Abstract

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Measuring Quality of Life: lessons from the past – prospects for the future

The history of what is often mistakenly referred to as "quality of life" can be dated back some 35 years or so. In those days researchers faced the same fundamental issue in evaluating the effects of healthcare as we face today, namely the need to measure the change in health status that results from treatment. The problem then, as now, was to be able to compare health outcomes in different therapeutic areas. Limitations in healthcare resources in every country mean that choices about how resources are used and distributed rely upon an understanding of the relative efficiency of their use. The first generation of generic health status measures emerged during the early 1970s in the US, Canada and the UK. Progress was slow and patchy and made less clear with the development of a huge variety of condition-specific measures. However, since the mid-1980s there has been quite spectacular growth in the development and application of generic measures, with some degree of standardisation, so that today the technology of generic health outcome measurement is dominated by a small set of indexes.

The central issue that underpins all generic index measures used in the evaluation of new health technologies is that of determining the *value* of health status, or more precisely the *value* of change in health status over time. There are essentially three elements that must be considered – the method to be used in eliciting such values, the people who should be asked and the way in which their values should be represented. The narrow, conventional view of the health economist is that such values should represent the views of the general population measured under particular circumstances – as utilities or preferences expressed under conditions of uncertainty. However, this restrictive view can be rightly criticised as forcing decision-makers to accept the dominant role of health economics in determining social choice. More fundamental is the flawed nature of the case in support of utility as the quality-adjustment factor in computing QALYs (quality-adjusted life years).

For the future health and wellbeing of decision-makers who use quality of life data, and for the patients who are affected by their decisions, we need a robust assessment of fundamental ideas that have shaped the historical development of economic evaluation in health. Decision-making in a democracy must be transparent and open to review by ALL citizens. The methods that we choose to represent "quality of life" outcomes in economic evaluation of health care, test our commitment to achieving that goal.