

COMMENTARY ON SUPPLEMENT 44: G. ICF Core Sets for Chronic Conditions

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The following papers from Supplement 44, 2004, in Journal of Rehabilitation are considered:

Introduction: ICF Core Set development of patients with chronic conditions

Alarcos Cieza, Thomas Ewert, T. Berdirhan Üstün, Somnath Chatterji, Nenad Kostanjsek and Gerold Stucki (1)

Identification of the most common patient problems in patients with chronic conditions using the ICF checklist

Thomas Ewert, Michaela Fuessl, Alarcos Cieza, Christina Andersen, Somnath Chatterji, Nenad Kostanjsek and Gerold Stucki (2)

ICF Core Set for rheumatoid arthritis

Gerold Stucki, Alarcos Cieza, Szilvia Geyh, Linamara Battistella, Jill Lloyd, Deborah Symmons, Nenad Kostanjsek and Jan Schouten

ICF Core Set of osteoarthritis

Karsten Dreinhöfer, Gerold Stucki, Thomas Ewert, Erika Huber, Gerold Ebenbichler, Christoph Gutenbrunner, Nenad Kostanjsek and Alarcos Cieza (10)

ICF Core Set for diabetes mellitus

Jörg Ruof, Alarcos Cieza, Birgit Wolff, Felix Angst, Dimitrios Ergeletzis, Zaliha Omar, Nenad Kostanjsek and Gerold Stucki (9)

The International Classification of Functioning, Disability and Health (ICF) is an ambitious project to establish generally-agreed-upon domains of assessment associated with the functioning of patients with specific conditions. The ICF is intended to complement the International Classification of Disease (ICD) and to operate at 2 levels. The Brief ICF Core Set for any condition is designed to specify the minimum data that will be collected in studies of that condition. This appears to be largely, in the case of clinical studies, in order to establish similarities and differences of participants in different studies. The Comprehensive ICF Core Set is designed to specify in any condition the minimal agreed categories needed to be comprehensive in a multidisciplinary assessment of patients functioning (1). The process of reaching agreement was careful and laborious and is well described in these papers.

Ewert et al. (2) examine the most common problems in patients with a range of chronic conditions. A convenience

sample of in- and out-patients attending rehabilitation were scored on a checklist and a rating scale (reduced in the analyses to present or absent) of the severity of the problem by healthcare professionals using 125 of the 362 ICF second-level categories. The purpose of this study was to examine and compare the frequency of problems scored in the 12 conditions selected for study. The main thrust of the findings are in the identification of those ICF categories in the 5 areas of “body structure”, “body functions”, “activities and participation”, “environment – barrier” and “environment – facilitator” that were identified in each condition for at least 30% of the sample (except in the case of “environment – barrier” where for some reason a figure of 20% was selected). The paper succeeds in describing the range of functions across the 5 areas and the tendency for different conditions to have different patterns of functional problems. The authors assert that this demonstrates the need for a condition-specific approach when describing function for use in clinical practice. This is reminiscent of the discussions regarding the need for condition-specific measures of quality of life, leading to the general acceptance that a generic measure is required, to establish comparability but that a specific measure was necessary to capture the specific aspects of “quality of life” affected by the condition. To some extent the findings, therefore, are not surprising but underpin the exercise of describing core sets for each condition. The ways in which these scores relate to both disease specific and generic measures of quality of life is an empirical question but will require the need to use the rating scale of the severity of any functional problems.

The authors express surprise that their view that the brain is involved in depression was not supported by the data. This perhaps reflects their reductionist approach to mental illness, as it would seem likely that, with this view, any mental conditions (anxiety, personality disorder, etc.) would all be considered to involve the brain. It is unclear whether this would be helpful to discriminating functional impact between mental illnesses. The domain “body structure” obviously encourages this approach and it is appropriate for some rehabilitative interventions that are directed towards body structure.

The authors find that the body function of pain was scored in over 30% of patients in all the conditions under study. This implies that the severity of some patients in some groups, such as diabetes, that find their way to rehabilitation must have been somewhat advanced. The whole exercise of sampling from rehabilitation is an obvious limitation but perhaps reflects the orientation and purposes of the authors to develop a tool for

clinical use in rehabilitation. A surprising finding is, however, that 7% of the clinical group, chronic widespread pain, do not have pain scored as a problem.

“Sleep” and “energy and drive” functions are also commonly scored as present in most conditions. This is not surprising as “fatigue” is often the most highly rated symptom reported by individuals with chronic conditions (see, e.g. 3, 4). It is disappointing that “fatigue” is not a category that is included in the ICF as it is a clear and neglected topic in chronic conditions. For instance fatigue in cancer has been found to be common but also associated with depression where studies have shown that depression correlates with the degree of fatigue (5, 6). The relationship between these 2 constructs is clearly complex as fatigue may be the cause or a result of depression (7). Improving cancer patients’ levels of fatigue has been significantly associated with a reduction in anxiety and depression (8). These findings suggest that the complex interaction between these functions is important and the ICF may in the future allow a more complex analysis between, for example, the items reflecting fatigue and emotions.

The limitation of a specific group of patients being studied and that the ICF functions need to be examined in patients at different stages of their condition and under different treatments is clear and acknowledged by the authors. It also limits the generalizability of the study, but it sets up the process for the examination in more detail of each condition in order to develop “a parsimonious set of items (that) will enable busy clinicians to rapidly evaluate functioning and disability across different health conditions ...” It also demonstrates that, with training, these issues can be scored but this is only a little comfort, as it does not present the reliability of the training and the techniques of different healthcare professionals assessments of the same patient. It is, however, in the development of the core sets in individual conditions rather than in contrasting the conditions that the real test of the utility of the ICF enterprise needs to be established.

The core set for diabetes mellitus (DM) used the consensus approach and given the system of voting, the background of the experts in determining the categories is important (9). Over half (8) of the experts were physicians. The remainder consisted of 5 physical therapists, 1 epidemiologist and 1 social worker. While the specializations may differ by country, the absence of a dietician is a major omission but also lacking are specialist nurses and chiropractors. An important omission, of occupational therapist occurs in the osteoarthritis paper (10). This professional group is perhaps closest to the integration of patients into the environment and their viewpoint must be seen as central to the rehabilitation process of patients with osteoarthritis as well as rheumatoid arthritis (RA). The test of the utility and the gradual evolution of the core sets from this first version may take place when the range of specialities have had the opportunity to use the Brief ICF core set and the Comprehensive ICF core set.

The difference between the processes of a group of healthcare professionals arriving at a consensus for the core set and what categories are scored by professionals when patients arrive at

a rehabilitation centre is informed by contrasting the categories identified in diabetes in the papers by Ewert et al. (2) and Ruoff et al. (9). The experts had the data from the preliminary empirical studies but also had available systematic review data and the preliminary Delphi exercise. In the presence of patients, categories in “body function” (e.g. “pain” 37.3%, “mobility of joints” 36.4% (2; Table III) were identified in over 30% of patients but not considered sufficiently important by the expert panel to be included as part of the core sets. Examples in “body structure” include “trunk” identified in 35.7% of patients (2; Table II) and in “environmental factors” where “individual attitudes” were identified in 67.7% of patients (2) but also not considered as part of the core sets (9; Table V). This highlights the importance of the processes attached to defining brief and comprehensive sets. The great attraction to the processes adopted is not only their transparency but also their tentativeness. Recognizing that any group of brief and comprehensive core set categories will evolve over time is a great strength of the process.

The level of agreement on the core sets in diabetes was impressive with the percentage of agreement in the items reaching the 50% cut-off never falling below 69% and the nearest item to achieving inclusion being endorsed by only 23% of experts (9; Table V). The gap between those excluded after the 50% cut-off was applied was not as great in RA (11; Table V) and unfortunately was not reported in the same manner in the osteoarthritis (OA) paper (10). It would have been more informative to lay out the findings in similar ways as this enables a comparison to be made of the process of arriving at consensus decisions in each condition, which is at the core of the ICF enterprise. Nonetheless, the lower level of agreement of the experts in RA of items to be included in the Brief ICF core set perhaps reflects the widespread impact of the condition on patients’ lives. It is, therefore, not surprising to find a number of items in the “activities and participation” section, such as “lifting and carrying objects” (endorsed by 45%) and “using transportation” (40%) that came close to the 50% cut-off. Given that the process was performed by 17 people, a change in view of 1 and 2 members, respectively, would have elevated these items into the core set. As with any cut-off the magic of a 50% endorsement does lead to some dilemmas at the margins.

Perhaps the most surprising finding in both the OA and RA is the absence of fatigue (“energy and drive functions”) in the core list. Fatigue is a key symptom reported in all arthritic conditions and its absence from the core set is surprising (4, 12–14). It is particularly surprising given that it is included in the core set for DM. The process of arriving at a consensus is difficult and often dependent upon the dynamics of the group. It is interesting to note that the core set (i.e. achieving agreement of at least 50% of experts) numbered 28 in diabetes, 20 in RA and 13 in OA. Only 3 of the items in OA were not included in the core set for RA (“body structure” – additional musculoskeletal structures related to movement; “activities and participation” – “dressing and environmental factors” – “public use”). This overlap suggests that some expected commonalities did emerge,

but a useful exercise would have been to have each of the panels assess both conditions. This would be one manner of examining the influence of group processes in defining what is perhaps the more difficult process of specifying the brief core set.

Overall it depends on how this information is ultimately to be used. If the brief core sets are to define the minimum reported data for studies in the conditions to enable comparability then a further exercise will need to be defined as to how these are to be measured. If the comprehensive sets are to be used for the guidance of the rehabilitation process then one will need to be clear that some categories may only become important as the condition evolves (e.g. "pain" in DM, see 9). One big unanswered question is how to encompass the variable impact on function of the condition without this becoming stereotyped per condition. The dangers of having a set of categories, even if they are considered comprehensive, is that the large variability of individuals response to a chronic condition may be missed if the set is slavishly followed. This potential misuse of the comprehensive set needs to be guarded against and it needs to be recognized that the consensus process may lead to the picture of the functioning of the archetypal patient. The need to ensure that this is supplemented by an open-ended questioning of the patients perspective on functioning is necessary if all areas of concern for individual patients are to be incorporated and the patient voice heard.

Perhaps the biggest challenge involves how to incorporate the range of psychological beliefs and cognitions that patients hold about their illness and its treatments. Why these are important is that they often appear to guide the responses of patients and impact on quality of life of their condition and its treatments. As this also incorporates the rehabilitative process it seems necessary that the patients beliefs needs somehow to be captured in the ICF process. These beliefs can be viewed as mediating factors between the condition, its treatments and its impact on functioning and quality of life. Issues such as whether patients will choose to perform certain behaviours including attendance at rehabilitation, adherence to treatment recommendations, activities around the house and recreation appear to be dependent upon their attitudes or cognitions about their illness and themselves. This not only emphasizes the importance of patients beliefs and their influence on functioning but also their potential to act as a guide to the rehabilitation process.

Given the concerns and caveats expressed above it is important to recognize the value of both the processes and the products

of the ICF exercise which is well represented in the 4 papers considered here. The impact of bringing together healthcare professionals of different background to discuss key features of functioning in different conditions should not be underestimated. The process of participating in the meetings leads to a broader understanding of the impact of the condition on functioning. The publication of this supplement exposes the processes and outcomes to a wider audience and therefore increases the debate about processes, outcomes and ultimate perception of the value of the ICF enterprise.

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