

MATTERS ARISING

Handicap one year after a stroke: validity of a new scale

There are problems with the paper by Harwood *et al.*¹ The authors, by paraphrasing the World Health Organisation (WHO) definition of handicap,² lose the sense that handicap is a social value that, for a person with impairment and disability, results in limitation or prevention of fulfilment of a role. Thus rehabilitation is concerned with the prevention and reduction of both disability and handicap, and not just with the reduction of handicap. The WHO definition, rather than being "closely defined", is so broad as to require an operational approach. Rather than attempt to classify the values associated with impairment and disability that limit or prevent roles, the WHO propose six key accomplishments necessary for social survival.

These are, as Harwood and his colleagues state, orientation, mobility, physical independence, occupation, social integration, and economic self sufficiency. The WHO, however, did not consider that these six accomplishments exhausted the dimensions of handicap,³ by contrast with Harwood and his colleagues. The WHO also did not consider that these dimensions were mutually exclusive,⁴ a major problem for classification, more so for a measurement scale. Harwood and his colleagues assert that more complex roles can be described in terms of these six dimensions of survival, a claim not made by the WHO, and sustainable only by valuing most human activities as of equal importance, as when Harwood and his colleagues equate "work . . . watching television . . . and going on holiday" in their preamble to the dimension of occupation.

Despite their efforts to form the WHO classification into an interval scale, their scale may be seen as yet another ordinal quality of life index. The assaying of opinion of a small sample of people and subsequent mathematical manipulation and extrapolation that produced the weights associated with the dimensions has not been shown by Harwood and his colleagues to be stable over time, over different samples of the population in the United Kingdom, or over different cultures.

The problem with a single summed score in a multidimensional scale is that information may be lost rather than gained in the process of summation. Given two groups with the same low score on this particular scale, one does not know automatically which group is poor, which is immobile, and which lacks community support services. Cook, *et al.*⁵ recently showed the advantages of a non-parametric approach to a multidimensional scale, the functional independence measure. Their approach seems to be a more satisfactory method of dealing with multidimensional scales than this attempt to develop an interval scale of

social value based on an incorrect simplistic operational definition of an extremely broad concept.

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- 1 Harwood RH, Gompertz P, Ebrahim S. Handicap one year after a stroke: validity of a new scale. *J Neurol Neurosurg Psychiatry* 1994;57:825-9.
- 2 World Health Organisation. *International classification of impairments, disabilities, and handicaps*. Geneva: WHO, 1980:29.
- 3 World Health Organisation. *International classification of impairments, disabilities, and handicaps*. Geneva: WHO, 1980:39.
- 4 World Health Organisation. *International classification of impairments, disabilities, and handicaps*. Geneva: WHO, 1980:41.
- 5 Cook L, Smith DS, Truman G. Using functional independence measure profiles as an index of outcome in the rehabilitation of brain-injured patients. *Arch Phys Med Rehabil* 1994;75:390-3.

Harwood replies:

Perhaps it is worth reproducing the exact wording of the WHO *international classification of impairments, disabilities, and handicaps* definition of handicap: "In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual". Further, the introduction to the classification emphasises that handicap is concerned with the value attached to an individual's circumstances. The handicap classification "is a classification of circumstances in which disabled people are likely to find themselves". Finally, "in the handicap classification it is desirable that individuals always be identified on each dimension. This will provide a profile of their disadvantage status".

The definition as it stands is ambiguous. Is it the disadvantage that prevents or limits fulfilment of a role? or is the disadvantage the limitation due to impairment or disability? The actual categories given in the classification make it clear that it is the second. We are dealing with problems caused by ill health, in their "social" context, which includes the physical environment, the use of wealth to overcome problems, and the subjects' perception of their situation. The concept itself is closely defined, especially in comparison with others such as health or quality of life.

The six dimensions are unlikely to be independent (uncorrelated). They can, however, be made mutually exclusive by dropping the requirement that reliance on help in any one dimension constitutes a disadvantage in that dimension (rather than just physical independence handicap). This criterion was required for the scale weighting exercise. The seventh dimension of "other handicaps" contains only minor items, such as the wearing of glasses or dentures and "the state of being delicate". Its inclusion in our scheme would have implied a precision that would not be justifiable.

The questionnaire we have presented is simply an operational version of the classification. It is objective, but still allows the subject to choose how disadvantaged they perceive themselves. The important question regarding the classification scheme is whether it provides a valid and comprehen-

sive description of handicap. We believe that it does, apart perhaps from the psychological sequelae of chronic disease. We would be interested to hear of examples of disadvantages that cannot be adequately described in terms of the six handicap dimensions. None is immediately apparent to us.

We agree that it is useful to retain a descriptive handicap profile comprising the levels of disadvantage on each dimension as well as deriving an overall score. When presenting group data we quoted the proportion of subjects falling into each level of disadvantage. For comparative work in therapeutic trials or aetiological epidemiology, a single summary score is very useful. We do not claim that "most human activities are of equal importance"; the system of scale weights ensures that this is not the case. Any given profile of disadvantages on the six dimensions will be more or less desirable to a particular subject. We can quantify this by measuring its utility. The measurement task is not easy, and many people we will be interested in measuring will be incapable of undertaking it. Thus we have argued that for epidemiological work, a set of utilities derived from a representative external population will be valid, recognising that these will have limited validity when applied to individual subjects.¹ As there are a large number of possible combinations or "profiles" we have modelled the responses to a sample of handicap scenarios, and the scale weights for the different items simply represent the coefficients from the model.

The interval level of measurement is a consequence of the measurement and statistical methods used, and has been well described elsewhere.^{2,3} It is not an ordinal scale as there are no ordered categories. The additive model may be questioned on grounds of plausibility, but is justified in practice by the fact that it gives an adequate and simple model of how disadvantages in different dimensions lead to an overall judgement of the utility of a health state. The model fits well, both for the scenarios from which it was derived, and for additional test scenarios. We have since compared scale weights derived from four different populations as part of ongoing development work. Good (but not perfect, $r = 0.85$) agreement is achieved even when estimates from the model constructed for one population are compared with actual measurements made on another. It would be best to reweight the scale for each study population to which it will be applied, but this is labour intensive, and the weights from the general population sample we presented will usually be reasonable. The use of a utility based system to derive scale weights allows the essential element of value or desirability to be adequately represented (for groups or populations but not individual subjects). Given two groups with the same low score, one may not know exactly why the scores are low, but one does know that their situations are equally undesirable. The work on the development of the scoring system has been described in greater detail elsewhere.⁴

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- 1 Harwood RH, Jitapunkul S, Dickinson E, Ebrahim S. Measuring handicaps: motives, method and model. *Quality in Health Care* 1994;3:53-7.