EDITORIAL COMMENTARY

# Quality of life in multiple sclerosis

> "Far better an approximate answer to the right question, which is often vague, than an exact answer to the wrong question, which can always be made precise."
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> Tukey JW. *Ann Math Statistics* 1962:**33**;13–14

There has been an upsurge in interest in health related quality of life (HRQoL) in the medical literature over the past few years. MEDLINE (1966–98) contains over 24 000 papers identified by the search term *quality of life*, the vast majority of which were published within the past five years. Of the 100 or so papers linking *quality of life* and *multiple sclerosis*, 80% were published since 1991. Despite this level of interest in HRQoL, many clinicians still mistrust such social science type research. Data are perceived to be *vague* and to lack validity when compared to *hard* laboratory derived information. We would rather put our faith in our own measurements, or those of our machines, than in an apparently subjective assessment made by our patients. However, this is not only arrogant, it is also deluded. The utility of any measurement depends on its validity, reproducibility, and responsiveness. Many apparently *hard* measurements, on which we base so much or our clinical decision making, such as neurological signs[1] and polymerase chain reaction based assays,[2] have very poor reproducibility. Assessment of HRQoL, on the other hand, can be highly reproducible.[3] Murphy *et al* (this volume, pp 460–466) have shown that, in patients with multiple sclerosis, one such assessment (functional status questionnaire) also has a high level of validity. Results obtained from patients with multiple sclerosis in three European countries differed substantially from those obtained from local controls (construct validity). The physical function domain of the scale was highly correlated with the Kurtzke EDSS score (concurrent validity). Identical findings have been reported for another generic measurement of HRQoL, the short form 36[4]. In other words, these apparently subjective assessments produce hard data.

But why measure quality of life? The most obvious manifestation of multiple sclerosis is neurological impairment. Surely this is the most appropriate measure of progression of disease for clinical trials of potentially disease modifying treatments. There are two main arguments against relying solely on measurements of impairment and disability, and in favour of using HRQoL as a primary outcome measure in clinical trials in multiple sclerosis. Firstly, HRQoL includes several important domains of health, including general well being, social function, and psychological function, which are not directly related to neurological impairment or disability, but which are regarded by patients as being more important determinants of their overall health status than impaired physical function.[4] Murphy *et al* and others[4] have shown that these domains are substantially decreased in patients with multiple sclerosis compared with controls, and that these changes correlate poorly with neurological impairment and disability as measured by the EDSS. If we intend to measure the effect of treatments on what patients consider important, then we would seem to have little choice but to measure HRQoL. The second argument in favour of HRQoL is that it allows us to measure the overall balance between the benefit derived from treatment and the harm caused by the side effects and the constraints of treatment. Side effects are rarely incorporated in the overall trial result. Rather, they are listed separately and often ignored. Measurement of outcome using HRQoL at least records the patient's perspective on whether or not the effects of treatment were worse than the effects of the disease itself.

There are, however, many important issues relating to HRQoL which remain to be resolved. There is no satisfactory definition of HRQoL. There are problems with its conceptual basis—it seems to combine elements of impairment, disability, and handicap. It is unclear which of the many instruments should be used for which purposes. There is no consensus about the use of generic or disease specific measures. Although there is increasing evidence from cross sectional studies that measurement of HRQoL in multiple sclerosis, and in other diseases, is valid and reproducible, there are little or no data from cohort studies on the responsiveness HRQoL—that is, the sensitivity of measures to disease progression. However, on the basis of the evidence available so far, one could certainly argue that, for the purpose of outcome measurement in large clinical trials, far better an apparently vague measure of outcome which is valid, reproducible, and important to patients than an apparently exact measure which only partly reflects the concerns of patients and which ignores the side effects of treatments.

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