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There is increasing scientific interest in assessment of the impact of disease and the efficacy of intervention. In most studies, the term 'quality of life' (QoL) is used to illustrate the patient's perspective. The value attributed to the outcome of QoL assessment can be high and lead to a preference for one intervention over another. The term QoL, however, may be used for related – but very different – concepts. Furthermore, most studies use measures that may not truly assess QoL.

Frequently used aspects of patient-based outcomes are QoL, health-related QoL (HRQoL) and perceived health status (HS), which are all multidimensional concepts that incorporate the physical, psychological and social aspects of life. Associated with these concepts are generic and disease-specific questionnaires. This article focuses on generic measures whose questionnaires are applicable across a variety of diseases. With regard to differences between the various concepts and their outcomes, however, the same reasoning applies to disease-specific measures. There is no single fully agreed definition of QoL, although a working group of the World Health Organization (WHO) has defined the concept with emphasis on the personal evaluation of functioning in relation to individual and/or cultural standards, values, expectations and goals[1].

HS measures assess physical, mental and social functioning, but bears no relationship to the perception of the individual and his or her values and expectations[2]. Consequently, it does not capture an individual's QoL. The concept of QoL is first and foremost subjective and can only be determined by the individual. This implies that, for the full assessment of QoL, the perception of disease and treatment should not only be *recorded* (as by HS), but also *evaluated* by the patient. So QoL and HS are different concepts that must be distinguished. HRQoL is a restricted definition of QoL, which has been designed to exclude factors that, strictly speaking, lie outside the area of healthcare, such as housing, neighbourhood and financial matters[3]. For the purposes of this article, however, QoL and HRQoL are considered together.

The critical issue in the concept of QoL is the uniqueness of the individual. Many instruments used for measuring QoL make an inadequate evaluation of the subjective experience of a disease and the effect of an intervention. These instruments are, typically, early versions based on what healthcare professionals believe to be relevant, such as the Medical Outcomes Study 36 Item Short Form Health Survey (SF-36®; Medical Outcomes Trust, Waltham, Massachusetts, USA)[4] and the European Quality of Life instrument (EuroQol)[5]. Although other measures, such as the Nottingham Health Profile[6], do include the patient's opinion of the impact of disease or treatment on his or her life, these questionnaires do not weigh the importance of different aspects of QoL for the individual patient. They are, therefore, HS measures rather than QoL instruments. In an attempt to capture an individual's QoL accurately, several newer questionnaires have been developed, such as the WHO QOL Assessment Instrument 100 (WHOQOL-100)[1] and the Schedule for Evaluation of Individual QoL (SEIQoL)[7].

The choice of measure may have important consequences for the interpretation of outcome. People have individual expectations about health and illness, and have differing abilities to cope with limitations and to tolerate discomfort. Expectations and coping abilities modulate objective HS facts into subjective values, representing an individual's QoL[8]. In other words, although HS may indicate whether a disease or an intervention causes limitations and can classify the levels of such limitations, QoL, in addition, reflects the extent to which an individual experiences limitations as a problem in daily life. Two people with identical restrictions in functioning (HS) might evaluate these restrictions differently, leading to different QoLs. For example, the frequency and intensity of pain is recorded in the widely used SF-36®, whereas in the WHOQOL-100 the patient is asked whether his or her life is actually affected by having pain. Another example can be found in social functioning; the SF-36® asks only about the frequency and intensity of social activities, resulting in a low score for patients with limited social contacts. In the WHOQOL-100, feelings of loneliness, satisfaction with relationships and the ability to support others are incorporated in

the social domain. This recognizes that attempts to improve social functioning based solely on HS results might not, themselves, contribute to a better QoL[9]. For instance, someone who has difficulty climbing stairs because of pulmonary, cardiac or peripheral vascular disease has limited functional status and so experiences difficulty in shopping and may be socially isolated; this has an impact on HS. How much these objective limitations really hamper the patient, however, can only be evaluated by QoL measures. A person living on the ground floor with a helpful neighbour is likely to perceive the limitations of impaired mobility differently from someone living in solitude on the third floor. Whether intervention is desirable and, if so, which intervention is indicated may depend on whether HS or QoL is the basis of decision-making. If it is the individual patient's interest that has priority, assessment by a modern QoL instrument is necessary.

But how should the results of such assessments be interpreted? QoL scores, unlike distances or weights, have no dimensions or units; they can be compared only with themselves. There are no 'standard' or 'normal' values of QoL. Although extreme scores within a study population represent discrepancies from the average or 'norm' scores, individual variations in QoL are inevitable. Caution should therefore be applied when interpreting scores that do not exclusively represent an individual's QoL. Unfortunately, QoL at baseline can be assessed only against means from reference groups. The efficacy of treatment for an individual is best assessed by comparing his or her QoL scores over time, rather than comparing these scores with those of other patients. Comparison over time should identify those whose experience of life fails to improve[10].

In summary, many widely used patient-based outcome measures do not really evaluate QoL, only HS, and so are inadequate in making any attempt to appreciate the perception of an individual patient. Measuring HS can yield useful information, but its limitations must be appreciated. So far, experience of genuine QoL instruments in clinical studies is limited, but a true assessment of the impact of illness and the outcome of treatment can be made only if the perception of the patient as an individual is evaluated properly.

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