The OMERACT-ICF Reference Group: Integrating the ICF into the OMERACT Process: Opportunities and Challenges

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ABSTRACT. At OMERACT 8 in May 2006 in Malta, the International Classification of Functioning, Disability and Health (ICF) was introduced as a universal model and a universal classification to describe human functioning. The potential usefulness of the ICF for the OMERACT process was highlighted and reported in a position paper following the OMERACT 8 meeting. Since then representatives of several OMERACT working groups with an interest in the ICF joined an OMERACT-ICF reference group. Most members had experience with the ICF and worked further to integrate the ICF into OMERACT. We describe the main roles of the ICF in the OMERACT process and the challenges when practice confronts theory. (J Rheumatol 2009;36:2057–60; doi:10.3899/jrheum.090357)

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ICF AS A MODEL AND CLASSIFICATION FOR FUNCTIONING

Aristotle eloquently stated that "He knows things best, who has seen things from their start," and it seems wise to briefly consider the history of the International Classification of Functioning (ICF). For the World Health Organisation (WHO), survival is still the main outcome. Parallel with improved worldwide mortality rates, disability and handicap become an increasing concern, calling for a better measurement and information system for this aspect of health. The initial impairment, disability, handicap model (International Classification of Impairments, Disabilities, and Handicaps, or ICIDH) tried to fill the gap but applied a narrow biomedical view on disease, used negative terminology, and only recognized unidirectional causality[2]. Moreover, the model did not provide a system to describe in detail the different types of impairments, limitations, and participation restrictions, thus limiting the application of this model.

In 2001 the ICF was endorsed by the World Health Assembly as a universal framework and classification system[3]. The new ICF framework supports the biopsychosocial model of disease, recognizing the role of contextual factors (personal and environmental), in addition to impairments in body function and body structure, limitations in activities (execution of a task by the individual), and restrictions in participation (taking part in social life) when describing the influence of a disease on health. The ICF classification comprises 1545 categories divided over the 4 ICF components

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(body functions and structures, activities and participation, environmental factors, and personal factors). A category can be considered as the smallest definable "unit" that is a necessary aspect for the description of functioning. As such, the ICF classification can be considered as the "Esperanto" dictionary that contains the words to describe functioning. Second-level categories are non-overlapping unique units, while third- and fourth-level categories are specifications of the overlying second-level category. Second-level categories are grouped into chapters. It is important to understand that the ICF classification primarily describes "what to measure" and not "how to measure."

"What to measure": Selecting health domains. To make the ICF classification applicable in healthcare, ICF Core Sets are developed for specific diseases or specific situations. ICF Core Sets are selections of ICF categories necessary to describe the influence of the disease on functioning. As in spoken language, we do not need all the "words" of the ICF Esperanto dictionary to establish effective communication and information on functioning. The selection of ICF categories for the ICF Core Sets follows an evidence-based, iterative, consensus-building process that integrates expert knowledge and evidence gathered from preliminary studies. As such, this process is inspired by the OMERACT example.

The main differences from the OMERACT process of selection of health domains are that a standardized operating procedure is applied across conditions to develop the disease-specific ICF Core Sets, and the language of the health areas concerned is defined by the universal categories of the ICF classification, enhancing comparability of ICF Core Sets across diseases.

Typically, an ICF Core Set should integrate the perspective of patients as well as researchers and healthcare providers, and should contain categories from all ICF components (body functions and structures, activities and participation, environmental factors, and personal factors). A broad perspective, the standardized consensus-based procedure integrating evidence, and use of a universal language enable the ICF Core Sets to act potentially as the external standard on "what to measure" when defining functioning.

In the field of musculoskeletal conditions, between 2002 and 2004, the WHO initiated development of ICF Core Sets for rheumatoid arthritis (RA)[4], osteoporosis (OP)[5], osteoarthritis (OA)[6], chronic low back pain (LBP)[7], and chronic widespread pain (CWP)[8]. Several OMERACT members were involved in these ICF Core Set developments. The WHO also encourages research groups to initiate and conduct Core Set developments. As such, the Assessments in SpondyloArthritis international Society (ASAS) working group completed, in September 2007, the ICF Core Set procedure for Ankylosing Spondylitis (AS) during the Core Set consensus meeting. The psoriatic arthritis (PsA) group (under the GRAPPA umbrella) is in an advanced stage of development of an ICF Core Set, and the fibromyalgia (FM) group is exploring the possible role of the ICF in addition to the personal initiatives in the choice of outcome domains.

During OMERACT 9, the Core Set for AS was presented as an example of a Core Set in development and was discussed with the audience, which included representatives of the AS, PsA, FM, gout, and back pain groups as well as representatives from the patient perspective group.

Advantages of Core Set development were identified, as follows: Recognizes the biopsychosocial model, including contextual factors; Can be used as starting point and as outcome (consequence) when assessing patients; Language represented in the categories is universally agreed on; Perspective of the patient is included, as well as clinical and researcher perspective, offering the possibility to compare across perspectives; Possibility to compare functioning across rheumatic disease; and Can potentially be used as starting point for instrument development, instrument validation, and development of an ICF-based item banking.

On the other hand, limitations were recognized:
Developing a Core Set is a lengthy procedure (recognizing this can be performed with OMERACT Core Set development and would overlap considerably); Lack of familiarity of researchers and patients with ICF language (recognizing that learning to apply a new language always requires training and time); Gaps and redundancies in the ICF categories (recognizing these can be adjusted in new versions of ICF classification and Core Set); Concerns about validity, especially in the Brief Core sets, and limited data on reproducibility and sensitivity to change (recognizing that research is ongoing); Although contextual factors are important, instruments to assess them are scarce; and Personal factors not yet having been defined as categories (recognizing this issue is now a WHO priority).

After discussions, participants of the special interest group concluded that on balance the ICF model and classification seems to be the best available "external" standard to define functioning and health.

"WHAT TO MEASURE": CONTENT COMPARISON OF DOMAINS IN EXISTING INSTRUMENTS

If we accept the ICF disease-specific Core Sets as the "external" standard to describe functioning, Core Sets could play a role when examining the aspect of "truth" of the OMERACT filter of validity. Where the development of new questionnaires is considered, the ICF categories of the Core Set can serve as a starting point for item selection before entering the next steps of item description and item reduction following accepted procedures. Alternatively, for questionnaires developed following classic approaches, the content of the items can be linked to ICF categories of the full ICF or specific ICF Core Set to validate the "truth." Linking refers to the procedure in which the *concepts* within the

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items of the questionnaire are "translated" into ICF language, meaning the concepts are fitted to the most closely related ICF category.

In addition, the ICF Classification can help to perform the content comparison between instruments when checking the "truth" aspect of the OMERACT filter of validity.

At OMERACT 9, Anne-Christine Rat described how the "truth" of the recently developed Osteoarthritis Hip and Knee (OAKH) Questionnaire[9] was further validated by linking (mapping) its contents to the ICF, and compared the matched ICF categories with categories covered by other instruments used to assess functioning in OA (Medical Outcome Study Short-form 36, WOMAC, Lequesne, and Health Assessment Questionnaire)[10]. After discussion, the group concluded that the ICF Core Sets can be used to develop new instruments for item generation and item reduction (same chapters/categories covered); the ICF classification is useful to explore content of single instruments and performs well as an external reference to compare contents of different outcome measures.

The ICF, therefore, offers a new way to explore the "truth" component of the OMERACT filter. However, some limitations were recognized: Some concepts cannot be linked or are difficult to link (including the personal factors that are not defined: The concept in items "I'm able to plan activities in advance" is a positive activity and cannot be linked. Concepts in items such as "I worry what will become of me," "I feel I annoy those close to me" cannot be linked and are considered to be part of personal factors.

Some categories are not very precise for specific conditions: The questionnaires that were compared contained concepts such as "being anxious," "feeling depressed," "being worried." Although these seem to be different concepts, they are all linked to the same ICF category, b152, emotional functions.

The relationship between some concepts within items is lost after linking to categories: The item "I need help for things like housework, shopping, etc." links to several ICF categories — e3, support and relationships; d640, doing housework; and dd6200, acquisition of goods. The linking procedure, however, does not indicate that "need for help" should be interpreted in the context of restrictions of tasks and chores. Similarly, in the item "I wake up because of pain," 2 categories are linked but their relationship cannot be made clear when presenting the linked categories.

Another example, not presented during the workshop but relevant within OMERACT, is offered by the OMERACT Worker Productivity group that aims to select the most appropriate instrument to assess absenteeism and presenteeism. A systematic review identified 18 questionnaires that differed largely in their objectives and content. Linking the concepts identified in the questionnaires to the related ICF category greatly facilitated appreciation of the differences between instruments.

"HOW TO MEASURE": MEASURING ICF CATEGORIES BY EXISTING QUESTIONNAIRES

For OMERACT, of equal importance as the question "what to measure" is the question "how to measure." When changing the scope of measuring, issues emerge about whether and how the ICF can contribute in this process, keeping in mind the availability of previously developed and well validated instruments. Item response theory (IRT), also a methods group within OMERACT, offers possibilities to move the ICF classification into the world of measurement. IRT argues that an important step during the development of a measure is to explore whether the selected items (read ICF categories) fit the same overlying domain/dimension. For items/categories that fit the unidimensionality, IRT offers a technique to rank these items/categories by their difficulty on a single scale (representing the measured dimension), making it possible also to identify a person's ability on the same scale, based on their answers on (a sample of) ranked categories.

Using preliminary data of ICF interviews in patients with AS it was shown that the categories of the ICF Core Set fulfil the assumption of unidimensionality, and that IRT can have a role in the further development of instruments by ranking categories on a single scale. An outstanding question and concern among outcome researchers is how existing instruments can be compatible with the ICF. Although the ICF categories can be "measured" by the ICF qualifiers, an equally valid approach would be to "measure" categories with items from existing questionnaires. An explorative example exists on how IRT can handle a pool of items from existing questionnaires (SF-36, CES-D, MVI, etc.) that address the dimension/trait "fatigue" (described by the ICF category b130, energy and drive). IRT enables the exploration of unidimensionality of the different items, can rank these items on a single fatigue scale, and can make the answering categories comparable between the questionnaire-items and with the ICF qualifier.

"HOW TO REPORT": REPORTING HEALTH STATUS IN CLINICAL STUDIES

When accepting the ICF framework and classification as a step forward in describing and exploring functioning, it becomes important to implement it when designing and reporting studies. OMERACT could develop a brief guideline with recommendations how the ICF framework and language could be used when reporting on the domain functioning across rheumatic diseases or when designing studies. At OMERACT 9, this issue was raised but not discussed in depth due to time constraints. Group members made this a project for OMERACT 10. A questionnaire survey among a larger OMERACT audience could explore the perceived feasibility of such a guideline, and complete and rank suggested issues for such a guideline.

In conclusion, the ICF framework and classification

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could support the OMERACT process of developing and validating instruments for outcome research and facilitate research to gain a fuller understanding of human functioning. Notwithstanding the increasing acceptance and application of the ICF, it is important to recognize not only strengths but also weaknesses of the ICF. The OMERACT Special Interest Group of the OMERACT-ICF reference group in Kananaskis aims to contribute to the efficient integration of the ICF into the OMERACT process. Participants of the special interest group agreed the ICF Core Sets are the best available "external standards" of functioning and should ideally be available for all conditions that are represented by OMERACT. This was formulated in a series of recommendations that were accepted in the final plenary session:

1. The ICF should be the starting point when defining the domain "Function and Health" in new OMERACT Core Sets;
2. It was encouraged to redefine the domain "Functioning and Health" in the existing OMERACT Core Sets according to the ICF;
3. The ICF should be considered when addressing content of (new) instruments for function; and
4. OMERACT should further endeavor to enhance the ICF.

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