qualitative analysis and linking

For the *early post-acute context*, a total of 3122 relevant concepts were identified. These concepts were linked to 171 different second-level categories. In all, 158 concepts (5%) were too unspecific to be linked to ICF categories—for example, *'everything is different'*. Thirty-six (1%) were not classified by the ICF—for example, *'it takes time for your body to adjust'*. Of interest, 306 (10%) could be assigned to the yet to be classified *Personal Factors* component—for example, *'feelings of being a burden'*.

For the *long-term context*, a total of 4423 relevant concepts were identified in the focus groups. These concepts were linked to 188 different second-level categories. Again, 268 concepts (6%) were too unspecific to be linked to ICF categories—for example, *'it's just diabolically difficult'*. Further, 113 (3%) were not classified by the ICF—for example, *'discrimination'*. Again, 444 (10%) could be assigned to the yet to be classified *Personal Factors* component—for example, *'faith and optimism'*.

Irrespective of the context, all chapters of the ICF components *Body functions*, *Activities and Participation* and *Environmental factors* were represented by the ICF categories identified by the participants (see Tables 5–8).

Within the ICF component *Body Functions* the whole spectrum of typical functional problems associated with SCI were identified.<sup>4,5</sup> From the chapter *b1 Mental functions*, the ICF category *b152 Emotional functions* was most frequently identified in the focus groups (see Table 5). ICF categories addressing chapter 2 *Sensory functions and pain* were frequently identified in the analysis:

'...but also a lot of pain since the injury, chronic pain. That's pretty much it'.

**Table 4** SCI level, severity and American Spinal Injury Association (ASIA) Impairment Scale grading stratified by county (percent and 95% confidence interval)

Country	Context (n)	SCI level			SCI severity			AIS <sup>a</sup>			
		Paraplegia	Tetraplegia	Complete	Incomplete	Unknown	A	B	C	D	Unknown
Israel	EPA <sup>b</sup> (n=25)	56.0 (37.1;73.3)	44.0 (26.7;62.9)	28.0 (14.3;47.6)	72.0 (52.4;85.7)	—	28.0 (14.3;47.6)	4.0 (0.7;19.5)	36.0 (20.2;55.5)	28.0 (14.3;47.6)	4.0 (0.7;19.5)
	LT <sup>c</sup> (n=24)	54.2 (35.1;72.1)	45.8 (27.9;64.9)	54.2 (35.1;72.1)	37.5 (21.2;57.3)	8.3 (2.3;25.8)	59.1 (38.7;76.7)	—	27.3 (13.2;48.2)	9.1 (2.5;27.8)	4.5 (0.8;21.8)
New Zealand	EPA <sup>b</sup> (n=22)	45.5 (26.9;65.3)	54.5 (34.7;73.1)	50.0 (30.7;69.3)	50.0 (30.7;69.3)	—	50.0 (30.7;69.3)	4.5 (0.8;21.8)	18.2 (7.3;38.5)	27.3 (13.2;48.2)	—
	LT <sup>c</sup> (n=22)	45.5 (26.9;65.3)	54.5 (34.7;73.1)	36.4 (19.7;57.0)	31.8 (16.4;52.7)	31.8 (16.4;52.7)	53.3 (30.1;75.2)	—	6.7 (1.2;29.8)	40.0 (19.8;64.3)	—
South Africa	EPA <sup>b</sup> (n=8)	75.0 (40.9;92.9)	25.0 (7.1;59.1)	50.0 (21.5;78.5)	50.0 (21.5;78.5)	—	50.0 (21.5;78.5)	25.0 (7.1;59.1)	12.5 (2.2;47.1)	12.5 (2.2;47.1)	—
	LT <sup>c</sup> (n=13)	53.8 (29.1;76.8)	46.2 (23.2;70.9)	76.9 (49.7;91.8)	23.1 (8.2;50.3)	—	76.9 (49.7;91.8)	—	15.4 (4.3;42.2)	7.7 (1.4;33.3)	—
Switzerland	EPA <sup>b</sup> (n=20)	70.0 (48.1;85.5)	30.0 (14.5;51.9)	40.0 (21.9;61.3)	60.0 (38.7;78.1)	3.4 (0.6;17.2)	40.0 (21.9;61.3)	25.0 (11.2;46.9)	20.0 (8.1;41.6)	15.0 (5.2;36.0)	—
	LT <sup>c</sup> (n=29)	37.9 (22.7;56)	37.9 (22.7;56)	62.1 (44.0;77.3)	34.5 (19.9;52.7)	—	64.3 (45.8;79.3)	10.7 (3.7;27.2)	17.9 (7.9;35.6)	7.1 (2.0;22.6)	—
Thailand	EPA <sup>b</sup> (n=16)	37.5 (18.5;61.4)	62.5 (38.6;81.5)	37.5 (18.5;61.4)	62.5 (38.6;81.5)	—	37.5 (18.5;61.4)	18.8 (6.6;43.0)	12.5 (3.5;36.0)	31.3 (14.2;55.6)	—
	LT <sup>c</sup> (n=24)	66.7 (46.7;82)	33.3 (18.5;53.3)	75.0 (55.1;88.0)	25.0 (12.4;49.9)	—	75.0 (55.1;88.0)	12.5 (4.3;31.0)	8.3 (2.3;25.8)	4.2 (0.7;20.2)	—
USA	EPA <sup>b</sup> (n=7)	—	100 (64.6;100)	71.4 (35.9;91.8)	28.6 (8.2;64.1)	—	71.4 (35.9;91.8)	—	28.6 (8.2;64.1)	—	—
	LT <sup>c</sup> (n=20)	35.0 (18.1;56.7)	65.0 (43.3;81.9)	50.0 (29.9;70.1)	50.0 (29.9;70.1)	—	50.0 (29.9;70.1)	25.0 (11.2;46.9)	15.0 (5.2;36.0)	10.0 (2.8;30.1)	—
Total	EPA <sup>b</sup> (n=98)	51.0 (41.3;60.7)	49.0 (39.3;58.7)	41.8 (32.6;51.7)	58.2 (48.3;67.4)	—	41.8 (32.6;51.7)	12.2 (7.1;20.2)	22.5 (15.3;31.7)	22.5 (15.3;31.7)	1.0 (0.2;5.6)
	LT <sup>c</sup> (n=132)	53.8 (45.3;62.1)	46.2 (37.9;54.7)	58.3 (49.8;66.4)	34.1 (26.6;42.5)	7.9 (4.2;13.4)	63.1 (54.3;71.2)	9.0 (5.1;15.4)	15.6 (10.2;23.0)	11.5 (7.0;18.3)	0.8 (0.1;4.5)

<sup>a</sup>AIS: American Spinal Injury Association (ASIA) Impairment Scale.

<sup>b</sup>Early post-acute.

<sup>c</sup>Long-term.

**Table 5** Body functions (b): Number of focus groups in which ICF categories (second level) were identified by the participants

ICF code	ICF category title	Early post-acute context (n = 22)	Long-term context (n = 27)
<i>Chapter 1: Mental functions</i>			
b126	Temperament and personality functions	1	6
b130	Energy and drive functions	11	8
b134	Sleep functions	5	11
b140	Attention functions	1	5
b152	Emotional functions	15	18
b156	Perceptual functions	—	2
b160	Thought functions	5	3
b164	Higher-level cognitive functions	3	5
b180	Experience of self and time functions	5	6
<i>Chapter 2: Sensory functions and pain</i>			
b260	Proprioceptive function	7	8
b265	Touch function	16	16
b270	Sensory functions related to temperature and other stimuli	13	16
b280	Sensation of pain	19	23
<i>Chapter 4: Functions of the cardiovascular, haematological, immunological and respiratory systems</i>			
b410	Heart functions	—	2
b415	Blood vessel functions	—	4
b420	Blood pressure functions	—	5
b435	Immunological system functions	1	5
b440	Respiration functions	2	4
b445	Respiratory muscle functions	3	4
b450	Additional respiratory functions	2	1
b455	Exercise tolerance functions	7	11
<i>Chapter 5: Functions of the digestive, metabolic and endocrine systems</i>			
b510	Ingestion functions	2	3
b515	Digestive functions	3	5
b525	Defecation functions	21	23
b530	Weight maintenance functions	2	7
b535	Sensations associated with the digestive system	1	4
b545	Water, mineral and electrolyte balance functions	1	5
b550	Thermoregulatory functions	5	7
<i>Chapter 6: Genitourinary and reproductive functions</i>			
b610	Urinary excretory functions	3	3
b620	Urination functions	21	25
b630	Sensations associated with urinary functions	5	4
b640	Sexual functions	12	14
b660	Procreation functions	3	1
<i>Chapter 7: Neuromusculoskeletal and movement-related functions</i>			
b710	Mobility of joint functions	8	6
b720	Mobility of bone functions	—	2
b730	Muscle power functions	20	26
b735	Muscle tone functions	9	17
b750	Motor reflex functions	5	6
b755	Involuntary movement reaction functions	8	6
b760	Control of voluntary movement functions	7	7
b765	Involuntary movement functions	2	5
b770	Gait pattern functions	4	2
b780	Sensations related to muscles and movement functions	8	9
<i>Chapter 8: Functions of the skin and related structures</i>			
b810	Protective functions of the skin	5	10
b820	Repair functions of the skin	2	2
b830	Other functions of the skin	1	3
b840	Sensation related to the skin	2	3

Only categories that were identified in more than one focus group in at least one context are listed.

**Table 6** Body structures (s): Number of focus groups in which ICF categories (second level) were identified by the participants

ICF code	ICF category title	Early post-acute context (n = 22)	Long-term context (n = 27)
<i>Chapter 1: Structures of the nervous system</i>			
s120	Spinal cord and related structures	6	7
<i>Chapter 6: Structures related to the genitourinary and reproductive systems</i>			
s610	Structure of urinary system	5	3
<i>Chapter 7: Structures related to movement</i>			
s710	Structure of head and neck region	2	1
s720	Structure of shoulder region	3	1
s730	Structure of upper extremity	2	—
s740	Structure of pelvic region	2	1
s750	Structure of lower extremity	3	5
s760	Structure of trunk	7	6
<i>Chapter 8: Skin and related structures</i>			
s810	Structure of areas of skin	6	9

Only categories that were identified in more than one focus group in at least one context are listed.

**Table 7** Activities and Participation (d): Number of focus groups in which ICF categories (second level) were identified by the participants

ICF code	ICF category title	Early post-acute context (n = 22)	Long-term context (n = 27)
<i>Chapter 1: Learning and applying knowledge</i>			
d110	Watching	—	2
d155	Acquiring skills	5	—
<i>Chapter 2: General tasks and demands</i>			
d210	Undertaking a single task	2	—
d230	Carrying out daily routine	8	8
d240	Handling stress and other psychological demands	4	3
<i>Chapter 3: Communication</i>			
d330	Speaking	—	2
d350	Conversation	—	2
d360	Using communication devices and techniques	3	4
<i>Chapter 4: Mobility</i>			
d410	Changing basic body position	17	15
d415	Maintaining a body position	11	10
d420	Transferring oneself	14	12
d430	Lifting and carrying objects	6	10
d440	Fine hand use	14	16
d445	Hand and arm use	11	13
d450	Walking	17	18
d455	Moving around	10	16
d460	Moving around in different locations	9	12
d465	Moving around using equipment	8	15
d470	Using transportation	5	8
d475	Driving	9	11
<i>Chapter 5: Self-care</i>			
d510	Washing oneself	14	11
d520	Caring for body parts	10	4
d530	Toileting	11	16
d540	Dressing	14	12
d550	Eating	12	8

**Table 7** Continued

ICF code	ICF category title	Early post-acute context (n = 22)	Long-term context (n = 27)
d560	Drinking	5	2
d570	Looking after one's health	4	11
<i>Chapter 6: Domestic life</i>			
d610	Acquiring a place to live	1	3
d620	Acquisition of goods and services	4	10
d630	Preparing meals	12	9
d640	Doing housework	5	9
d650	Caring for household objects	4	9
d660	Assisting others	2	4
<i>Chapter 7: Interpersonal interactions and relationships</i>			
d710	Basic interpersonal interactions	2	4
d720	Complex interpersonal interactions	1	4
d730	Relating with strangers	2	1
d740	Formal relationships	—	3
d750	Informal social relationships	2	6
d760	Family relationships	6	6
d770	Intimate relationships	7	5
<i>Chapter 8: Major life areas</i>			
d825	Vocational training	—	2
d830	Higher education	—	3
d845	Acquiring, keeping and terminating a job	14	13
d850	Remunerative employment	10	12
d855	Non-remunerative employment	—	4
d870	Economic self-sufficiency	1	3
<i>Chapter 9: Community, social and civic life</i>			
d910	Community life	4	3
d920	Recreation and leisure	12	15
d930	Religion and spirituality	2	1
d940	Human rights	1	2
d950	Political life and citizenship	1	2

Only categories that were identified in more than one focus group in at least one context are listed.

Other frequently identified categories refer to functions of defecation and urination and sexual functions, which are covered by the ICF chapters b5 and b6:

'... for me bladder and bowel control is probably the biggest stumbling block when I became paralysed'.

A majority of the body functions mentioned address chapter 7 *Neuromusculoskeletal and movement-related functions*, for example, loss of muscle power, spasticity and coordination of movements. Furthermore, all second-level ICF categories that relate to impaired skin functions (ICF chapter 8) were identified (see Table 5).

The body structures named correspond to the body functions listed above (see Table 6).

From the component *Activities and Participation*, the chapters *d4 Mobility* and *d5 Self-Care* emerged as the most relevant topics for the participants in the early post-acute as well as in the long-term context. Examples include:

'Washing, showering, going to the toilet, that's a problem area every day' (Early post-acute context).

'Yes, you must have your own transport and if you don't have megabucks, to buy a car in a hurry is now a big problem as well because everyone wants to sell you their scrap, you

**Table 8** Environmental factors (e): Number of focus groups in which ICF categories (second level) were identified by the participants

ICF code	ICF category title	Early post-acute context (n = 22)	Long-term context (n = 27)
<i>Chapter 1: Products and technology</i>			
e110	Products or substances for personal consumption	13	17
e115	Products and technology for personal use in daily living	15	25
e120	Products and technology for personal indoor and outdoor mobility and transportation	15	21
e125	Products and technology for communication	2	13
e130	Products and technology for education	1	2
e135	Products and technology for employment	1	5
e140	Products and technology for culture, recreation and sport	5	8
e150	Design, construction and building products, and technology of buildings for public use	15	25
e155	Design, construction and building products, and technology of buildings for private use	15	24
e160	Products and technology of land development	8	18
e165	Assets	5	12
<i>Chapter 2: Natural environment and human-made changes to environment</i>			
e210	Physical geography	6	12
e215	Population	2	3
e220	Flora and fauna	2	2
e225	Climate	1	18
<i>Chapter 3: Support and relationships</i>			
e310	Immediate family	20	23
e315	Extended family	12	11
e320	Friends	15	18
e325	Acquaintances, peers, colleagues, neighbours and community members	7	20
e330	People in positions of authority	1	5
e340	Personal care providers and personal assistants	15	16
e345	Strangers	4	14
e350	Domesticated animals	3	1
e355	Health professionals	15	13
e360	Other professionals	2	10
<i>Chapter 4: Attitudes</i>			
e410	Individual attitudes of immediate family members	2	8
e415	Individual attitudes of extended family members	1	3
e420	Individual attitudes of friends	3	4
e425	Individual attitudes of acquaintances, peers, colleagues, neighbours and community members	5	5
e430	Individual attitudes of people in positions of authority	2	6
e445	Individual attitudes of strangers	4	10
e450	Individual attitudes of health professionals	9	4
e455	Individual attitudes of health-related professionals	—	5
e460	Societal attitudes	2	18
e465	Social norms, practices and ideologies	2	4
<i>Chapter 5: Services, systems and policies</i>			
e510	Services, systems and policies for the production of consumer goods	1	4
e515	Architecture and construction services, systems and policies	4	12
e520	Open space planning services, systems and policies	2	5
e525	Housing services, systems and policies	1	3
e530	Utilities services, systems and policies	—	5
e535	Communication services, systems and policies	—	4
e540	Transportation services, systems and policies	7	13
e545	Civil protection services, systems and policies	—	3
e550	Legal services, systems and policies	1	5
e555	Associations and organizational services, systems and policies	2	10
e560	Media services, systems and policies	—	3
e565	Economic services, systems and policies	—	3
e570	Social security services, systems and policies	3	12
e575	General social support services, systems and policies	1	6
e580	Health services, systems and policies	15	19
e585	Education and training services, systems and policies	—	4
e590	Labour and employment services, systems and policies	2	7
e595	Political services, systems and policies	—	5

Only categories that were identified in more than one focus group in at least one context are listed.

know. So that, transport is a big problem. I think one of the biggest' (Long-term context).

Three ICF categories addressing major life areas such as education and work were only identified in the long-term groups: *d825 Vocational training*, *d830 Higher education* and *d855 Non-remunerative employment*, whereas *d845 Acquiring, keeping and terminating a job* and *d850 Remunerative employment* were also identified in the early post-acute groups (see Table 7).

Regarding the ICF component *Environmental factors* irrespective of the context, both groups mentioned the chapters *e1 Products and technologies*, *e3 Support and relationships* and *e4 Attitudes*. From chapter 5 *Services, systems and policies*, seven ICF categories including *e585 Education and training services, systems and policies* and *e595 Political services, systems and policies* were only identified by the long-term groups (see Table 8). However, *e580 Health system, services and policies* was identified in almost all groups for both contexts:

'... For me, I'm glad this didn't happen in Guatemala! We do have the best health care system and it's better to have the option to get out and get moving instead of having the government dictate when they'll put you into rehab or if they'll put you into rehab' (Participant from New Zealand).

Participants from different countries reported different individual experiences with health systems and services but in general in all countries positive as well as negative aspects were identified:

'... but they [rehab centers] are only available to those that can afford it again' (Participant from South Africa).

Furthermore, participants from the Europe, United States and New Zealand repeatedly reported regarding their experience that a huge amount of extra time is needed for any activity, activities have to be planned ahead carefully and consequently spontaneity is lacking:

'... A lot of things you're doing different and it takes longer. I guess the time that it takes is one of the biggest things with me. It gets easier as you go, but like getting ready in the morning to get out for the day and you have to allow that extra time'.

These aspects were not mentioned in the focus groups in South Africa, Israel and Thailand, and are not covered by the ICF.

#### *Accuracy of the analysis*

The peer review was performed in all countries except South Africa and Israel. The Kappa coefficients for agreement ranged between 0.39 and 0.76 for the early post-acute context, and 0.46 and 0.73 for the long-term context (see Table 2).

## Discussion

To our knowledge this is the first qualitative study examining the problems of people with SCI from a worldwide perspective using the ICF as a frame of reference. A wide range of health aspects associated with SCI in the early post-acute and the long-term context were reported by the participants worldwide. A majority of the problems were reported both in the early post-acute and the long-term focus

groups. However, from these findings it cannot be concluded that those problems are equally relevant for all persons with SCI or equally frequent. The number of focus groups in which a specific problem came up may provide a rough impression regarding the potential relevance of a problem. It is essential to take into account that the qualitative methodology used in this study aimed at identifying the problems. The determination of the frequency of problems needs further investigation using quantitative methods.

In general, the findings from our qualitative study are supported by previous studies using quantitative methods. Regarding the ICF component *Body functions* the following aspects should be discussed.

Problems regarding sensory functions, pain, functions of defecation and urination and sexual functions were frequently experienced by the participants in our study. The relevance of pain in people with SCI was supported by a recent systematic review reporting chronic pain prevalence rates ranging from 26 to 96% in 42 studies.<sup>32</sup> In the literature, bladder and bowel dysfunction are reported to be common problems<sup>33,34</sup> and to be associated with low levels of physical quality of life domains<sup>35,36</sup> and satisfaction with life.<sup>37</sup> Furthermore, lack of bowel-bladder autonomy was predictive for mortality, occurrence of complications and re-admissions.<sup>33</sup> The impairment of sexual functions reported by the participants in our study was confirmed by studies showing that SCI not only impairs male erectile function and ejaculatory ability but also alters sexual arousal in men and women.<sup>38,39</sup>

Further, typical movement-related functions such as loss of muscle power, spasticity and coordination of movements were identified as major problems by the participants in our study. Regarding spasticity, it is important to note that the discomfort people with SCI experience was found to be only moderately related to the perceived degree of spasticity during an activity.<sup>40</sup> Clinical measures of muscle-tone-related spasticity should therefore be complemented by a self-rating to get a clearer picture of the individuals' perspective on the problem.<sup>41</sup> These findings highlight the need to carefully consider the consumer perspective in the treatment of SCI. In addition, it is important to recognize that impairments in the body functions such as pain, bowel, bladder and sexual function and spasticity mentioned above have a considerable negative effect on physical and mental quality of life as recently shown by Noonan *et al.*<sup>42</sup>

Skin problems were frequently mentioned by the participants in our study. Again, this result is supported by studies reporting 33–40% incidence of pressure ulcers during acute rehabilitation and a similar prevalence for people with SCI living in the community.<sup>43,44</sup> Furthermore, high rates of recurrence have been reported ranging from 31 to 79%.<sup>45,46</sup>

The participants reported a wide range of emotional problems such as depression or anxiety, which is covered by the ICF category *b152 Emotional functions*. It could be shown by several studies that depressive symptoms and anxiety are highly prevalent in people with SCI.<sup>47,48</sup> A recent systematic review suggests that approximately 30% of people with SCI are at risk of having a depressive disorder in the rehabilitation phase, and approximately 27% are at risk of



having raised depressive symptoms when living in the community. This review also establishes that people with SCI have higher comparative risks of anxiety disorder and elevated levels of anxiety.<sup>49</sup>

Finally, it is of interest that recent studies indicate that secondary conditions such as pressure ulcers and depressive symptoms are not only related with a loss of quality of life but also associated with a higher risk of mortality.<sup>50</sup> Thus, it seems most important to carefully consider them in SCI treatment.

Regarding the ICF component *Activities and Participation*, problems with self-care and mobility as well as restrictions regarding employment and leisure activities were most frequently addressed by the participants in our study. Previous research has consistently shown that people with SCI experience decreased employment opportunities, limited access to recreational activities and a lack of accessible transportation.<sup>51–54</sup> Problems with self-care have been identified as most important barrier to physical activities in the early post-acute situation.<sup>55</sup> Moreover, Liem *et al.*<sup>56</sup> reported a 42% increased odds of needing more help with activities of daily living per decade after SCI. The results of another study suggest positive changes within the first two decades after SCI, followed by a period of stability and a decline with ageing in some participation aspects.<sup>57</sup> Furthermore, participation was found to be strongly related to life satisfaction.<sup>58</sup>

The large number of identified ICF categories assigned to the component *Environmental factors* shows that many aspects of an individuals' environment can be important facilitators or barriers for people with SCI. Previous studies have already highlighted the role of environmental factors in participation<sup>59</sup> and even reported a potential effect on mortality.<sup>60</sup> The ICF category *e580 Health systems, services and policies* was identified in almost all groups irrespective of the context and the country. The relevance of this finding is supported by Whiteneck *et al.*<sup>52</sup> who reported that the provision of health care was one of the main environmental barriers from the perspective of people with SCI. Interestingly, our study participants also noticed and reported the positive aspects of the health-care system and services.

As mentioned, the vast number of experiences that relate to *Personal Factors* is an important finding. A majority of the personal factors mentioned refer to strategies of coping with the injury. Specifically, keeping a positive attitude and being optimistic was identified frequently as a way to positively influence ones life after SCI. The relevance of this finding is supported by studies, which investigated the meaning of 'hope' in the process of coping with a SCI or the influence of personal factors such as coping and cognitive appraisal on adjustment to the injury.<sup>61–64</sup> Thus, it seems essential that those aspects are considered when applying the ICF.<sup>65,66</sup> To describe personal factors systematically and comprehensively, a classification of the ICF component *Personal factors* could be helpful in the future.<sup>18</sup>

There are also some limitations of this study that should be mentioned. Kappa coefficients showed levels of agreement between the researchers who performed the linking in the different countries that ranged from low to high. Although

the training workshop for the Regional Coordinators included familiarization of the linking process and rules, the quality of the linking varied. If applying the same methodology in future studies a more intensive training of the researchers should be provided.

Saturation is worth mention. The criterion of saturation was not fulfilled by 3 of the 12 sub-studies and even when applying the specific criterion participants in an additional focus group still might name new themes and concepts not yet reported.

In qualitative research, sample sizes are typically small because intensive data analysis is required. In addition, qualitative inquiry focuses on the generation of hypotheses rather than on testing of research questions. The international approach of our study made it possible to include a high number of participants and to generate a large amount of information to assure that the whole spectrum of lived experiences of persons with SCI is covered. Although the inclusion of people with SCI in all World Health Organization world regions contributed to the international generalizability of the results, it could be argued that the external validity of the results is restricted by the selection of specific study centers in a limited number of countries with an unbalanced representation of participants from the African world region.

Furthermore, it should be considered that the AIS grade A was not equally represented among the early post-acute and long-term focus groups. In addition, the early post-acute focus groups performed in United States significantly differed from other countries regarding SCI level and AIS grade. This may also have influenced the results.

Overall, it is important that the primary objective of this study was to describe the lived experience of persons with SCI using the language of the ICF. The results showed that the ICF language in general covers a broad range of the individual experiences of persons with SCI. However, there are several details that cannot be expressed when simply using the ICF categories. Verbatim examples show that participants provided relevant information regarding the relations between functional problems and contextual factors. Further in-depth content analysis of the focus groups could be performed to contribute to a greater understanding of the experience of living with SCI.

Moreover, data analysis indicated that cultural differences may have contributed to some findings, for example, the reported amount of extra time needed for activities, the lack of spontaneity as well as differences in the perception of the health-care system. Further detailed qualitative analysis is needed to capture the potential influence of cultural differences on the problems experienced by people with SCI in our study.

Finally and not least, participants largely appreciated the opportunity to talk regarding issues that may not be addressed and to share their experiences with other persons concerned:

Participant A: 'The thing is, [moderators' name], is that these are things that people never ask'. Participant B: 'Yeah—we don't typically talk about most of this stuff—I mean I do with friends and family but it's not an every day

occurrence that you talk about this stuff'. Participant C: 'And we don't get to talk about this to each other'.

### Conflict of interest

The authors declare no conflict of interest.

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