

ORIGINAL ARTICLE

Explanatory power does not equal clinical importance: study of the use of the Brief ICF Core Sets for Spinal Cord Injury with a purely statistical approach

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Study design: Psychometric study analyzing the data of a cross-sectional, multicentric study with 1048 persons with spinal cord injury (SCI).

Objective: To shed light on how to apply the Brief Core Sets for SCI of the International Classification of Functioning, Disability and Health (ICF) by determining whether the ICF categories contained in the Core Sets capture differences in overall health.

Methods: Lasso regression was applied using overall health, rated by the patients and health professionals, as dependent variables and the ICF categories of the Comprehensive ICF Core Sets for SCI as independent variables.

Results: The ICF categories that best capture differences in overall health refer to areas of life such as self-care, relationships, economic self-sufficiency and community life. Only about 25% of the ICF categories of the Brief ICF Core Sets for the early post-acute and for long-term contexts were selected in the Lasso regression and differentiate, therefore, among levels of overall health.

Conclusion: ICF categories such as *d570 Looking after one's health*, *d870 Economic self-sufficiency*, *d620 Acquisition of goods and services* and *d910 Community life*, which capture changes in overall health in patients with SCI, should be considered in addition to those of the Brief ICF Core Sets in clinical and epidemiological studies in persons with SCI.

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INTRODUCTION

Information about and measures of domains of functioning affected by spinal cord injury (SCI) are available from various studies, but this information is very heterogeneous because different assessment instruments are used.¹ To address this issue of heterogeneous information, some initiatives have emerged over the previous years to define 'what to measure' and 'which measures to use' in SCI clinical practice and research.

The data sets of the International Spinal Cord Society (ISCoS), for example, standardize the collection and reporting of the minimal number of domains needed to evaluate and compare the results of published studies.² The ISCoS is developing additional data sets, including ones about quality of life and participation. At the moment, however, the available ISCoS data sets focus on impairments of body systems (www.iscos.org.uk).

Researchers at the ICF Research Branch, a cooperation partner of the WHO Collaborating Centre for the Family of International Classifications in Germany (at DIMDI), with WHO and ISCoS have developed both Comprehensive and Brief Core Sets using the International Classification of Functioning, Disability and Health (ICF)³ for early post-acute (EPA) and long-term (LT) contexts.⁴ 'Early post-acute' refers to the phase between the beginning and completion

of comprehensive rehabilitation, whereas 'long-term' refers to the time following completion of comprehensive rehabilitation and when people with SCI live in the community.

The Brief ICF Core Sets for SCI are composed of the essential ICF categories that need to be taken into account for any patient with SCI in the EPA or LT contexts. They serve as a starting point for SCI-specific research and clinical documentation.⁵ As the Brief ICF Core Sets are international standards for describing the functioning in SCI, their usefulness is clear. However, potential limitations in their use need further investigation. One open question is whether the ICF categories in the Brief ICF Cores Sets are those that best capture differences in levels of overall functioning in persons with SCI. This characteristic is important for the application of the ICF Core Sets in clinical practice, as they were designed to monitor disease and rehabilitation management and follow up patients over their life spans.⁶

The general objective of this study was, therefore, to determine whether the ICF categories of the Brief ICF Core Sets for SCI are the ones that best capture differences in levels of overall functioning. The first specific aim was to identify the set of ICF categories that best capture differences in overall health as reported by patients and by health professionals in the EPA and LT contexts. As we adopted the

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WHO position that functioning is the operationalization of health, we used a general-health question as external standard. The second aim was to compare those ICF categories with the ones already existing in the Brief Core Sets.

MATERIALS AND METHODS

Study design

This was a psychometric study, in which secondary analyses of data collected in a cross-sectional, multicentric study performed within the international project called 'Development of ICF Core Sets for Spinal Cord Injury' were conducted. Data were collected in 16 SCI-specialized centers in 14 countries from June 2006 to January 2008.⁷

Health professionals recorded the participants' functional problems as well as the relevant environmental factors using all 264 second-level ICF categories. The ICF categories of the components *body functions*, *body structures*, and *activities and participation* were coded dichotomously: 0 indicated no impairment, limitation or restriction and 1, the presence of an impairment, limitation or restriction. In the ICF component *environmental factors*, the health professional recorded whether an ICF category was a facilitator (+1), a barrier (-1) or did not have any influence (0). In addition, the overall health of persons with SCI was self-reported as well as rated by the health professional performing the interview in a scale from 0 (excellent) to 10 (poor).

In this study, we did not use the 264 second-level categories, but only the 149 contained in the Comprehensive ICF Core Set for EPA and the 169 of the Comprehensive ICF Core Set for LT.

Study population

In total 1048 persons (489 in the EPA and 559 in the LT contexts) over 18 years of age with SCI participated in the study and were included in the analyses. Women represented 23.1% of the participants in the EPA context and 21.6% in the LT context. In the EPA 50.5% of the participants suffered from paraplegia, in the LT they were 56.9%. The remaining participants were persons with a tetraplegia.⁷

Statistical analysis

Lasso regression was used to identify the ICF categories that best capture differences in levels of overall health. Lasso is a regression technique that selects variables by setting the regression coefficients of those independent variables with low explanatory value to zero. The more an estimated regression coefficient deviates from zero, the higher the explanatory value of the independent variable with respect to the dependent variable.

The rating of the participants about their health and the rating of the health professional were the dependent variables. Both self-perceived health as well as the ratings of the health professionals were used because health professionals and patients refer to different but complementary aspects of health when they rate health.^{8,9}

The ICF categories contained in the Comprehensive ICF Core Sets were the independent variables. However, we decided not to enter 15 and 7 ICF categories from the 149 and 169 second-level ICF categories of the Comprehensive ICF Core Sets for EPA¹⁰ and LT¹¹ in the regression analyses because they are either a problem (ICF categories with frequencies >90%) or not a problem for most of the patients (ICF categories with frequencies <10%). As they do not vary, they cannot explain the variability of the dependent variable. If they were still included despite the lack of variation, they would bias the regression modeling. See Table 1 for the ICF categories with frequencies >90%. The explanatory value of ICF categories for overall health was ranked according to the size of their regression coefficients resulting from the Lasso regression.¹²

Each environmental factor was recoded in two dichotomous variables: facilitator (coded as f) and barrier (coded as e), with 0 indicating no facilitator or barrier and 1 indicating the presence of barrier or facilitator.

To achieve our two study aims, several analysis steps were performed for both dependent variables, overall health reported by patients and by health professionals, and the respective SCI contexts, the EPA and LT:

- (1) A Lasso regression model for each ICF component separately was computed.
- (2) A Lasso regression overall selected ICF categories in step 1 was computed.
- (3) The ICF categories resulting from step 2, which correlated (>0.5) with another ICF category and presented a lower correlation with the dependent overall health rating, were excluded from the analyses. This step was performed to avoid redundancy of information in the independent variables.
- (4) A final Lasso regression with the remaining ICF categories from step 3 was computed.
- (5) The results of step (4) were compared with the ICF categories contained in the respective Brief ICF Core Sets for EPA and LT.

The software package lars¹³ was used for the computation of the Lasso regression with R.¹⁴

RESULTS

The mean and standard deviations (s.d.) of patients' self-reported overall health were 4.14 (s.d. = 2.49) in the EPA context and 3.68 (s.d. = 2.28) in the LT context. The mean overall health rated by health professionals in the EPA context was 5.90 (s.d. = 2.13) and 6.55 (s.d. = 2.05) in the LT context.

Table 1 presents in the first and fifth columns after the titles of the ICF categories the ICF categories of the Brief ICF Core Sets.^{10,11} The following columns show the ranks across ICF components representing the relevance of the ICF categories with respect to their ability to capture differences in levels of overall health as reported by patients and health professionals in the EPA and LT contexts, respectively. We decided not to set an arbitrary cutoff and to present all the ICF categories selected with the Lasso regression in the table because in this way clinicians and researchers can get insight into the importance of those ICF categories that they may want to describe or assess in their patients with respect to overall health.

Comparing the columns of Table 1 containing the Brief ICF Core Sets and those with the ranks of the ICF categories resulting from the Lasso regression allows to extract the commonalities and differences between the ICF categories of the Brief ICF Core Sets and those selected in this study.

The comparison of the ICF categories selected in the Lasso regression with the ones already existing in the Brief Core Sets reveals that in the EPA context only 8 out of 30 ICF categories of the Brief ICF Core Set were selected in the Lasso regression. These ICF categories and their corresponding ranks when using the rating of the patients (P) and the health professionals (HP) as independent variables, respectively, were: *b152 Emotional functions* (P:11), *b620 Urination functions* (HP:6), *b810 Protective functions of the skin* (P:15), *s430 Structure of respiratory system* (HP:13), *s610 Structure of urinary system* (P:8), *d530 Toileting* (P:7), *e120 Products and technology for personal indoor and outdoor mobility* (P:9; HP:20), and *f340 Personal care providers and personal assistants* (HP:8).

In the LT context, 10 of 42 ICF categories of the Brief ICF Core Set obtained a rank in the Lasso regression, namely: *b152 Emotional functions* (P:6; HP:27), *b620 Urination functions* (HP:34), *b640 Sexual functions* (HP:19), *b810 Protective functions of the skin* (HP:37), *d240 Handling stress and other psychological demands* (P:9), *d445 Hand and arm use* (P:16; HP:16), *d520 Caring for body parts* (HP:2), *f150 Design, construction and building products and technology of buildings for public use* (P:12), *f155 Design, construction and building products and technology of buildings for private use* (HP:20), and *f340 Personal care providers and personal assistants* (HP:14).

All but one (*d520 Caring for body parts* in the LT context) of the ICF categories that obtained ranks 1 to 3 in the Lasso selection were

Table 1 ICF categories from the Brief ICF Core Sets for spinal cord injury, the ICF categories with frequencies >90%, and the ranked ICF categories from the Lasso regressions in the health professional and patient's general health perspectives, for the EPA and LT contexts respectively

	ICF-code	Title	EPA				LT			
			Brief	90%	Lasso		Brief	90%	Lasso	
					Patient	HP			Patient	HP
Body functions	b126	Temperament and personality functions			17	12			6	27
	b130	Energy and drive functions			6				7	7
	b134	Sleep functions							5	22
	b152	Emotional functions	x		11		x		4	6
	b270	Sensory functions related to temperature and other stimuli				19				
	b280	Sensation of pain	x				x			
	b415	Blood vessel functions			28	7				
	b420	Blood pressure functions								29
	b430	Haematological system functions			27	11				
	b440	Respiration functions	x							
	b445	Respiratory muscle functions				15				
	b455	Exercise tolerance functions								35
	b525	Defecation functions	x				x			
	b530	Weight maintenance functions								26
	b550	Thermoregulatory functions				16				
	b610	Urinary excretory functions								33
	b620	Urination functions	x			6	x			34
	b640	Sexual functions					x			19
	b670	Sensations associated with genital and reproductive functions			20					
	b710	Mobility of joint functions			14		x			
	b715	Stability of joint functions				18				
	b730	Muscle power functions	x	x			x	x		
	b735	Muscle tone functions	x				x	x		
b740	Muscle endurance functions		x				x			
b750	Motor reflex functions						x			
b755	Involuntary movement reaction functions			13						
b760	Control of voluntary movement functions			24						
b780	Sensations related to muscles and movement functions				17					
b810	Protective functions of the skin	x		15		x			37	
b840	Sensation related to the skin							13	15	
Body structures	s120	Spinal cord and related structures	x	x			x	x		
	s430	Structure of respiratory system	x			13	x			
	s610	Structure of urinary system	x		8		x			
	s720	Structure of shoulder region			29					
	s810	Structure of areas of skin				22	x			
Activities and participation	d155	Acquiring skills								12
	d230	Carrying out daily routine					x			
	d240	Handling stress and other psychological demands				9	x		9	
	d360	Using communication devices and techniques								4
	d410	Changing basic body position	x				x			
	d420	Transferring oneself	x				x			
	d435	Moving objects with lower extremities		x						
	d445	Hand and arm use	x				x		16	16
	d450	Walking	x							
	d455	Moving around		x			x	x		
	d460	Moving around in different locations		x						
	d465	Moving around using equipment			4	3	x			
	d470	Using transportation					x			
	d475	Driving								10
	d510	Washing oneself	x							
	d520	Caring for body parts					x			2
	d530	Toileting	x		7		x			

Table 1 (Continued)

ICF-code	Title	EPA			LT				
		Brief	90%	Lasso		Brief	90%	Lasso	
				Patient	HP			Patient	HP
d540	Dressing	x							
d550	Eating	x			x				
d560	Drinking	x							
d570	Looking after one's health			1				3	
d620	Acquisition of goods and services							1	
d630	Preparing meals			2	2				
d660	Assisting others							11 3	
d770	Intimate relationships			3	4			8 11	
d820	School education							18	
d840	Apprenticeship (work preparation)							17	
d845	Acquiring, keeping and terminating a job							5	
d870	Economic self-sufficiency				1			2	
d910	Community life							1	
d930	Religion and spirituality			18	10				
Environmental factors (barriers)	e110	Products or substances for personal consumption				x			
	e115	Products and technology for personal use in daily living	x			x			
	e120	Products and technology for personal indoor and outdoor mobility and transportation	x		9	20	x		
	e125	Products and technology for communication			26				
	e135	Products and technology for employment			25	14		31	
	e140	Products and technology for culture, recreation and sport			22				
	e150	Design, construction and building products and technology of buildings for public use					x		
	e155	Design, construction and building products and technology of buildings for private use					x		
	e310	Immediate family	x				x		
	e325	Acquaintances, peers, colleagues, neighbours and community members			10			17	
	e340	Personal care providers and personal assistants	x				x		
	e355	Health professionals	x				x		
	e360	Health-related professionals			16				
	e415	Individual attitudes of extended family members						14 8	
	e455	Individual attitudes of health-related professionals						25	
	e525	Housing services, systems and policies						32	
	e555	Associations and organizational services, systems and policies			5	5		18	
e575	General social support services, systems and policies			12					
e580	Health services, systems and policies					x			
Environmental factors (facilitators)	f110	Products or substances for personal consumption				x			
	f115	Products and technology for personal use in daily living	x			x			
	f120	Products and technology for personal indoor and outdoor mobility and transportation	x				x		
	f140	Products and technology for culture, recreation and sport			23			15 9	
	f150	Design, construction and building products and technology of buildings for public use			19		x	12	
	f155	Design, construction and building products and technology of buildings for private use					x	20	
	f165	Assets						21 39	
	f310	Immediate family	x	x			x		
	f325	Acquaintances, peers, colleagues, neighbours and community members			21				
	f340	Personal care providers and personal assistants	x			8	x	14	
	f355	Health professionals	x	x			x		
f360	Health-related professionals			30			30		

Table 1 (Continued)

ICF-code	Title	EPA			LT		
		Brief	90%	Lasso	Brief	90%	Lasso
				Patient			HP
f420	Individual attitudes of friends						36
f440	Individual attitudes of personal care providers and personal assistants					19	
f450	Individual attitudes of health professionals		x			20	
f460	Societal attitudes						28
f510	Services, systems and policies for the production of consumer goods						21
f515	Architecture and construction services, systems and policies						13
f530	Utilities services, systems and policies						23
f540	Transportation services, systems and policies					21	
f575	General social support services, systems and policies						38
f580	Health services, systems and policies				x		
f585	Education and training services, systems and policies					10	24

Abbreviations: EPA, early post-acute; HP, health professionals; ICF, International Classification of Functioning, Disability and Health; LT, long-term.

Column *Brief* presents the ICF categories contained in the Brief ICF Core Sets for Spinal Cord Injury in the early post-acute (EPA) and long-term (LT) context. Columns Lasso Patients and Lasso HP present the ranks representing the relevance of the ICF categories and their ability to capture differences in levels of overall health as reported by patients and health professionals in the EPA and LT contexts, respectively. Columns 90% show the ICF categories with frequencies >90% that were not included in the analyses because of the lack of variance.

not included in the Brief ICF Core Sets. These ICF categories were, in the EPA context, *d465 Moving around using equipment* (HP:3), *d570 Looking after one's health* (P:1), *d630 Preparing meals* (P:2; HP:2), *d770 Intimate relationships* (P:3) and *d870 Economic self-sufficiency* (HP:1). In the LT context the ICF categories were *d520 Caring for body parts* (HP:2), *d570 Looking after one's health* (P:3), *d620 Acquisition of goods and services* (P:1), *d660 Assisting others* (HP:3), *d870 Economic self-sufficiency* (P:2) and *d910 Community life* (HP:1).

Table 1 also includes the ICF categories with frequencies >90%, which were not included in the Lasso regression because of their lack of variance but are very relevant for the description of the functioning and health of persons with SCI.

DISCUSSION

This investigation reveals that the ICF categories that best capture differences in overall health as reported by patients and health professionals in the EPA and LT contexts are areas of life included in the ICF component *activities and participation* and mainly refer to self-care, relationships, economic self-sufficiency and community life. Interestingly, only one of those identified ICF categories is also included in one of the Brief ICF Core Sets for SCI, namely *d520 Caring for body parts*. We also show that only about 25% of the ICF categories of the Brief ICF Core Sets for the EPA and for LT were selected in the Lasso regression and differentiate, therefore, among levels of overall health.

There are reasons that explain why there is little overlap between the categories of the Brief ICF Core Sets and those resulting from this investigation. Still there are practical implications of this research for the use of the Brief ICF Core Sets, especially when they are used in combination with a dichotomous scale (0: no problem; 1: problem) as in this study. We will first discuss the reasons why there is little overlap before turning to the implications for their use.

First, ICF categories that are central for the description of functioning and health in SCI (those with frequencies >90%) and that are part of the Brief ICF Core Sets were not included in the analyses and, therefore, are not part of the Lasso selection.

Second, the dependent variables were overall health reported by patients and by health professionals. This choice is based on the assumption that functioning and, more concretely, the ICF categories are an operationalization of the health concept.¹⁵ However, the experts at the conference were not asked to think about how to describe the health of their patients during the decision-making and consensus process, but to select those ICF categories that are most relevant in SCI and should be reported in every clinical study.

Third, the Brief ICF Core Sets contains the ICF categories, which are considered to be relevant from the perspective of clinical experts treating persons with SCI. They represent the minimum catalog of ICF categories that are necessary from a clinical point of view to characterize functioning in a population of persons with SCI regardless of any psychometric considerations. Therefore, issues such as *b280 Sensation of pain* and *d420 Transferring oneself* cannot be omitted from the Brief ICF Core Sets. The clinical expertise, as well as the SCI literature, shows that they are fundamental aspects of functioning in SCI.¹⁶ The Lasso set was developed on the basis of a regression technique in which the variability of both dependent and independent variables is fundamental. The selection leads by definition to a set of ICF categories that differentiates among different levels of the dependent variable, regardless of their clinical relevance.

How would a researcher proceed in light of the results of this investigation? S/he would, in any study focusing on functioning and disability, assess those categories included in the Brief ICF Core Sets of the respective context. In addition, s/he would go through Table 1 and add those categories that have a rank in the columns 'Lasso', making sure that those with the best ranks are first included. If for practical reasons not all ranked ICF categories can be included, a cutoff would have to be established according to the specific situation.

This strategy would imply that many different ICF categories, such as *d570 Looking after one's health*, *d870 Economic self-sufficiency*, *d620 Acquisition of goods and services* and *d910 Community life*, that had rank 1 in the Lasso regression, would be in addition considered in clinical and epidemiological studies to capture changes in overall health in patients with SCI.

In addition, the importance of describing areas of life related to *activities and participation* domains in persons living with SCI when capturing overall health is emphasized for both the EPA and the LT context. Thus, this study encourages researchers to always consider these areas when performing studies with persons with SCI.

Finally, it is important to mention that the component *environmental factors* (barriers and facilitators) contains a large number of ICF categories that were ranked as relevant in both the EPA and LT contexts from the perspectives of the patients and the health professionals. This supports the importance of the environment in the life of persons with SCI and the need to address it. It is worthy to invest additional efforts in assessing information about them in clinical and epidemiological studies.¹⁷

CONCLUSION

In this investigation, a set of ICF categories is identified that best capture differences in overall health in persons with SCI as reported by patients and health professionals in the EPA or LT contexts. We recommend using these ICF categories in addition to those in the respective ICF Core Sets in clinical and epidemiological studies. However, these results have to be confirmed in future investigations, the final result of which could be the adaptation of the Brief ICF Core Sets for SCI.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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