CONCEPTUALIZING AND DEFINING OUTCOME

This year marks the twentieth anniversary of the first formal presentation of the draft [1] of what was to become the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) [2]. The ICIDH describes itself as a manual of classification relating to the consequences of disease. As such it offers a conceptual basis for thinking about outcome associated with disease. In its schema, disease gives rise to impairment which is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function". Impairment itself may lead to disability, defined as "any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being". Impairments and disabilities, by interacting with the physical and social environment, can result in handicap. This is defined as a "disadvantage for the given individual ... that limits or prevents the fulfilment of a role that is normal". This progression from disease to handicap is illustrated in Fig. 1. To this has been added quality of life (QoL), which we believe to extend beyond the disease-handicap continuum, as it is mediated by a whole series of other factors. These include self-esteem, coping skills, age, gender and ethnicity [3-7].

The ICIDH has particular relevance to chronic disease generally and, specifically, rheumatic disease. We can imagine impairments such as pain, limited range of motion or fatigue, giving rise to disabilities, for example, in walking, dexterity or personal care. These impairments and disabilities may be further mediated by environmental factors to produce, for example, mobility handicap. Thereafter, personal attributes such as coping skills, or external factors such as level of disability benefits, will determine the impact of the disease and its consequences upon QoL. All the attributes of the continuum can be considered to be indicators of outcome.

Conceptualizing outcome in this way helps us to think about what we are measuring. For example, consider the American College of Rheumatology's (ACR) core disease activity measures of RA for use in clinical trials [8]. When we operationalize the conceptual continuum by specifying the various components of outcome, we find that much of the ACR core set clusters under disease (e.g. acute-phase reactant value) and impairment (e.g. pain). What is surprising is the increasing lack of specification as the proposed measures move away from the disease end of the continuum. For example, the disease activity measure 'patient's assessment of physical function' can be operationalized by well-known measures such as the Stanford Health Assessment Questionnaire (HAQ) [9], the Arthritis Impact Measurement Scale (AIMS) [10] or the Quality of Well-Being Scale (QWBS) [11]. It is acknowledged that some of these instruments measure more than just physical function. However, given the salience of physical disabilities to arthritis (as shown in Fig. 1), can the instruments be considered equivalent? A brief perusal of these scales shows that they are quite different. For example, the QWBS enquires about ability to utilize public transport (handicap rather than disability) in its mobility domain, and mixes locomotor disability (walking) and mobility handicap (confined to bed or couch) in its physical activity domain. In contrast, the HAQ (in its UK version [12]) has eight sections dealing with upper and lower limb functions which by and large reflect the disabilities shown in Fig. 1. Did the ACR deliberately set out to provide such a broad specification under its 'physical function' domain? It is certainly inconsistent with the more narrowly defined measures of disease activity and impairment.

Recent developments in measurement techniques emphasize the need to have a clear conceptual basis. These developments centre upon 'probabilistic conjoint measurement' [13], which is more generally known under the label 'the Rasch model' [14]. This model formalizes desirable characteristics of measurement, e.g. unidimensionality. Fitting data to the model allows us to draw inferences that the observations we have made enjoy these desirable characteristics [15].

![Conceptual Continuum](image-url)

**Fig. 1.**—Conceptualization of outcome in rheumatology.
If data fit the Rasch model, it is possible to link different measures of disability into a single measurement system, an innovation already applied to functional assessment in rehabilitation [16]. This co-calibration of scales has major potential for standardizing measurement of impairments, disabilities and handicaps across different studies and, across different countries. The potential for QoL measurement is even more exciting. Consider the development of QoL measures using the 'needs-based' approach [17]. This approach tells us that the influence of health on QoL is not simply the direct effect on how people feel physically or emotionally, but on what their health allows them to do [18]. Furthermore, the items derived reflect the subjective expression of the impact of the disease on people's lives, taking into account relevant mediating factors. QoL scales can be developed for different diseases, e.g. rheumatoid arthritis and ankylosing spondylitis. However, as long as these separate scales share some items, it will be possible to compare them directly using the underlying calibration derived from the Rasch model. This principle would apply to comparing QoL scales across all diseases. Thus, disease-specific QoL instruments can be developed which are nevertheless directly comparable, rendering the disease-specific versus generic debate obsolete.

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REFERENCES


