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Developing Core Sets for Persons With Traumatic Brain Injury Based on the International Classification of Functioning, Disability, and Health

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The authors outline the process for developing the International Classification of Functioning, Disability, and Health (ICF) Core Sets for traumatic brain injury (TBI). ICF Core Sets are selections of categories of the ICF that identify relevant categories of patients affected by specific diseases. Comprehensive and brief ICF Core Sets for TBI should become useful for clinical practice and for research. The final definition of the ICF Core Sets for TBI will be determined at an ICF Core Sets Consensus Conference, which will integrate evidence from preliminary studies. The development of ICF Core Sets is an inclusive and open process and rehabilitation professionals are invited to participate.

Keywords: *ICF Core Set; TBI, Neurorehabilitation; Head trauma*

Traumatic brain injury (TBI), according to the TBI model system,[1] is defined as a damage to a brain tissue caused by an external mechanical force as evidenced by loss of consciousness or posttraumatic amnesia (PTA) because of brain trauma or by objective neurological findings that can be reasonably attributed to TBI on physical examination or mental status examination. It can follow a variety of clinical courses and it may be difficult to predict its prognosis. Impairment, activity limitations, and participation restrictions are very important consequences of TBI.[2,3]

A major issue for professionals working with TBI concerns the large variation in the currently available measures to address functioning and disability in TBI.[4-6] There is little standardization in the use of these instruments and, therefore, comparisons among studies or data from different centers and countries are difficult and almost impossible.[7]

Since the approval of the International Classification of Functioning, Disability, and Health (ICF) by the World Health Assembly in 2001, there is a comprehensive and universally accepted framework to classify functioning, disability, and health in persons who have acquired a TBI.[8]

The ICF[9] is one of the World Health Organization's (WHO's) family of international classifications, of which, the best known member is the International Statistical Classification of Diseases and Related Health Problems (ICD-10). Within this context of the WHO international classifications, the ICF complements the information on diagnosis, diseases, disorders, and other health conditions provided by the ICD-10 by classifying information on functioning and disability. Thus, ICD and ICF are complementary classifications from which the WHO envisions a common application in clinical medicine and research.

The ICF contains an exhaustive list of globally acceptable descriptions of what can be relevant to describe functioning, disability, and health when persons have health conditions. In other terms, the ICF contains the words of an international vocabulary to describe functioning, disability, and health. Thus, the ICF is usually referred to as the unified and standard language of human functioning, disability, and health.

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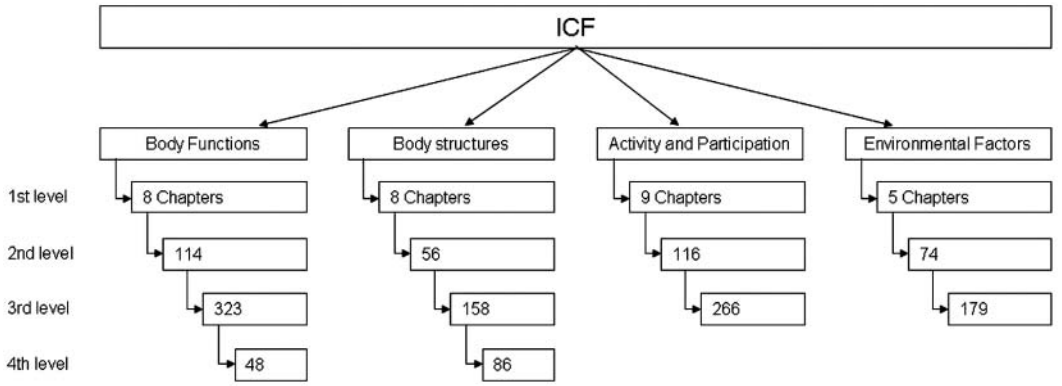
Anyone who wishes to actively participate in this process is invited to contact the project coordinators (slaxe@guttmann.com or rlopez.investigacio@guttmann.com). The project will be guided by a steering committee composed by Anthony Ward, Montserrat Bernabeu, Gerold Stucki, Michael Barnes, Nathan Zasler, John Whyte, Nenad Kostanjsek, Robyn Tate, and Geoffrey Reed. The project is partially funded by the Institut Guttmann Foundation.

Figure 1
Distribution of the International Classification of Functioning, Disability, and Health (ICF)



The words of the vocabulary contained in the ICF are called ICF categories. The ICF contains a total of 1454 ICF categories included in one of the different components of the model of functioning, disability, and health on which it is based (Figure 1), including: 493 body functions, 310 body structures, 393 activities and participation domains, and 258 environmental factors. The personal factors component has not yet been classified.

Similar to a textbook or manual, the ICF categories are hierarchically organized. The first level of this hierarchy and the first frame of reference on the basis of which we can find information within the ICF is made up of chapters (categories at the first level). Each chapter consists of second-level categories and, in turn, these are then comprised of third-level and fourth-level categories. The second-, third-, and fourth-level categories correspond to subheadings in textbooks or manuals and represent a more detailed frame of reference to find information within the ICF. Figure 1 illustrates the structure of the ICF. An example from the body functions component is presented in the following:

- b1, mental functions: first chapter/level
- b114, orientation functions: second chapter/level
- b1142, orientation to person: third chapter/level
- b11420, orientation to self: fourth chapter/level

The idea of generating lists of generally agreed on ICF categories likely to be most relevant to patients having TBI will help to describe and measure the spectrum of limitations in functioning of persons with this health condition and facilitate the use of a standard set of variables. These lists are the so-called ICF Core Sets.[9]

ICF Core Sets allow clinicians and researchers to classify and describe an individual's functioning using widely accepted terminology.[10,11] Shared terminology and common definitions permit both national and international studies to compare the consequences of different conditions.[12] It can also be used to rate the content validity of health status measures and thereby select appropriate instruments for the specific needs of TBI.[13] In the future, the ICF and the ICF Core Sets may become the new base for not only the further development of such measures, but also for the creation of item banking relevant to individuals with TBI.[14]

In this context, it is important to recall the difference between ICF categories versus items, such as self-reported health status measures, for example. The ICF categories represent constructs. One of these constructs is, for example, energy and drive functions, which is represented by the code b130 and defined in the ICF as general mental functions of physiological and psychological mechanisms that cause the individual to move toward satisfying specific needs and general goals in a persistent manner. Items, on the other hand, are indicators of constructs used to estimate the variation in those constructs. For example, the items "Did you feel worn out?" of the Short-Form 36[15] and "I feel very active" of the Multidimensional Fatigue Inventory can be used as indicators to estimate the level of energy and drive of a person.[16]

This distinction emphasizes the differences and the potential interactions between the development of ICF Core Sets and other research activities, such as the National Institutes of Health (NIH) Patient Reported Outcomes Measurement Information System (PROMIS) initiative, which develops, validates, and standardizes item banks to measure patient-reported outcomes (PROs).[17,18] The starting point of the PROMIS initiative is the WHO differentiation of physical, mental, and social health to which hierarchical domains are subordinated for each item bank being created.[8] For example, physical health is divided into subdimensions of physical function and symptoms. In turn, the subdimension, symptoms, is divided into pain and fatigue, for which item banks have already been created.

It would be thinkable that the PROMIS initiative uses ICF categories and not hypothesized subdimensions as a starting point for the development of item banks in future developments. In line with this thought, the Committee on Disability in America has encouraged the PROMIS initiative to map the domains of outcomes and measures to ICF concepts.[19]

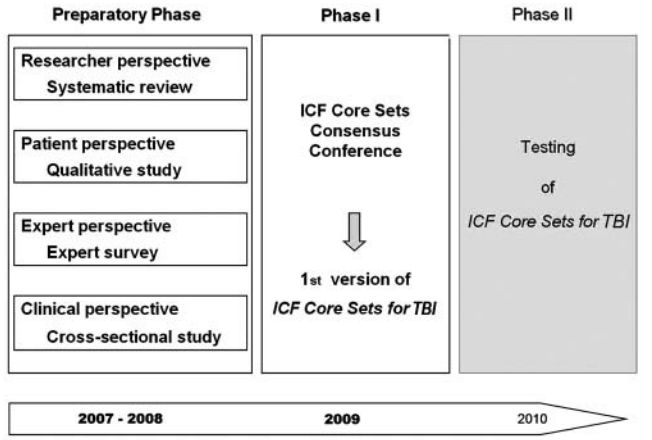
ICF Core Sets for 15 chronic conditions have also been developed. These are presented in Table 1.[9,20-32] For each health

Table 1
ICF Core Sets For Chronic Conditions Already Developed or Under Development

ICF Core Sets For Chronic Conditions Already Developed
Ankylosing spondylitis
Breast cancer
Chronic ischemic heart disease
Chronic widespread pain
Depression
Diabetes mellitus
Head and neck cancer
Low back pain
Multiple sclerosis
Obesity
Obstructive pulmonary diseases
Osteoarthritis
Osteoporosis
Rheumatoid arthritis
Spinal Cord Injury
Stroke

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

Figure 2
ICF Developing Process



Note: ICF indicates International Classification of Functioning, Disability, and Health; TBI, traumatic brain injury.

condition both a Brief Core Set (for clinical or epidemiological study) as well as a Comprehensive ICF Core Set (for multidisciplinary assessments) has been established.[9,12,13,20-37]

The development to the ICF Core Sets for TBI is a cooperative effort between WHO, the Institut Guttmann (Barcelona, Spain), the ICF Branch of the WHO collaboration Centre for the Family of International Classifications at the Ludwig Maximilian University in Munich (Germany), and the International Society of Physical and Rehabilitation Medicine (ISPRM).

Preparatory Phase

There are 3 phases in the development of the ICF Core Sets (preparatory phase, phase I, and phase II).[9] Within the preparatory phase, 4 studies will be conducted to address adequately different perspectives (Figure 2).

Systematic review: researcher perspective. A systematic literature review will be performed to identify measures and outcomes used in studies involving patients with TBI and published in the last 5 years (2002-2007), and to identify and quantify the concepts contained in those measures and outcomes using the ICF as a reference.[38,39]

Qualitative study: patient's perspective. Focus groups and individual interviews with TBI patients and their caregivers will be performed to identify the aspects of functioning and health, which are important to the individuals and to list those aspects using the ICF as a reference.

Expert survey: expert perspective. An expert survey will be performed via e-mail to gather the opinion of an international pool of experts (eg, physicians, nurses, physical therapists, occupational therapists, psychologists, speech therapists, and social workers) regarding the most relevant and typical areas of functioning and disability to be considered in persons with TBI.

Empirical cross sectional study: clinical perspective. A cross sectional study with at least 200 patients will be performed to describe functioning and health of individuals with TBI and to identify the most common problems using the classification system of the ICF.[40,41]

Phase I

The information collected during the preparatory phase will be presented at an international ICF Core Set Consensus Conference and experts in the field of TBI will work actively together to arrive at a consensus on the most adequate ICF categories to be included in the Comprehensive and Brief ICF Core Sets for TBI.[42]

Phase II

For phase II of the project, the testing and implementation of the ICF Core Sets for TBI a cross sectional, multicenter, validation international study with patients with the main diagnosis of TBI will be performed to study the content validity and feasibility of the Comprehensive and Brief ICF Core Sets for TBI.

The project will be conducted in conformity with the ethical principles of the Declaration of Helsinki. The development of ICF Core Sets for TBI is an inclusive and open process. Anyone who wishes to actively participate in this process is invited to contact the project coordinators.

In conclusion, the development of the ICF Core Sets for TBI will encourage a unified approach to research leading to an improved understanding of functioning, disability, and health in TBI. In addition, they could also be the basis for

developing assessment instruments to quantify the severity of TBI, to measure change over time, and to measure effectiveness of interventions. ICF Core Sets may also serve as the basis for setting clinical significance thresholds in the organizations of diagnostic assessment systems. Finally, it is hoped that such research will lead to interventions that improve restoration and maintenance of functioning and minimize disability among people with TBI throughout the world.

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