

Quality of life measurements in eating disorders, angina, and transplant candidates: are they comparable?

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Summary

The measurement of health-related quality of life has attracted much attention and is now a component of most big clinical trials. As we evaluate and choose between treatments and make judgements about priorities in health care, it is important that the equivalent data are available for different patient groups^{1,2}.

Introduction

The measurement of the health-related quality of life can be used in three quite separate ways to evaluate treatment. The first is to assess the net overall results of a particular treatment for a given illness. The generic instruments are intended to look beyond specific symptoms (for example, angina, depression, or breathlessness) which must be evaluated by symptom-specific scales, to the more general positive and negative effects of the treatment. The second use may be to compare the relative merits of two different treatments for the same condition. Thirdly, comparisons may be made in the cost effectiveness of different treatments for different diseases. The improvement in quality of life, and the expected time over which that change can be maintained may be used to justify allocation of resources in one direction rather than another¹.

If health choices are to be influenced by the quality of life gained, within or between disease states², it is vital that equivalent data are available for untreated patients in order to give any validity to these techniques. Some of the hypothetical illustrative examples, such as the implication that the 80% of 5 year olds who survive heart transplantation return to 'full healthy life'¹ are out of touch with reality. While life may be transformed for an individual, the assumption that it is 'full' either in its quality or duration, may be false on critical analysis. It is for that reason that we must make adjustments for quality of those years of life.

The whole philosophy is abhorrent to some. While this is understandable, it would seem reasonable to seek explicit evidence of the degree to which life's quality is impaired in one disease state rather than another and, so that we can assess in a rational way, by how much, for how long, and what cost can that state be improved. If it is accepted that equitable distribution of care includes directing resources towards those suffering most, and within those groups

to identify how their suffering can be most effectively relieved, then we must endeavour to provide the best possible data, using validated instruments. However, we still have to examine whether it is possible to make realistic comparisons.

The quality of life has been headlined as 'the missing measurement in health care' in a book which devotes chapters to cancer, AIDS, cardiovascular disease, arthritis, and the elderly, but amongst them psychiatry is a missing discipline³. The expression 'quality of life' is now used very loosely. A substantial volume entitled *Quality of Life after Open Heart Surgery*⁴, in fact contains very few measurements derived by formal instruments and, in most instances, the authors describe the familiar outcome measures of cardiac surgical success such as simple survival statistics and disease specific measures such as the relief of haemodynamic disorder. These are of vital importance within the field, but without actually measuring the health profile with a generic quality of life instruments, inferences about overall quality cannot be drawn.

In a much larger study we have measured the self-reported quality of life, using the Nottingham Health Profile (NHP)⁵ amongst other generic and symptom specific instruments in young people with eating disorders and a reference population of college students. We attempt to tackle the difficult issue of making a comparison with data sets of patients with other illnesses by putting our results alongside those reported from patients awaiting different forms of cardiothoracic surgery⁶⁻⁸. If this cannot be done, the whole principle of using quality of life measurements for comparative purposes must be questioned. The NHP is widely used in clinical trials to see change before and after treatment, but can it be used to make value judgements about the burden of morbidity between different groups?

Methods

Nottingham Health Profile data on six groups of patients are drawn from two different sources.

- 1 Data on young women with eating disorders (anorexia nervosa and bulimia nervosa) and from a comparable group of young women were obtained as part of a prospective study in which several generic quality of life scales were obtained for comparison with a symptom specific scale.
- 2 Data on patients with advanced cardiopulmonary disease are available from the literature⁶⁻⁸. NHP data continues to be widely used in clinical trials, including for example the Randomised Intervention in Treatment of Angina (RITA) trial and therefore provides a means of making comparisons.

The eating disorder patients and their comparison group

A consecutive series of new referrals to a tertiary treatment centre for eating disorder patients with

DSM-III-R⁹ diagnosis of anorexia nervosa, or bulimia nervosa were included in the study. Patients with eating disorders not otherwise specified, or other main diagnoses, were excluded. A comparison group was recruited from female polytechnic students.

Amongst several health-related questionnaires, patients were asked to complete the NHP⁶, a self report inventory which consists of 38 statements in six dimensions: energy, pain, sleep, mobility, emotional reaction or social isolation. A weight is applied to each Yes/No statement which enables a score ranging from 0-100 to be calculated for each dimension. The higher the score, the greater the perceived health problems in that area¹⁰. They also completed the second part of the NHP which asks whether they are limited in any of seven areas of daily life.

Socioeconomic status was coded using Hollingshead's two-factor index based on father's occupation¹¹.

Patients with advanced cardiopulmonary disease

All these NHP data are from published reports from the Papworth group⁶⁻⁸.

Coronary artery disease. This group are all men ($N=98$) aged (37-59) whose predominant symptom is angina. The mean scores for the group on the self report inventory are available. Also the proportion of patients reporting limitation in seven areas of daily life are available⁶ from Caine and colleagues.

Heart transplant candidate. A group of 122 patients (M:F) are described by Caine *et al.*⁷. The mean scores on the six dimensions of the NHP part I are available.

Cystic fibrosis. Caine *et al.* have also provided data on 54 younger patients (M-F)⁸. They provide NHP I mean scores and the proportion of patients reporting limitation in daily life on NHP II.

Statistical presentation of data. In order to permit visual inspection of the data we have ranked the six elements of NHP I and the seven elements of NHP

II according to magnitude in the eating groups thus creating a profile against which the cardiopulmonary disease groups can be compared.

A single mean or median conveys little information and 95% range spans 0-100 in several instances. For NHP I we have used 70% range for the scores as a compromise. This approximates to the use of standard deviation. We have used the mean rather than the median because that is what is provided in the publications which we have used for comparison⁶⁻⁸.

For NHP II the data comprises the proportion of Yes/No responses for the group. The 70% confidence limit of the proportion has similar dimensions to the standard error of the mean for parametric data. Where the bars do not overlap, a true difference is likely.

Results

A total of 142 eating disorder patients fulfilling DSM-III-R criteria for anorexia nervosa ($n=62$, 57 females) or bulimia nervosa ($n=80$; all female) were seen between September 1991 and March 1992 and completed symptom specific and generic quality of life instruments. One hundred and twenty-six (89%) returned the NHP questionnaire. The comparison group comprised 95 female students from two London Colleges with a response rate of 91/95 (96%). The mean ages of the groups were all in the mid 20s with standard deviations indicating a spread of ages from late teens to early 30s in all groups.

Both patient groups showed significantly more impairment than controls in the health domains of the NHP (Figure 1). The highest levels of impairment were perceived in energy and in the psychosocial domains, emotional reaction and social isolation, and in disturbance in sleep. Anorexia nervosa patients had significantly reduced mobility compared with the bulimia nervosa patients and controls.

In addition to health difficulties, the patient group also reported functional difficulties in daily living (Figure 2) which were highly significant compared with the controls. The anorexia nervosa group had more problems with their social life and home relationships than the bulimia nervosa patients but in other aspects the two groups were equally impaired.

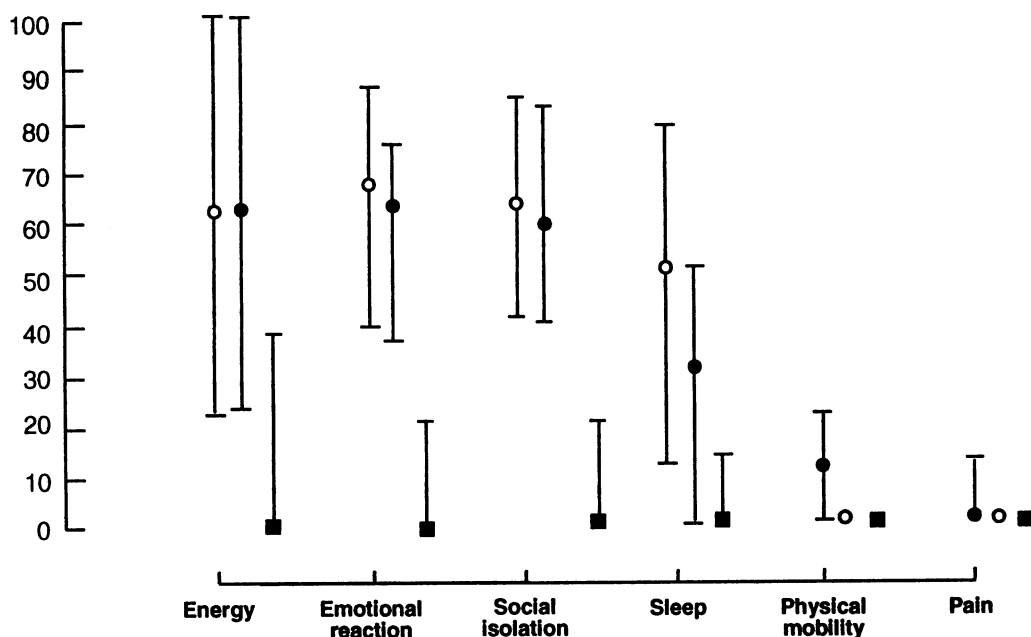


Figure 1. Nottingham Health Profile results set out in order of severity of disturbance. The mean score and 70% range for 52 subjects with anorexia nervosa (open circles), 74 subjects with bulimia nervosa (closed circles) and 91 young healthy women for comparison (squares)

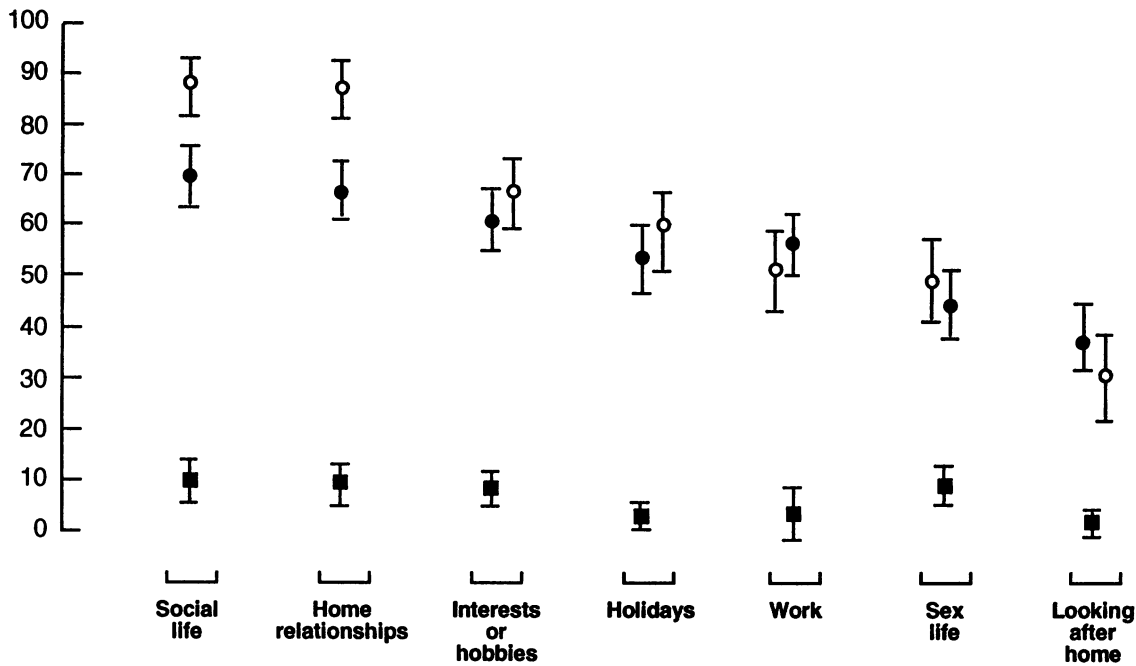


Figure 2. Proportion of subjects reporting impairment in seven domains with the 70% confidence limit of the proportion. This has been chosen because it behaves similarly to the standard error of the mean in that if the confidence limits do not overlap the difference in proportions is likely to be significant by the usual criteria. Data are for 52 subjects with anorexia nervosa (open circles), 74 subjects with bulimia nervosa (closed circles) and 91 young healthy women for comparison (squares)

Other aspects of these patients will be reported elsewhere (Keilen, in preparation).

Discussion

The results of the NHP measurements in the eating disorders patients have been set out (Figures 1 and 2) ranked from left to right according to their magnitude, thus creating a visual 'profile'. Against these profiles we have set out reported measurements obtained in a group of 98 men waiting for coronary surgery⁶, a group of 122 patients with end stage heart disease prior to cardiac transplantation⁷, and 54 patients selected for heart/lung transplantation for cystic fibrosis⁸ (Figures 3 and 4).

The mean scores for these three reported groups of patients, who are selected largely on the basis of

the severity of their symptoms for expensive high technology health care, are set alongside the 30-70% range of the six domains of the NHP for the 126 eating disorder patients (Figure 3). The 98 men with angina have more pain and a lower level of physical mobility but less emotional reaction and social isolation. Impairment in sleep and energy in the cardiac patients are within the range for eating disorder patients. In the patients with cystic fibrosis, the instrument has identified a much lower level of mobility in this very breathless group whereas emotional reaction and social isolation are less impaired than in the eating disorder group.

Much attention has been given to the quality of life evaluation and its improvement with heart transplantation¹³ and NHP data are available⁷ (Figure 3).

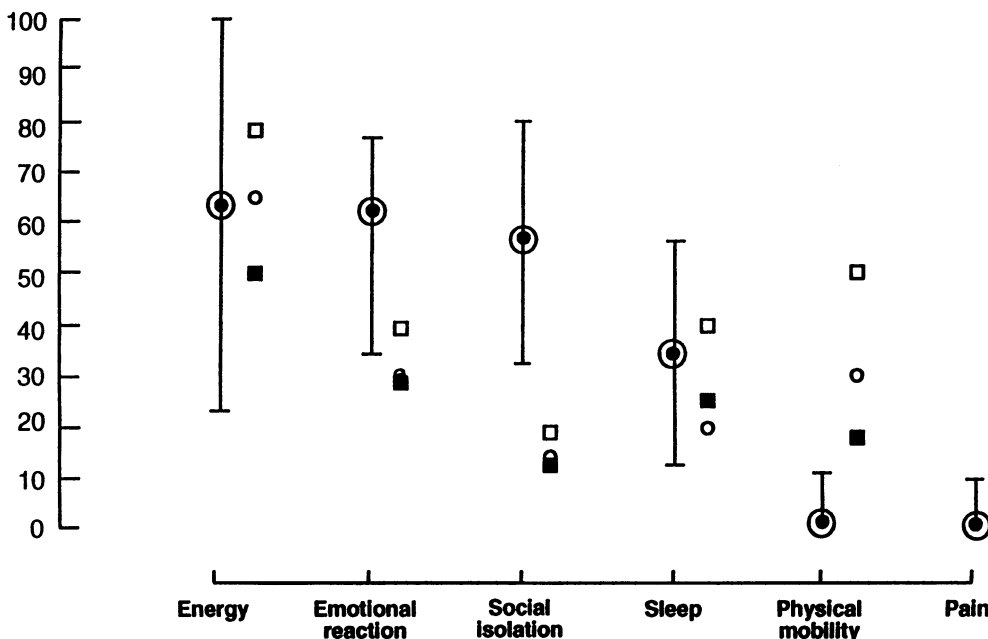


Figure 3. The eating disorder data for anorexia and bulimia (N=126) from Figure 1 have been pooled (closed within open circles) presented as the mean with 70% range. The mean scores for 98 men under 60 awaiting coronary surgery for angina (open circles) [from Ref 6], 54 candidates for heart/lung transplantation (closed squares) [from Ref 8] and 122 patients selected for heart transplantation (open squares) [from Ref 7] are plotted against the eating disorder profile

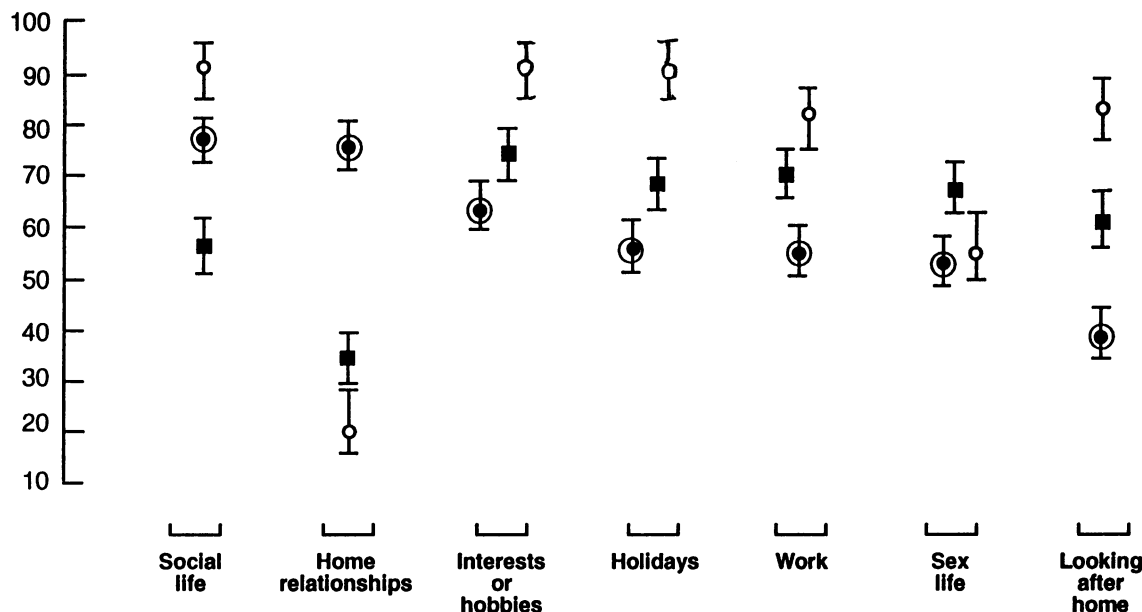


Figure 4. The eating disorder data for anorexia and bulimia (N=126) from Figure 2 have been pooled (closed within open circles) presented as the proportion with 70% confidence limits. The results for 98 men under 60 awaiting coronary surgery for angina (open circles) [from Ref 6], and 54 candidates for heart/lung transplantation (closed squares) [from Ref 8] are given for comparison

Severe impairment of mobility is again seen but overall the profile is not obviously worse than the patients with eating disorders.

On the second part of the NHP, aspects of daily living, data are available for comparison for the cystic fibrosis sufferers and those with angina (Figure 4). In all seven aspects more than half of the eating disorder patients reported impairment. Overall, the patients with cardiac and respiratory disease were even worse although they reported less problems with home relationships.

Quality of life measures (QALYs) offer a broad definition of successful medical care and treatment outcome¹⁴. Many studies in eating disorders have focused upon weight, eating behaviour and psychiatric symptoms¹⁵, which may fail to capture the extent of the disability caused by the illness. Similarly, operative treatment for cardiac and pulmonary disease has concentrated on survival, and after that disease specific indices of success. The net gain in quality of life has received less attention. If we collect similar data for these two very different sets of patients, undergoing very different forms of care, can we make valid comparisons? These are at least real data sets and if the comparisons are unhelpful we should use these discrepancies to refine the instruments.

To what extent can a profile of impaired health related quality of life be compared between different disease population? In this example we cover a wide age range, very different pathological processes and disease where the potential treatments are at opposite ends of the spectrum, from the high technology required for heart and heart/lung transplantation to the highly individual psychotherapeutic treatment of eating disorders.

In the Rosser Kind Index which has been used for the calculation of QALYs all the data for an individual, and then for a set of individuals are collapsed to form a single utility to be used in comparative calculations.

The NHP is not designed to be used in this way and one can readily appreciate why on inspection of Figures 3 and 4. The trade-offs inherent in collapsing the data and the assumptions that would be implicit in that process are beyond any sensible use of the data.

Why should the data derived from any other questionnaire, used across the full range of ages, disease states and social class be any safer? Superficially neat numbers can be derived but perhaps only

at the expense of sacrificing data. Our findings in this study have made us wary in accepting the use of data beyond their original purpose and design. The relative weighting of the more physical symptoms in cardio-pulmonary disease and emotional in eating disorders is not a judgement we feel prepared to make.

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