

What Matters: The Lived Experience with Musculoskeletal Health Conditions



“Non enim vivere bonum est sed bene vivere”
[What is good is not just living, but living well...]
— Seneca, Epistulae Morales

Today, living and living well are the 2 main health-related social goals. Social progress and modern medicine have made it possible for more and more people in developed societies to enjoy a lifespan approaching the biological limit of human nature. The true challenge, then, is how people can live well over the whole lifespan, especially when experiencing health impairments.

Rheumatology is a case in point with respect to the success of modern medicine to achieve this. With the development of biological treatments and the evolution of the evaluation sciences and clinical quality management, patients with adverse musculoskeletal health conditions now have a better chance than ever to live a full life comparable to people without any health problems.

The continuous development of even better interventions and the systematic evaluation of their benefits and harms rely on a shared and valid conceptualization of health. Unfortunately, Jadad and O’Grady have pessimistically concluded in a recent *British Medical Journal* editorial that “to define health is futile”¹. We believe the main reason for this is that the philosophical conceptualization of health from a purely biological perspective does not provide an adequate definition of health². Ultimately, the lack of a universally agreed on and practical conceptualization of health has contributed to a Tower of Babel in the world of outcome measurement.

Fortunately, there is a solution on the horizon. The key is to forego the futile claim to a universally agreed-on definition of health and instead focus on a universally agreed-on operationalization of health. Such an operationalization is exactly what the World Health Organization (WHO) has provided with its International Classification of Functioning, Disability and Health (ICF), endorsed by the World Health Assembly in 2001^{3,4}.

The WHO conceptualization of functioning merges 2 distinct continua: first, a horizontal continuum of discrete categories of functioning ranged in 3 dimensions: body func-

tions and structures, activities, and participation; and second, a vertical continuum of degrees of functioning from a total lack to complete presence of functioning. This continuum applies to each category and, in principle, across a range of categories.

The study by Taylor, *et al* presented in this issue of *The Journal*, which is part of a series of studies towards the development of ICF Core Sets for psoriatic arthritis (PsA), makes use of the WHO concept of functioning with respect to these 2 distinct continua⁵.

With respect to the first notion of functioning, the study found that “The ICF provides an important framework to consider the range of ways that disease can affect individuals...” The fact that the results from the clinical study confirm “the range of problems voiced by patients elicited from focus group research”⁶ is encouraging. In addition, the other results with respect to the influence of environmental factors and expected differences with rheumatoid arthritis and ankylosing spondylitis are reassuring with respect to the use of the ICF as an external standard when defining functioning in the context of the OMERACT process^{7,8}. In other words, with respect to both its conceptualization and its classification, the ICF provides the best framework for defining the spectrum of life experiences relevant for assessment of the influence of PsA.

Much more puzzling were the results of Taylor, *et al* with respect to the second notion of functioning, the degree of functioning from a total lack to complete presence (Figure 1). Only a very limited number of studies have explored the use of the ICF to assess a person’s functioning level. Using Rasch methodology, those studies found that in principle it is possible to aggregate information from ratings of individual ICF categories across a range of categories and to place a person’s experience of functioning on a continuum^{9,10,11}. As a consequence, it is possible to develop ICF and, more specifically, ICF Core Sets based on measurement instruments for clinical assessment as well as research or statistics. Also, it is clear that the level of aggregation depends on the perspective of the resulting quantitative information¹². For health statistics, a rather broad perspective on overall functioning is most suitable, whereas for

See Effect of PsA according to the affected categories of the ICF, page 1885

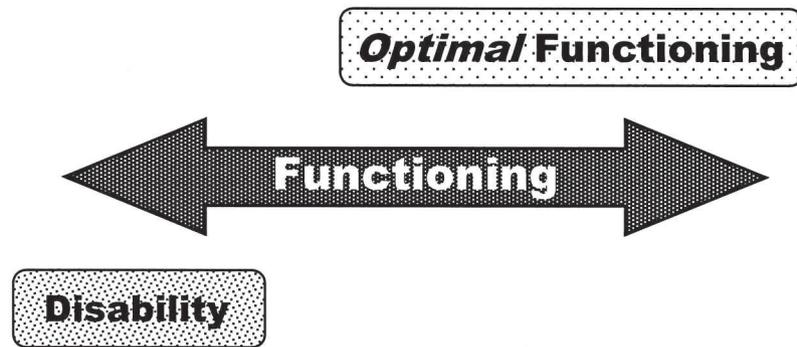


Figure 1. Functioning as universal experience.

the reporting of clinical studies a component-based approach is preferable. Finally, for efficient analysis of the effects of a treatment in a randomized control trial, a meaningful subset is preferred¹³. While this all is plausible, the authors were puzzled by some unexpected findings when cross-walking the ICF to the world of measures.

According to their expectation, they found a high association between the number of activities and participation, ICF categories with scores of 2 generic health status instruments, the WHO Disability Assessment Schedule (WHODAS) and the Medical Outcome Study Short-Form 36 (SF-36). They also found high associations with the disease-specific Health Assessment Questionnaire Disability Index (HAQ-DI) and a new instrument claiming to be ICF-based (PAR-PRO)¹⁴. The Spearman correlation coefficients ranged between 0.38 (SF-36 role emotional) and 0.69 (HAQ-DI). They did not find, however, the expected differential associations between ICF categories of specific ICF chapters with the mentioned measurements, which would seem more highly correlated than others. The authors then correctly ask why this is the case and conclude that the problem lies with the ICF, adding that the quantitative integration of affected ICF categories may not produce valid scores that “represent the concepts embodied within chapter headings.”

We agree with the authors that “further work is clearly necessary to clarify the best approach of numerically representing the extent of affected ICF categories.” Most important, this involves the selection of reliable operationalizations of individual ICF categories that can then be cross-calibrated to the ICF qualifier, WHO’s reference standard for reporting^{10,15}. For this, there is no need to reinvent the wheel. We can safely assume that, for the range of ICF categories relevant for PsA and other musculoskeletal health conditions, there are numerous patient-reported items or clinical tests that can be used for this purpose. More specifically, one may use items from condition-specific outcome measures such as the HAQ, generic measurements such as the WHODAS or the SF-36, as well as items from the World Health Survey or the Patient Reported Outcome Information System (PROMIS) network initiative. Ideally, the now

emerging international endeavor to operationalize single ICF categories should be based on an exchange of experiences, if not coordination, for example led by OMERACT (Outcome Measures for Rheumatology Clinical Trials).

Beyond the necessary operationalization of single ICF categories, it is important to stress the need to better understand the qualitative as well as the quantitative relationship of the most pertinent outcome measurement instruments used in PsA and other musculoskeletal conditions with the ICF. As readers of this study, we have no way of understanding what is in the black box of each individual measurement instrument without linking these concepts contained in those measurement instruments to the ICF^{15,16,17}. As has been found in many such linking exercises for other health conditions, the instruments may not contain what they claim they do, using often highly individualized and hence not internationally shared terms with respect to functioning and disability^{7,8}. Indeed, the authors mention that they set out to do exactly this. It would be important for them to report whether the incongruence of concepts contained in certain measures can explain the lack of differential association of measurements made by those instruments with respect to ICF subscores for specific ICF chapters.

In conclusion, their study again provides evidence for the suitability of the ICF when defining the spectrum of life experiences relevant for the assessment of the impact of health conditions such as PsA. However, we are just at the starting point with respect to use of the ICF as an international reference standard for the reporting of functioning on a continuum.

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