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INVITED REVIEW

Setting Up a Cohort Study on Functioning
Deciding What to Measure

ABSTRACT

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The objectives of this article were to (1) answer the question of what to measure in a cohort study in which the main focus is the understanding of functioning over time for a specific population and to (2) describe the process of determining what to measure using a theory-informed selection of domains of functioning based on the International Classification of Functioning, Disability and Health (ICF). The Swiss Spinal Cord Injury Cohort Study, a cohort study being carried out in Switzerland for a population of persons with spinal cord injury, was used as an example. A set of domains for the Swiss Spinal Cord Injury Cohort Study was identified demonstrating the application of the methodology. This set consisted of 45 categories of the ICF. Defining what to measure using the ICF is a valuable technique for the cohort researcher because it guarantees comparability of data and comprehensiveness of scope, enhancing the prospects of the study results being understood and is consequently used by health professionals as well as in other contexts, such as in health and social policy.

Key Words: Research Design, Epidemiology, Cohort Studies, ICF, Spinal Cord Injury

Health, for an individual or a population, is important not only for what it is but also for what it makes possible. Health "broadens fair opportunity;"[1] it is a precondition for any plan, aspiration, or goal in life. When the health of an individual or a population is compromised, what matters to them is at risk. In spinal cord injury (SCI), for example, individuals will experience profound and far-reaching changes in their heath that threaten to undermine nearly all aspects of their life that define who they are as individuals. It is, therefore, essential to understand this impact of ill health and respond in ways that ensure, as far as possible, that this life disruption does not destroy what is important to people and how they wish to live their lives.

Understanding Functioning and Health

Understanding all that health is and what its determinants are is one of the main challenges for health researchers, clinicians, and health policymakers.

Unless health is made concrete and operational, however, it cannot be measured or analyzed. The concept of functioning, as currently defined by the World Health Organization, is the operationalization of health that comprehensively captures what matters to people.[2] Studies that aim to comprehensively understand health and its impact on people's lives, such as the example used in this paper, the Swiss Spinal Cord Injury Cohort Study (SwiSCI), therefore relies on functioning as a meaningful operationalization of health.

Functioning can be described in discrete categories, such as memory, grasping, walking, self-care, and interpersonal relationships, and in terms of these categories, it can be measured. We know much about functioning and problems with functioning; our knowledge, however, is usually restricted to specific and isolated categories that are directly affected by adverse health conditions such as diseases, disorders, and injuries. In addition, we know relatively little about how functioning in persons with health conditions, such as SCI, changes over the life span. Our knowledge is fragmentary, and we do not have a comprehensive understanding of how areas of functioning interact or affect each other.

The World Health Organization has taken the first step to address the challenge of a comprehensive understanding of functioning by developing an international descriptive classification in the International Classification of Functioning, Disability, and Health (ICF).[3] The ICF is both a comprehensive conceptual model of functioning and a classification of functioning and its determinants in the environment and in the person. The ICF model and classification are comprehensive, not only because it accounts for the determinants of functioning but also because it covers the full range of categories of functioning, from body level functions and structures to the categories of functioning at the person and societal levels as activities and participation.

The challenge of understanding changes in functioning over time is methodologically addressed by longitudinal studies, and in the case of the study of functioning in a specified population such as persons with SCI, a cohort study is the ideal design. A cohort study is a longitudinal study of the same group of people (the cohort) in time. Cohort studies aim the description of relationships among variables, especially casual relationships.[4]

Theory-Informed Approach to Performing Cohort Studies Using the ICF

Cohort studies are resource- and cost-intensive and have to be carefully planned so that only variables relevant to the main focus of interest are taken into account and no relevant variables are missed. When the cohort study focuses on functioning, from a comprehensive perspective, the ICF can ensure that all potentially relevant variables are taken into account. The use of the ICF avoids the practice of selecting variables based on convenience or other practical considerations, such as their use in available instruments, or based on tradition. Because the ICF is built on a comprehensive model, it allows researchers to determine what to measure in a top-down, theory-informed manner. In addition, the ICF contributes data comparability across populations and settings, which further adds to the value of cohort studies.

In the ICF, the determinants of functioning are the health condition, personal factors, and environmental factors. Health conditions are classified in the International Statistical Classification of Diseases and Related Health Problems, and the classification of environmental factors is provided in the ICF. How environmental factors can be incorporated into cohort studies is discussed in an adjunct paper.[5] Personal factors, however, are not classified in the ICF, but they can and should be included in a cohort study for a complete understanding of functioning. Lacking a classification, a cohort study such as SwiSCI is challenged to come up with its own proposal for capturing the psychologic-personal perspective on functioning and disability, and that proposal is also presented in an adjunct paper.[6]

Steps for Defining What to Measure in a Cohort Study

The ICF categories are hierarchically arranged in the classification, with increasing levels of specificity. The chapter headings are the most general, for example b1 Mental functions, and the second- (b152 Emotional Functions), third- (b1521 Regulation of Emotion Functions), and in the case of some body functions and structures, fourth-level categories are increasingly more specific. At any of these levels, however, for the purposes of determining what to measure, it is always important to identify particularly relevant aspects of these categories to measure. To distinguish among levels of specificity, the relationship between levels in the ICF, we will use the term *category specification* to denote those aspects of ICF categories that are appropriate for the task of determining what to measure.

For example, researchers should decide whether to assess an ICF category such as b152 Emotional

functions or an aspect of this category as a specification relevant to the study, such as "depression" or "anxiety," neither of which is ICF an third-level term under b152. A category specification of an ICF category must, at a minimum, be the same dimension of functioning as the category itself: only body structures can be specifications of body structures, only body functions can be specifications of body functions, and so on. By the same reasoning, only personal factors can be specifications of personal factors, and only environmental factors can be specifications of environmental factors. For guidance, the operational definition of each ICF category can be used to select possible category specifications because these definitions were designed to provide users of the ICF with sufficient guidance to apply on each ICF category. The task of the researcher is to decide at what level of detail he or she wishes to measure in the study and which category specifications to use.

For this reason, two steps are required when defining what to measure in a cohort study on functioning: first, determine which ICF categories have to be addressed for a comprehensive understanding of functioning for the specific population, which will be called the domain set here and second, determine which category specifications of ICF categories in the domain set need to be measured.

Objective and Specific Aims

The objective of this article, therefore, was to describe the process of addressing the question of what to measure in a cohort study in which the main focus is on the understanding of functioning in time for a specific population. The specific aims were (1) to describe the process that establishes a domain set of ICF categories that determine what to measure in a cohort study on functioning and (2) to describe an approach for selecting category specifications for each ICF category in the domain set to be measured in the study.

In this paper, SwiSCI, a cohort study being carried out in Switzerland on a population of persons with spinal cord injury, will be used as a case in point to demonstrate the methodology.[7]

METHODS
Domain Set of What to Measure

The process of selecting ICF categories that make up the Domain Set of what to measure has the following steps: (1) use the ICF categories of the Minimal Generic Set as the starting point or default set, (2) identify and add the ICF categories

of the ICF Core Set applicable to the cohort study population where available, and (3) determine and add relevant factors from the psychologic-personal perspective.

Use of the ICF Categories of the Minimal Generic Set

To facilitate data comparability across study populations and time, a Minimal Generic Set of ICF categories has been developed (Cieza et al., unpublished data, 2011). This minimal set contains the smallest number of categories of functioning that can explain significant differences between people with different levels of health. Its development was based on the eight functioning domains that were used in the World Health Survey conducted by the World Health Organization in the early 2000's and in a statistical analysis of population-based surveys. Any cohort study on functioning can profitably use the Minimal Generic Set as its starting point.

The following ICF categories contained in the current version of Minimal Generic Set[5] are the starting point of the domain set:

 b130 Energy and drive functions
 b152 Emotional functions
 b280 Sensation of pain
 d230 Carrying out daily routine
 d450 Walking
 d455 Moving around
 d850 Remunerative employment

Although the default is to include all of these ICF categories, in the case of d450 Walking and d455 Moving around, because both address related aspects of mobility, it might be preferable to select one for the study population.

Identifying and Adding ICF Categories from Applicable ICF Core Sets

In addition to the generic approach guaranteed by the Minimal Generic Set, ICF Core Sets have been developed across a range of the most burdensome health conditions[8] and settings. The ICF Core Sets are selections of ICF categories that capture the essence of what is relevant to people with specific health conditions or in determined health-care settings. The selection of categories for the ICF Core Sets is based on evidence and an international expert consensus process.[9]

For all of the 22 condition-specific ICF Core Sets developed to date, a brief and a comprehensive ICF Core Set has been created. The Brief ICF Core Set is composed of the essential ICF categories that

should be taken into account for any patient with the health condition or in any setting for which the core set was developed. The Brief Core Set, or simply the ICF Core Set, captures the essence of the experience of persons with a specific health condition or in a specific setting. It therefore serves as the starting point for condition-specific research and basic clinical documentation. The Comprehensive ICF Core Set serves as a reference pool of potentially relevant categories of functioning and determinants of functioning that can be drawn upon to describe specific issues of functioning in the population under study. The Comprehensive ICF Core Set may also be used in multidisciplinary rehabilitation programs.

The ICF Research Branch homepage (www.ICF-research-branch.org) provides a list of available ICF Core Sets, and the researcher can consult this list to determine which is applicable to the study population. The brief versions are the starting point because the domain set should only include the essential ICF categories. However, additional categories from the comprehensive sets (or the ICF as a whole if necessary) can always be considered and added to this set if required by the study objectives and study population. In general terms, if the ICF categories from the brief ICF Core Set were not already included in the Minimal Generic Set, they are then added to the domain set.

Determining and Adding Relevant Factors from the Psychologic-Personal Perspective

Finally, for the domain set of what to measure, a selection of relevant factors that capture the psychologic-personal perspective on functioning and disability need to be added. Until the research has been done to determine the conceptual nature of the component of personal factors in the content model for ICF,[10] two approaches can be followed to identify classes of such factors as candidates for inclusion in the domain set (Cieza et al., unpublished data, 2011):

Secondary analyses of existing data sets of putative psychologic-personal factors, such as the information collected within the scope of the development process of the ICF Core Sets in which information on psychologic factors from the patient's perspective and from the health professional perspective are available, and

A literature review combining a systematic search of the health conditions in the cohort study and the description of factors from the psy-

chologic-personal factors that are likely candidates for the Personal Factor classification in the ICF.

Selection of Category Specifications of What to Measure

The approach recommended for selecting category specifications for the domain set is based on an evidence-based process including literature search described in detail in the section "Electronic Literature Search." The aim was to find specific and concrete variables that have been previously studied that are aspects or examples of the ICF categories in the domain set and that are relevant to the primary focus of the cohort study. The category specifications are what the researcher needs to measure, either as a dependent or an independent variable. If, in the literature, a category specification has been studied with regard to its relationship with other variables, then this information can be used by the researcher to create hypotheses.

For environmental factors and some areas of activities and participation, the evidence for the category specification can often not be found in the literature because very little research involving the measurement of environmental factors exists. In these cases, an alternative approach was followed in the SwiSCI study and reported in a separate article.[7]

The steps described below are taken for each ICF category in the domain set. In addition, it may be necessary to create meaningful groups of ICF categories rather than to perform searches on individual categories. For example, if both s810 Structures of the skin and b810 Functions of the skin are in the domain set, it would not be reasonable to perform two literature searches. Instead, only one search needs to be performed on studies on the skin (Fig. 1).

Electronic Literature Search

The electronic search is performed for all relevant databases (such as PubMed, EMBASE, PsycINFO, Cumulative Index to Nursing and Allied Health Literature, and the Social Sciences Citation Index) using key terms that identify studies with the target population and keywords and MeSH terms that address the content of the ICF Category.

Abstract Selection

Selection of abstracts is based on inclusion criteria that focuses the search to those studies that the researcher believes are directly relevant to the aim and objectives of the cohort study, including
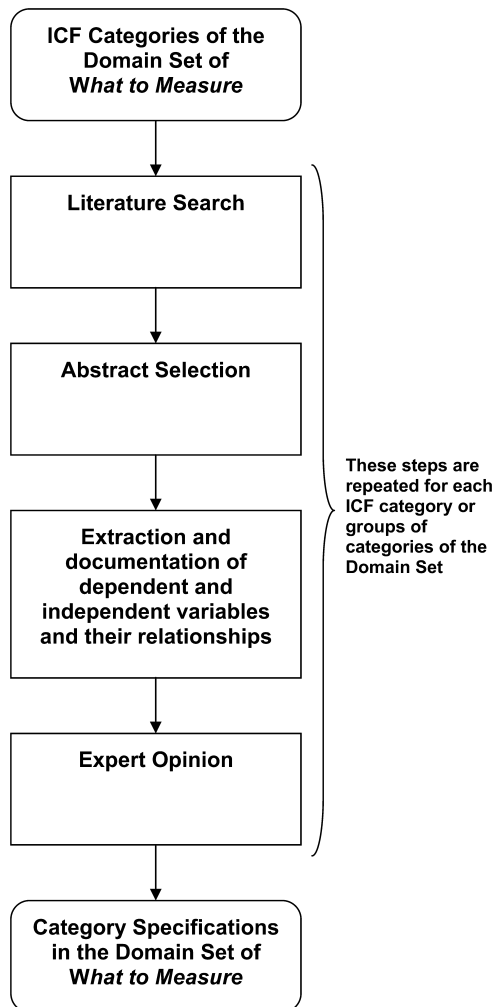
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│ ICF Categories of the│
│   Domain Set of      │
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│  Literature Search   │
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│  Abstract Selection  │
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│   Extraction and     │
│  documentation of    │
│ dependent and        │
│ independent variables│
│ and their relationships│
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│   Expert Opinion     │
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│ Category Specifications│
│  in the Domain Set of │
│   What to Measure     │
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These steps are repeated for each ICF category or groups of categories of the Domain Set

FIGURE 1 *Process followed for selecting category specifications of what to measure.*

the analysis of the relationships between two or more variables in the study design.

Extraction and Documentation of Information

The extraction and documentation of dependent and independent variables is performed at the same time as the abstract check. Significant relationships identified in the studies are also documented. Whenever the abstracts do not provide enough information to check the inclusion criteria or to extract the dependent and independent variables, the full-text paper is read. The extracted dependent and independent variables and relationships studied in the publication should be listed in the electronic database. To facilitate the further processing of the information, the names of the dependent and independent variables should be homogenized. For example, if the literature uses "emotional distress," "emotional stress," and

"emotional pressure," the most commonly used term "emotional distress" can be selected for all three because they refer to the same phenomena. The significant relationships between dependent and independent variables should also be documented. Of these variables, only those for which the definition of the ICF category or the group of meaningful categories applies are possible category specifications.

Final Decision

The final selection of the category specifications in the domain set involves two steps that are challenging because they cannot be mechanically performed but rely on the reasoning of experts in functioning and the health condition. However, these steps ensure the quality of the study to be performed.

First, the dependent and independent variables extracted and the information about significant relationships found in the studies should be provided to experts in the cohort study health condition, with the request that feedback on the relevance, suitability, and priority of the category specifications and study questions be provided. Second, with all information on hand, the study investigators should decide on the set of variables that will be used to specify the domain set and measured in the study.

RESULTS

The methodology described previously has been followed in the case of SwiSCI with the following results.

SwiSCI Domain Set of What to Measure

The complete list of ICF categories in the SwiSCI Domain Set and their sources are presented in Table 1.

Use of the ICF Categories of the Minimal Generic Set

As mentioned in "Methods," the ICF categories of the Minimal Generic Set were the starting point of the domain set of what to measure for SwiSCI (Table 1).

Identification of the Relevant Brief ICF Core Set for SwiSCI

The health condition under study in SwiSCI is SCI, both traumatic and nontraumatic. Two ICF Core Sets for SCI were developed, one for early postacute context and the other for the long-term context. The early postacute context was defined

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TABLE 1 List of ICF categories and personal factors included in the SwiSCI domain set, as well as the sources from which they have been identified.

Code	ICF Categories	Minimal Generic Set	Brief ICF Core Set for SCI in the EPA Context	Brief ICF Core Set for SCI in the LT Context
b130	Energy and drive functions	x		
b152	Emotional functions	x	x	x
b280	Sensation of pain	x	x	x
b440	Respiration functions		x	
b525	Defecation functions		x	x
b620	Urination functions		x	x
b640	Sexual functions			x
b710	Mobility of joint functions			x
b730	Muscle power functions		x	x
b735	Muscle tone functions		x	x
b810	Protective functions of the skin		x	x
d230	Carrying out daily routine	x		x
d240	Handling stress and other psychologic demands			x
d410	Changing basic body position		x	x
d420	Transferring oneself		x	x
d445	Hand and arm use		x	x
d450	Walking	x	x	
d455	Moving around	x		x
d465	Moving around using equipment			x
d470	Using transportation			x
d510	Washing oneself		x	
d520	Caring for body parts			x
d530	Toileting		x	x
d540	Dressing		x	
d550	Eating		x	x
d560	Drinking		x	
d850	Remunerative employment	x		
e110	Products or substances for personal consumption	x		x
e115	Products and technology for personal use in daily living	x	x	x
e120	Products and technology for personal indoor and outdoor mobility and transportation	x	x	x
e135	Products and technology for employment	x		
e150	Design, construction, and building products and technology of buildings for public use	x		x
e155	Design, construction, and building products and technology of buildings for private use	x		x
e225	Climate	x		
e310	Immediate family	x	x	x
e320	Friends	x		
e340	Personal care providers and personal assistants		x	x
e355	Health professionals		x	x
e450	Individual attitudes of health professionals	x		
e575	General social support services, systems, and policies	x		
e580	Health services, systems, and policies	x		x
s120	Spinal cord and related structures		x	x
s430	Structure of respiratory system		x	x
s610	Structure of urinary system		x	x
s810	Structure of areas of skin			x

Because of space restrictions, the psychologic-personal factors included in the SwiSCI Domain Set are presented only in Cieza et al. (unpublished data, 2011).

ICF, International Classification of Functioning, Disability, and Health; LT, long-term; EPA, early postacute; SCI, spinal cord injury; SwiSCI, Swiss SCI Cohort Study.

as any kind of setting (e.g., acute hospital, rehabilitation center, ambulatory care) in which the first comprehensive rehabilitation after the spinal cord lesion occurred is provided and to the variable period of time that begins and ends with the first comprehensive rehabilitation. The long-term context follows the early postacute period and typically is the period during which persons with SCI live in the community and may or may not receive clinical care.

The ICF categories not already in the Minimal Generic Set were added to the SwisSCI domain set from both Brief ICF Core Sets for SCI. ICF categories from both core sets were added because SwiSCI will follow a cohort of persons with SCI from the onset of the lesion to the period when they are living in the community and for a still to be determined open period of time that can last many years.[8]

The Brief ICF Core Set for the early postacute context contains 25 second-level categories—eight body functions, three body structures, nine activities and participation, and five environmental factors. The Brief ICF Core Set for the long-term context contains 33 second-level categories—9 body functions, 4 body structures, 11 activities and participation, and 9 environmental factors. The two Brief ICF Core Sets have 39 ICF categories in total, and 13 are already in the Minimal Generic Set. In total, 45 ICF categories are included in the SwisSCI domain set (Table 1).

Identification of Relevant Factors from the Psychologic-Personal Perspective

The process for the selection of factors relevant to the psychologic-personal perspective for SwiSCI is reported in a separate paper (Cieza et al., unpublished data, 2011).

Selection of Category Specifications of What to Measure for SwiSCI

The selection of the specification of environmental factors and some activities and participation strongly determined by environmental factors, such as d850 Remunerative employment, was carried out using other methods that are described in a separate article.[7]

Electronic Literature Search

Twenty-eight literature searches, one for each of the meaningful groups of ICF categories of the SwiSCI Domain Set, were performed. In SwiSCI, the electronic systematic literature search was ex-

clusively performed in PubMed. For all the searches performed, the following SCI-specific search was used:

#18 (#1) OR (#2) OR (#3) OR (#4) OR (#5) OR (#6) OR (#7) OR (#8) OR (#9) OR (#10) OR (#11) OR (#12) OR (#13) OR (#14) OR (#15) OR (#16) OR (#17)
#17 quadriplegia [tiab]
#16 paraplegia [tiab]
#15 tetraplegia [tiab]
#14 spinal cord vascular diseases [tiab]
#13 spinal cord neoplasm [tiab]
#12 spinal cord compression [tiab]
#11 Transverse Myelitis [tiab]
#10 Spinal Cord Injury [tiab]
#9 Spinal Cord Injuries [tiab]
#8 quadriplegia [Mesh]
#7 paraplegia [Mesh]
#6 tetraplegia [Mesh]
#5 spinal cord vascular diseases [Mesh]
#4 spinal cord neoplasm [Mesh]
#3 spinal cord compression [Mesh]
#2 Myelitis, Transverse [Mesh]
#1 Spinal Cord Injuries [Mesh]

From this point on, the ICF category b152 Emotional functions will be used here to exemplify the process (Fig. 2). Examples with complete information on the terms used to search the literature for all of the meaningful groups of ICF Categories, the number of identified publications, and the number of selected studies are found in the first four columns of Table 2. Additional detailed information can be obtained from the authors upon request.

The following is the search for b152 Emotional functions and was linked to SCI-specific search:

#25 (#19) OR (#20) OR (#21) OR (#22) OR (#23) OR (#24)
#24 (#18) AND mood [tiab]
#23 (#18) AND feeling [tiab]
#22 (#18) AND emotion*[tiab]
#21 (#18) AND affect*[tiab]
#20 (#18) AND anxiety [tiab]
#19 (#18) AND depression [tiab]

Additional limits included that the publication was not more than 10 yrs old, that the study populations included only adult humans, and that it was written in English.

Abstract Selection

The electronic search performed in PubMed retrieved 992 studies. The inclusion criteria were SCI

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│ 45 ICF categories were  │
│ included in the SwiSCI  │
│ Domain Set              │
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│ 28 systematic searches  │
│ were performed in       │
│ PubMed                  │
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            │
            ▼
┌─────────────────────────┐
│ 992 studies were        │
│ retrieved and 50 selected│
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            │
            ▼
┌─────────────────────────┐
│ 50 dependent and        │
│ independent variables   │
│ and 27 relationships were│
│ identified              │
│ (See Table 3)           │
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            ▼
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│ Expert Opinion          │
└─────────────────────────┘
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            ▼
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│ Depression, anxiety and │
│ feeling were the selected│
│ specifications          │
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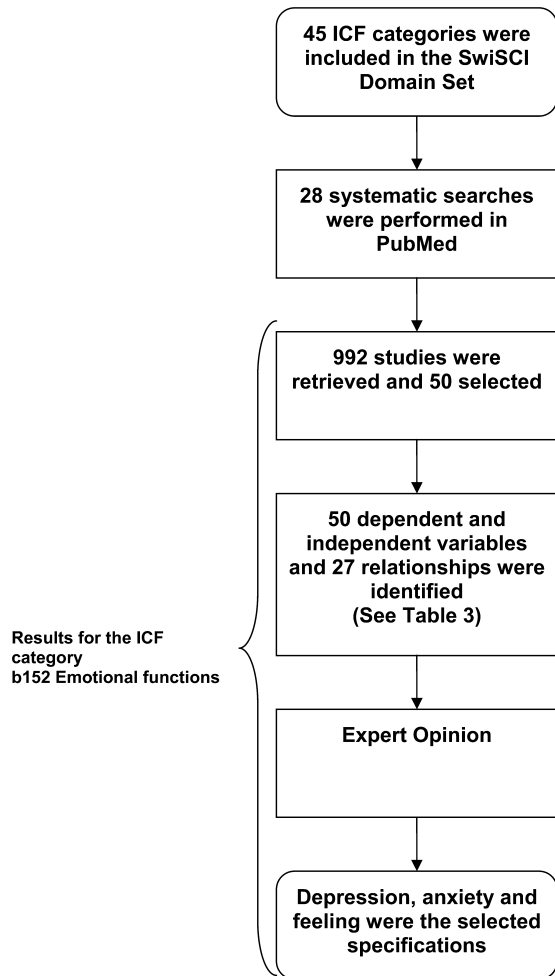Results for the ICF category b152 Emotional functions

FIGURE 2 *The process of selecting category specifications for b152 Emotional functions in SwiSCI. SwiSCI indicates Swiss Spinal Cord Injury Cohort Study; ICF, International Classification of Functioning, Disability, and Health.*

adult population; study performed in the last 10 yrs; published in English; and study focused on relationships between emotional functions and at least one additional variable. After applying the inclusion criteria, 50 studies were included.

Extraction and Documentation of Information

The total number of variables after the homogenization of their names was 50—some variables were dependent, some independent, and others both dependent and independent in different studies. Many different relationships were identified, with some variables (e.g., depression) being involved either as a dependent or an independent variable in as many as 27 relationships. The definition of b152 Emotional functions was used to identify potential category specifications of this ICF category, as marked in Table 3.

Final Decision

After an expert review of Table 3 in terms of the relevance, suitability, and priority of the potential category specifications, depression, anxiety, and feeling were selected, merely on the grounds that these were the most common and that many of the other variables are already addressed in the domain set of factors from the psychologic-personal perspective (Cieza et al., unpublished data, 2011). It is recommended to document the arguments used at this stage for later use as the study progresses and for the publication of the results.

DISCUSSION

In this article, we have transparently described an ICF-based approach that answers the question of what to measure in a cohort study in which the primary focus is to understand functioning as an operationalization of health. The first measurement challenge with cohort studies is to be efficient in the number of study variables used and to be effective in selecting the right variables. Because the approach builds on the strong methodologic basis of the Minimal Generic Set and the ICF Core Sets for specific health conditions, the cohort study researcher can be confident that the categories and category specifications identified in the domain set will be relevant to the salient features of the experience of living with a health condition. It will be noticed that some chapters of Activities and Participation are not represented in this list; in particular, there are no categories from Chapter 6, Domestic Life; Chapter 7, Interpersonal Interactions and Relationships; and Chapter 9, Community, Social, and Civic Life. As described in a separate article[7] addressing this issue, researchers consulted the Comprehensive Core Sets for SCI and the ICF Core Set for vocational rehabilitation because it is crucial for integration into the labor market, one of the major concerns of persons with SCI.

Comparability of data is facilitated by this approach because the ICF is the international standard language for health information, and the domain set is composed entirely of ICF categories or specifications of them. Comparability is further enhanced because the domain set includes, by default, the Generic ICF Set, which is the minimal set of ICF categories that must be considered in

TABLE 2 Examples of meaningful groups of ICF categories for which the specific searches were performed, of the specific terms used to search the literature, of the number of identified publications, of the number of selected studies, and of the selected category specifications to be included in SwiSCI

Meaningful Groups of ICF Categories of the SwiSCI Domain Set	Terms Used in Searches	Number of Identified Publications	Number of Selected Publications	Selected Category Specifications
Structure of pelvic region	Urinary Bladder [Mesh]	489	230	Continence
Structure of urinary system	Urinary Bladder Diseases [Mesh]			Kind of voiding the bladder (e.g., indwelling catheter, intermittent self-catheterization)
Urinary excretory functions	Urologic Surgical Procedures [Mesh]			Self-rated amount respectively health-professional rated amount of assistance/independency for bladder management
Urination functions	Urination Disorders [Mesh]			Use of external assistive devices (e.g., condom catheter or diapers)
Sensations associated with urinary functions	Urinary Catheterization [Mesh]			
Prod and technology for personal use in daily living	Urination [Mesh]			
	Urinary Bladder [TIAB]			
	Urinary Bladder Diseases [TIAB]			
	Urologic Surgical Procedures [TIAB]			
	Urination Disorders [TIAB]			
	Urinary Catheterization [TIAB]			
	Urination [TIAB]			
Structure of areas of the skin	Pressure ulcer [TIAB] and [Mesh]	532	123	Prevalence of pressure ulcer (localization and severity) (b810 and s810)
Protective functions of the skin	Skin care [TIAB] and [Mesh]			
Repair functions of the skin	Sweating [TIAB] and [Mesh]			
Other functions of the skin	Skin [TIAB] and [Mesh]			
Sensations related to the skin				
Carrying out daily routine	Activities of daily living [TIAB] and [Mesh]	336	76	Self-rated amount respectively health-professional rated amount of assistance/independency for:
Washing oneself	ADLs [TIAB]			Eating (d550)
Caring for body parts	Instrumental activities of daily living [TIAB]			Washing upper and lower body (d510)
	IADLs [TIAB]			
Toileting				Dressing and undressing upper and lower body (d540)
Dressing				Grooming (d520)
Eating				Toileting (d530)
Drinking				Use of assistive devices for ADLs (e115)
				Living situation at admittance at first hospital stay after SCI, at discharge from first hospital stay after SCI, and in the long term (as "proxi" for independency in ADLs)

ICF, International Classification of Functioning, Disability, and Health; SCI, spinal cord injury; SwiSCI, Swiss SCI Cohort Study.

TABLE 3 Independent and dependent variables identified in the search for b152 Emotional functions

Independent Variable	Dependent Variable
1. Depression (3,4,5,7,8,9,13,15,16,17,21)	**1. Depression (depressive symptoms) (2,3,4,5,6,7,8,9,10, 11,12,14,15,16,18,19,20,21,22,23,24,26,28,29,31,33)**
2. Coping behavior-strategies (fight spirit, acceptance) (1,2,3,7,10)	**2. Anxiety (2,4,5,7,8,9,10,12,18,22,26,32)**
3. Anxiety (1,3,5,7,8,13,16)	**3. Emotional distress (1,2,3,6,12,20,21)**
4. Physical Activities (1,2,9,11)	4. Quality-of-life/perceived quality-of-life (1,9,26)
5. Pain (1,2,6,20)	5. Life satisfaction (postrehabilitation subjective well-being) (1,3,14,17)
6. SCI characteristics (1,3,12)	**6. Mood (5,9,10,24)**
7. Group-based (1,2) intervention	7. Posttraumatic Stress Disorder (1,2,3,13)
8. Appraisals (1,2)	8. Work-Employment Status (1,3)
9. Stress (1,2,4,6)	9. Pain (1,4,19)
10. Health status (1,2,6)	10. Rehabilitation outcome (2,17)
11. Bowel functions/management (1)	**11. Feelings (4,30)**
12. Functioning	**12. Positive/negative affects/affective well-being (6)**
13. Emotional distress (7,14,15)	13. Future time orientation (1,3)
14. Emotions (1,5,14)	14. Physical performance/physical activity (13,14)
15. Age (1)	15. Participation (1,13)
16. Time since injury (1)	16. Adaptation to SCI (1,3)
17. Positive/negative affects (5,10)	17. Self-efficacy (1)
18. Sense of coherence (1,2)	18. Stress (23)
19. Locus of control (1,9)	**19. Emotional attributes (27)**
20. Sex (1,3)	**20. Emotional functioning (5)**
21. Social support (1,3)	21. Medical Complications (1)
22. Social self-efficacy (1,2)	22. Coping (27)
23. Health-related quality-of-life (1,18)	
24. Life satisfaction (1,6)	
25. Mood (4)	
26. Education (1,2)	
27. Autonomic response (19,22)	
28. Level of mobility (1)	
29. Personality dimensions (NEO five factor inventory) (1)	
30. Rehabilitation Environment 11)	
31. Marital Status (1)	
32. Incontinence (fecal) (2)	
33. Helplessness (1)	
34. Hospital discharge	
35. Negative attitudes toward emotional expression	
36. Completeness of injury	
37. Participation	
38. Medical complications	
39. Self-efficacy	
40. Life satisfaction	
41. Perceived emotional functioning	

Potential category specifications are in boldface. The numbers next to the independent variable refer to their relationships with the dependent variables and vice versa.

NEO, Neuroticism-Extroversion-Openness.

any research on functioning and health.[4] This comparability of data extends both across time, an essential requirement of cohort studies in general, and across healthcare settings, an important requirement of cohort studies such as the SwiSCI, in particular. Moreover, because the ICF is an international classification widely used across health professions, setting and sectors, the cohort study results will be both widely understood and usable in various contexts, including health and social policy.

In an emerging research area such as human functioning sciences in which the primary focus is the understanding of functioning and health, the approach described here will be especially valuable to researchers working in this area. Only with a conceptually based approach is there the potential of enabling researchers to go beyond standard health research questions and paradigms toward novel ways of understanding health from the perspective of the lived experience. Rather than rely directly on standard measurement instruments and

on identifying what to measure based on them, this approach transparently and comprehensibly makes it possible to take a fresh look at the requirements of measurement: first, define what to measure in terms of its importance to our understanding of health and living with a health condition and only then look at the more technical issues of how to measure. In addition, the process of selecting category specifications has the added value of generating potentially valuable research questions. For example, the study question, "What is the influence of depression on medical complication," can be derived from Table 3 in which the process for selecting the specifications for the category b152 Emotional functions was described.

There is a potential application of this approach that should be mentioned. As the process for updating the ICF has now been initiated by the World Health Organization, the data gathered using this ICF-based approach would provide highly relevant evidence for updating proposals. For example, if the cohort researcher, while searching for a specification of an ICF category, makes a proposal that is not explicitly mentioned in the definition of that category, the data gathered could provide an evidence base for the updating decision to add that specification to the ICF definition, or indeed to create a new ICF category.

As with any new approach, however, what is described here also presents challenges. The first is that defining what to measure without consideration of the practicalities of how to measure means that the Domain Set may contain ICF categories or category specifications that cannot be easily assessed, such as interpersonal relationships, spirituality, or political life and citizenship. Not taking account of assessment practicalities may limit the effectiveness of the cohort study or the usefulness of its conclusions. However, by highlighting the most relevant variables to measure, the researcher still has the option of setting aside some of these for cost or methodologic reasons and for coming back to them later should new approaches to measurement become available.

The second challenge arises when there is no ICF Core Set for the health condition under consideration. In that case, an evidence-based procedure, following the methodology of the ICF Core Set development,[6] could be used to determine a set of ICF categories that is comprehensive enough to describe the functioning of the target population but does not contain more categories than is necessary to do so. This is time consuming and would add considerable burden to the performance of the cohort study, although the methodology is well established and easily available.[11]

CONCLUSIONS

Cohort studies are time-consuming and resource-intensive endeavors, making it necessary to select research questions, measurement instruments, and category specifications with great care. This is especially true of cohort studies in which the main focus is the understanding of functioning over time for a specific population, such as the SwiSCI study. In this paper, we have proposed an ICF-based approach to define the first major step of measurement, namely what to measure. This approach is a valuable tool for the cohort researcher because it guarantees the comparability of data and comprehensiveness of scope, enhancing the prospects of the study results being understood and consequently used by different health professionals and in a different context, including health and social policy.

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