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*Editorial*


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## The measurement of health related quality of life

When the British Cardiac Society met in York in 1986, professor of economics Alan Williams addressed us on quality of life (QoL) measurements. He specifically dealt with their use to calculate the relative cost of gaining QALYs (quality adjusted life years) by interventions for angina.<sup>1</sup> QALYs were to help health planners make more objective assessments of how our treatments performed in terms of value for money. Such analyses would enable us to make rational choices in deciding which treatment is the most cost effective for a given condition and, taken a step further, on which diseases and on which treatments money is best spent. By Williams's calculations, the number of QALYs gained by interventions to relieve angina were modest, ranging from 0.5 for single vessel disease to 3.5 QALYs for a patient with left main stem stenosis with severe angina.<sup>1</sup> It was evident that the scale he used was relatively insensitive to the effects of symptoms because a patient with a C rating for distress (scale A-D) and V for disability (scale I-VIII) still scored at 0.9 quality of life (scale 1-0).<sup>1</sup>

Perhaps it was unsurprising that the attitude of an audience of cardiologists, expanding their angioplasty practice, ranged from sceptical, through indignant, to down right hostile. Whether those involved in health policy will use QALYs in the allocation of resources remains an issue,<sup>2</sup> but the concept of formal measurement of QoL has gained general acceptance. In 1992 the *BMJ* ran a series of articles on the subject.<sup>3-5</sup> Inclusion of QoL measurement was to be the norm in therapeutic trials and in 1993 this journal published an editorial encouraging cardiologists to be more ready to understand and use them.<sup>6</sup>

In this month's *Heart* we publish two prospective studies of five year follow up of QoL after coronary artery surgery.<sup>7,8</sup> This provides an opportunity to reflect on how these measurements have served us in the evaluation of the treatment of heart disease.

A problem is that the expression "quality of life" has entered common parlance to the extent of being trivialised. Medical students recite the phrase as an opening gambit in response to almost any question, while relatives readily chime in with "but it's all to do with quality of life, i'n't it doctor?". Well, yes, of course it is. However, interventions aimed at the coronary stenosis itself require a more tightly reasoned and logical approach. We first ask if the symptoms, which are detracting from life's quality, are directly attributable to a mechanically correctable cause, in this instance an obstruction to coronary blood flow. Next, will that symptom be relieved if the mechanical problem is corrected? Finally, can that benefit be obtained at an acceptably low risk? Unless the answer to each of these three questions is "yes" we think again. If what is impairing QoL is something else entirely (the hip, diabetes, bronchitis, bereavement, or the broken lift in the block of flats) an operation on the heart will not reverse it. Herlitz *et al* found that patients who had poor QoL scores before and operation, and in particular women and diabetics, reported poor QoL five years afterwards.<sup>7</sup> The question remains as to how

to use that information to guide future case selection. It certainly makes it difficult to argue that our treatments are "a good buy" in QALY terms if little upward movement in QoL measurements can be shown.

Cardiac practice differs from many other aspects of health care, in that a significant proportion of our work is performed for the continuation of life itself. In our own studies, at first sight, a disappointing number of patients (with aortic stenosis or anatomically threatening coronary disease, for example) showed a gain in QoL.<sup>9,10</sup> Intelligent inspection of the raw data (by which I mean a well informed individual, actually looking at them before the detail was obscured by too hasty StatsPac analysis) quickly revealed the reason. Some patients reported so little distress or disability before surgery, at least not of a type that would be revealed by generic QoL scales, that they were already scoring at the top of the range. Due to a ceiling effect, no upward movement in QoL scores could be shown. The gain for them was that they were alive to report the same good quality three years later. Interestingly, the EuroQol group note "problems surrounding the state 'dead'".<sup>2</sup> Doctors and economists will agree on that! Survival matters. Nor should we forget that most disabled people value their lives to a degree that sometimes surprises the hale and hearty, in spite of a daily burden of symptoms.

In the straight forward case of angina in relatively young men with good ventricles, the QoL gains are dramatic,<sup>11</sup> far out weighing any detrimental effects of wound pain or stroke. Most changes in QoL correlates with relief of angina<sup>12</sup> and life's quality deteriorates again as grafts fail and angina returns.<sup>8</sup> Where formal measurement of QoL has helped includes instances where there is an interaction of beneficial and detrimental effects, as in comparing surgery with angioplasty. Neither the Emory trial (EAST; Emory angioplasty versus surgery trial) or RITA (randomised intervention treatment of angina)<sup>12,13</sup> found a difference in QoL that went beyond that predicated by relief of angina, a link observed by Caine *et al*.<sup>8</sup>

There are many more complex problems to unravel in weighing up the advantages and disadvantages of treatments than relief of the presenting symptom. It is in the balance of benefit and detriment that QoL measurement should have its biggest impact. Clinical trials of treatment of hypertension and hypercholesterolaemia are examples—the primary effect may be obtained but, as both are asymptomatic conditions, the side effects of treatment may have an unacceptable impact. From the patient's perception (and the essence of these measurements is that they are self reported and patient centred) there is unlikely to be perceived health gain. How do we use such information? The trade off of immediate side effects and long term gains can at least be assessed objectively and compared between treatments. In another contentious area, it appears that the physiological advantage of dual chamber pacing does not carry much QoL advantage over simple pacing in the elderly.<sup>14</sup>

At the most difficult end of surgical practice is the question of eventual QoL in patients for whom we struggle hard during a protracted intensive care unit (ICU) course. The occurrence of multiple organ failure predicts poor QoL is the most expected finding.<sup>15</sup> In our studies we found that 60% of our long stay ICU patients were alive a year later, and they were enjoying a QoL not dissimilar from the 93% of our patients who had left ICU within 48 hours.<sup>16</sup> As we set out to explore whether identification of predictably poor QoL might be an argument for desisting in further care<sup>17</sup> this was a welcome and encouraging finding.

In our work we have found QoL measurements (Nottingham health profile, Rosser-Kind index, EuroQol, SF36) to be instructive and to give insight and objectivity in difficult areas, but healthy scepticism persists. Greenhalgh wonders "if the more patient centred the research becomes, the more some patients will find it intrusive and unacceptable" and asks if it is "None of our business?",<sup>18</sup> and this in the *BMJ*, which had so strongly promoted QoL measurements for all.<sup>3-5</sup> On the grounds of plausibility, I had been concerned at the postulate that a 5 year old, surviving heart transplantation, "will return to a full healthy life".<sup>5</sup> If that is the level of knowledge of outcomes among such influential authors, then it is very much our business as clinicians to make sure that the conclusions of health planners and desk bound doctors should not depend on such naive assumptions.

Recent work on self reported QoL found positive correlations with higher social class and higher educational standing<sup>19</sup> but what was the effect due to? Was there more disease, less care, or more general unhappiness in the less socially privileged?

There is considerable difficulty in weighing up gains and losses over the short and long term. There are imponderables in dealing with the elderly<sup>20</sup> who will always be disadvantaged if a calculation includes the number of years of benefit, simply because they have fewer left to put in the multiplier of a QALY calculation. "A generic measure should aim to capture physical, mental, and social functioning"<sup>2</sup> but how do we compare very different diseases such as the eating disorder patient with no pain and exercising excessively, with a transplant candidate who enjoys family life, holidays, and social interactions, despite a worsening burden of cardiovascular ill health?<sup>21</sup>

A large amount of work has been done, and knowledge gained, by the very committed workers in this difficult area of study.<sup>1 2 6 8 11 19 22</sup> We know that many studies still in progress have QoL measurements built in to their design as a result of the compelling arguments for them.<sup>3-5</sup> The con-

cept remains important, and will probably be of most value in the more difficult and contentious areas of clinical research. It is there we may gain better insight by measurements of QoL, rather than believing them to be self evident soft findings.<sup>23</sup>

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