From shroud waving to quality of life

Traditionally, cardiovascular treatments have focused on saving life rather than improving it. Before many important advances, such as thrombolysis and treatment with β blockers, were accepted as routine clinical practice they had to undergo rigorous assessment to show that they improved survival. But their effects on the quality of patients' lives were not measured with the same rigour. In the treatment of malignant tumours, however, such measures have already become integral components of most trials, and in the United States the FDA is said to be pressing for quality of life measures to be used as a new end point in all clinical trials. It looks as though the cardiological spotlight is widening too. This issue of the British Heart Journal features four articles on the measurement of the quality of life in patients with cardiovascular disease.

Townsend and Litter (p 373) draw attention to the fact that ACE inhibitors, though they prolong life, may do so in a way that does little to enhance the quality of the extra months or years gained. On the other hand Underwood et al on page 382 show how lack of treatment too can have measurable adverse emotional effects in patients waiting for coronary artery bypass surgery. A guide to the practicalities, technical methods, and terminology of assessing quality of life emanating from a conference supported by the British Heart Foundation which was held in October 1992, appears on page 460.

Trials in cardiovascular medicine should consider including quality of life assessment as a pre-specified outcome measure. An example of the use of such techniques is that we are likely to know more of the effect of angioplasty on our patients' lifestyles as a result of the inclusion of quality of life measures in the RITA trials.

Cost is an issue. The use of questionnaires may prove more practical than interviews, especially in multicentre studies. Indeed, in the editorial below, Lesley Fallowfield describes a specific instrument that has been used to study patients after myocardial infarction. Along with gene probes, cost and volume contracts, and audit these instruments from the social sciences are increasingly likely to become new tools of the trade for cardiologists. Like all tools their uses, and abuses, must be understood.

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Editorial

Quality of life assessment in patients with heart disease

Most clinicians care about the quality of their patients' lives. None the less, cardiologists have been slow to routinely employ appropriate measures to assess quality of life. Several concerns and misconceptions may account for this reluctance to use the psychometric tests available. Some worry that concepts such as quality of life are too vaguely defined to be measurable and that existing tests provide unreliable, subjective, "soft" data. Others claim that testing takes too long, that subsequent analysis is often complicated, or that patients may come to psychological harm if asked to fill in self-assessment questionnaires. There is little evidence to support these arguments.

Conceptual and theoretical vagueness

First, the phrase quality of life has been used vaguely, but its valid and reliable measurement is possible. Whatever the specific disease state or treatment being assessed, a satisfactory test should have items dealing with at least four core domains of functioning. These include physical, psychological, social, and occupational domains. Depending on the particular medical problems being treated, other important areas should and can be included. For example, any satisfactory assessment of quality of life after open heart surgery would be incomplete if it did not include cognitive and intellectual functioning. These functions are rarely mentioned as important goals of surgery, yet their effects on patients can be profound. Restoration of cardiac function may be deemed of little value if the cost is impaired cognition, with the consequent inability to work or socialise adequately.

Testing takes too long

In the light of other lengthy procedures that patients regularly endure this argument seems absurd. The measures that could be used in clinical practice as part of a routine work up do not need to be time consuming to provide important and interesting information. For example, the Hospital Anxiety and Depression Scale (HADS) takes 5–10 minutes to complete and is simple to analyse. Furthermore, it has the advantage of having been designed specifically for use with physically ill patients, assessing mood state changes not somatic items. This is important because many of the common symptoms diagnostic of depression such as lethargy or weight loss found
in tests for psychiatric disorder may be a function of physical disease rather than mood disturbance in cardiac patients. More comprehensive measures, which might not be feasible in clinical practice, could be used for research studies and trials, however.

Recently published data from the Cardiac Arrhythmia Suppression Trial (CAST) have shown the value of assessing symptoms, mental health, physical functioning, social functioning, life satisfaction, and life expectancy by a specially designed self-report quality of life questionnaire. This 21-item questionnaire could be used to assess disease progression and treatment effects; patients with heart failure and previous myocardial infarction and those with angina and dyspnoea had a significantly impaired quality of life compared with those patients without. This questionnaire seems appropriate for use in multicentre clinical trials.

Psychological inquiry harms patients
The notion that patients do not wish to be asked questions of a psychosocial nature or that doing so merely alerts them to concerns that they then worry about is fallacious. In other areas, for example oncology, there is empirical evidence that patients do not find such enquiries embarrassing, distressing, or an intrusion. On the contrary, they seem to welcome assessment as evidence of the doctor’s concern for them as individuals.

There are many self-report questionnaires measuring quality of life that are of potential value in cardiac disease. Choice of test and frequency of administration depends to a certain extent on the purpose of assessment—that is, for research or as a guide to designing appropriate supportive interventions or rehabilitation programmes. A clinical psychologist with expertise in neuropsychological assessment may be able to assist with more in-depth measures of cognitive and intellectual performance.

Good psychological assessment of patients before treatment permits the early identification of premorbid psychological problems. This enables the clinician to target the limited resources of counselling support and help on those who need it most before and after treatment. Not only does such assessment help patients before treatment begins, it also broadens the measures used to determine the cost-efficacy and cost-benefits of any medical and surgical interventions. A more comprehensive awareness of patients’ functioning before, during, and after treatment allows us to evaluate outcome more scientifically and to develop supportive interventions to facilitate social integration, cognitive, and sexual functioning and generally to enhance the quality of life. These aspects of care are becoming integral parts of assessment and therapy in other specialties and may often be the most important outcome measure for treatment efficacy and resource allocation.

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Br Heart J 1993 69: 371-372
doi: 10.1136/hrt.69.5.371-a

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