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Concept

A reformulation of quality of life for medical science

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Current quality of life measuring tools are suited for economic decision making, not to investigate causal processes which lead to patients making evaluations of their lives. An alternative approach is presented based on research into positive versus negative life-satisfaction. Quality of life is a causal sequence of psychological states where perceived symptoms cause problems and the problems and symptoms cause evaluations, and where the causal sequence is a complex interaction between morbidity and psychological factors. Different types of medical intervention affect different stages in the causal sequence and so different types of quality of life instrument are needed for different kinds of medical research.

Key words: Assessment, health, psychology, quality of life.

Despite the increasing acceptance that health related quality of life (QOL) is an important outcome measure in medicine,[1] this topic is characterized by a degree of diversity and multiplicity of approaches which is unusual in advanced sciences. Health related quality of life (QOL) can be conceptualized in two distinctly different ways. The multifaceted approach is that QOL is an aggregation of several, conventionally agreed, health indices; the causal process approach is that QOL is a causal sequence resulting from an interaction between morbidity and psychological factors. The multifaceted approach is currently the dominant approach in medicine. In this article I show that the multifaceted approach may be appropriate for economic decision making where the aim is to allocate scare resources within a health-care system. However, the causal process approach is needed for medical science where the aim is to understand the causal processes underlying QOL change.

The multifaceted approach

Writing within the context of health economics, Spilker[2] says "The major domains of quality of life generally (. . .) include the following categories: (1) Physical status and functional ability; (2) Psychological status and well-being; (3) Social interactions; (4) Economic status". Most QOL scales include one or more of these domains, and the decision to include a domain is agreed as a convention rather than being the outcome of scientific investigation. Consequently, different groups of researchers have different conventions about the domains that should be included in QOL assessment. For example, a recent review of scales measuring QOL for respiratory disease patients[3] concludes that although the scales differ in terms of whether symptom items and items measuring limits to activities are included, each of the differ - ent types of scale can be justified in terms of the aims of the researchers, and hence each of the scales has content validity.

The multifaceted approach to QOL assessment provides a single score of QOL by aggregating across the items and domains which the scale measures. The method of aggregation often involves ascribing 'weights' to the different items so that items with a greater impact on QOL have a statistically greater contribution to the total score. Whether to use weights or not is a convention which varies between groups of reseachers. The majority view[4,5] is that if items are weighted by the degree of distress caused by the problem described by that item, then an aggregation of weighted items provides a more accurate view of overall distress. Those who do not use weights[6] argue that it provides a spurious sense of accuracy.

The conventionally accepted, multifaceted approach to QOL assessment has parallels with

economic indices outside medicine. For example, as a measure of the costs of living, the price of a conventionally agreed shopping basket (e.g., retail price index) is calculated to see whether, on average, prices are rising or falling, and whether there are regional differences. The precise contents of this conventionally defined shopping basket is not questioned as it is merely a convenient approximation for examining price change and value for money. In the same way, by treating QOL as some conventionally defined aggregation of domains, it is possible to make broad statements about the advantages of different types of treatment, and which types of treatment are the most cost effective.

The disadvantage of the multifaceted approach, however, is that information about specific domains is lost in the process of aggregation, and this has led some researchers to suggest that QOL outcomes should be disaggregated.[7,8] In particular, information about causal processes is lost as causes operate on specific outcomes, not on conventional aggregations. Whereas economic decision making simply requires information about costs and outcomes, the medical objective of improving the QOL of patients is best achieved from knowledge not only of which treatments improve QOL but also the causal process whereby that improvement is achieved.

Quality of life as a causal sequence

When used in clinical trials, QOL is commonly treated as an outcome measure which is independent of morbidity and mortality data. That is, the outcome measures of QOL and morbidity are analysed as though there were unrelated dependent variables. In reality, QOL must be affected by morbidity, and indeed one method of validating a QOL scale is to show that it correlates with morbidity. However, QOL is also affected by psychological factors. QOL scales (like other scales of life satisfaction) correlate with personality; depending on the study, dispositional mood can account for up to about 40% of the variance in QOL scales.[9] Thus, the outcome measures which are called QOL must represent some kind of causal interaction between morbidity and psychological factors.

Figure 1 provides a general model of causal processes involving different kinds of appraisal. As a first stage in the causal sequence, morbidity causes symptoms and anticipated symptoms (e.g., breathlessness, pain, inability to move limb). The patient reports not the objective symptomatology but the subjective experience of those symptoms, and these subjective, symptoms reports are affected by general mood, more specifically, negative trait affect.[10] People with depressive or anxious personalities perceive they have more symptoms due to bias associated with the recognition (encoding); mood accounts for about 10% of variance of symptom reports.[10,11]

The second stage in the causal sequence is for symptoms (or anticipated symptoms) to cause problems. However, symptoms do not always cause problems as the relationship between these two variables is moderated by other psychological factors, namely coping strategy. People vary in their ability to cope with negative events,[12] and patients who have developed effective coping strategies are less likely to experience a problem following a symptom.

The final stage in the causal sequence is for

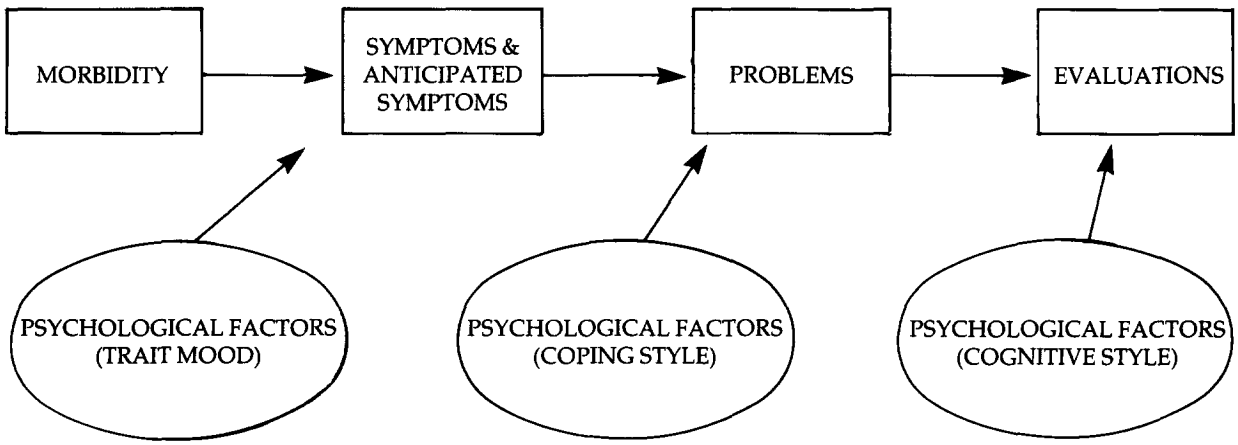

Figure 1. Quality of life represented as a causal sequence of symptoms, problems and evaluations.

patients to evaluate their problems/absence of problems and symptoms/absence of symptoms on evaluative dimensions, such as 'distress', 'lack of control', 'anxiety' or 'happiness'. These evaluations (which are assessed by the 'mood' or 'emotion' items in current QOL scales) are affected by a variety of cognitive factors including the perceived cause[13] and outcome of the illness. Evans[14] reports that transplant patients, haemodialysis patients and peritoneal dialysis patients who (objectively and subjectively) experience a variety of problems are more likely to rate themselves as 'very happy' than the general population. These data illustrate an important feature of the evaluative stage. The presence of illness, particularly life threatening illness, can lead to patients re-evaluating their lives, so that events which were previously neutral (e.g., meeting family and friends, looking at flowers) are evaluated more positively. The relationship between problems and evaluations is therefore a complex one, and it should not be assumed that the presence of problems necessarily means an unhappy life—or that the absence of health problems means a happy life. Evans' data has implications for present QOL assessment: the potential complexity of the relationship between problems and evaluations means that a statistical aggregation of problems, with or without weights, is unlikely to provide an accurate representation of the patient's real level of distress.

In conclusion, the perception of symptoms, problems and evaluations are causally related, but the causal relationship is moderated by different psychological variables. Using a multifaceted approach, many QOL instruments provide a summation of symptoms, problems and evaluations. From the perspective of medical science, this kind of aggregation is unusual. For example, consider the causal sequence in asthma where eosinophils cause bronchial hyper-reactivity which causes diurnal variation in peak flow. Eosinophil levels can be measured by Eosinophil Cationic Protein analysis (ECP), bronchial reactivity can be measured by the inhaled histamine concentration required to produce a 20% fall FEV1 (PC20), and diurnal variation by the maximum percentage morning–evening difference; but no one has ever aggregated ECP, PC20 and morning–evening difference into a single measure of morbidity. Yet it is precisely this kind of aggregation that is carried out for measures of health, or more specifically QOL. If QOL, like morbidity, is a causal sequence of events, it makes sense from the perspective of medical science to try to measure each of those events independently as a way of investigating the underlying causal process.

Positive versus negative quality of life

There is a considerable evidence showing that positive evaluations represent different causal processes from negative evaluations. For example, research into life satisfaction[15,16] shows that positive life satisfaction (being satisfied with one's life) has a low correlation with negative life satisfaction (being dissatisfied with one's life); that is, people vary independently in their level of positive and negative life satisfaction. Evidence that positive and negative life satisfaction are the consequence of different causal processes comes from findings that negative life satisfaction is correlated with dispositional mood, whereas positive life satisfaction is correlated with extraversion. Negative ('hassles') and positive ('uplifts') evaluations of daily events are also relatively independent in terms of frequency; evidence that they have different causal consequences comes from the finding that hassles but not uplifts are predictors of somatic complaints.[17,18] Finally, research on daily mood variation shows that positive and negative mood are only weakly correlated, and that daily negative mood but not positive mood is associated with somatic complaints.[19]

Current QOL scales ask the patient whether and to what extent daily living has been adversely affected by health. QOL scales allow the patient to express a series of complaints about health, and as such provide a measure of negative life quality rather than positive life quality. However, research into life satisfaction, daily events and mood all suggest that such complaints are likely to be independent of positive life quality, that is, the extent to which the patient is enjoying life. Current QOL instruments measure only one kind of appraisal, a negative appraisal, which patients make of their lives.

Coping strategy and positive/negative quality of life

People use a variety of coping strategies to deal with problems, health or otherwise, one such strategy being avoidance.[12,20] For example, an anxious student will not enrol for a difficult course as a way

way of avoiding the possibility of failure; an asthmatic may avoid social contacts where there is the possibility of an asthma attack. The tendency to avoid potentially problematic situations is a personality trait; people vary in the relative tendency to engage in success seeking versus failure avoiding behaviour.[21]

One method of coping with chronic illness is to restructure one's goals and expectations to achieve very little, thereby avoiding the possibility of failure. For example, by staying at home every evening, the asthmatic avoids the problem of an asthma attack in a public place; by avoiding busy places, the sufferer of venous leg ulcers avoids the possibility of having a knock which will start another ulcer. This avoidant style of coping reduces the incidence of negative life events, and thereby improves negative life quality. However, an avoidant coping style also reduces the number of positive life events and therefore reduces positive life quality. Thus, a patient who adopts an avoidant coping style may have a good negative life quality—and appear to have a good QOL using existing instruments—but may also have poor positive life quality—which will not be detected by existing instruments. This trade off between the richness of experience and the avoidance of problems will be determined, in part, by the patient's coping style.

Figure 2 is an elaboration of Figure 1 but showing two independent causal sequences relating to negative and positive life quality. In terms of negative life quality, symptoms cause problem events, where problem events are discrete occurrences which occur at a point in time (for example, breathlessness causing the asthmatic to be late for an appointment, pain causing the leg ulcer patient to go home). The problem events and symptoms are then evaluated primarily on negative dimensions such as distress, bother or unhappiness. In terms of positive life quality, or life richness, evaluation of life occurs on positive dimensions such as the degree of happiness. Happiness is affected by a variety of factors including the extent to which the patient avoids positive situations as part of an avoidant coping strategy—as well as personality and social circumstances independent of the patient's disease. I have called the avoidance of situations 'problem happenings' as they are not specific events which happen at a particular time but rather the absence of those positive events which typically occur in the well person. Thus, the antecedents of negative life quality evaluations are different from the antecedents to positive life quality evaluations, and, extrapolating from life satisfaction research, negative evaluations should correlate with dispositional mood and positive evaluations with extraversion. However, both

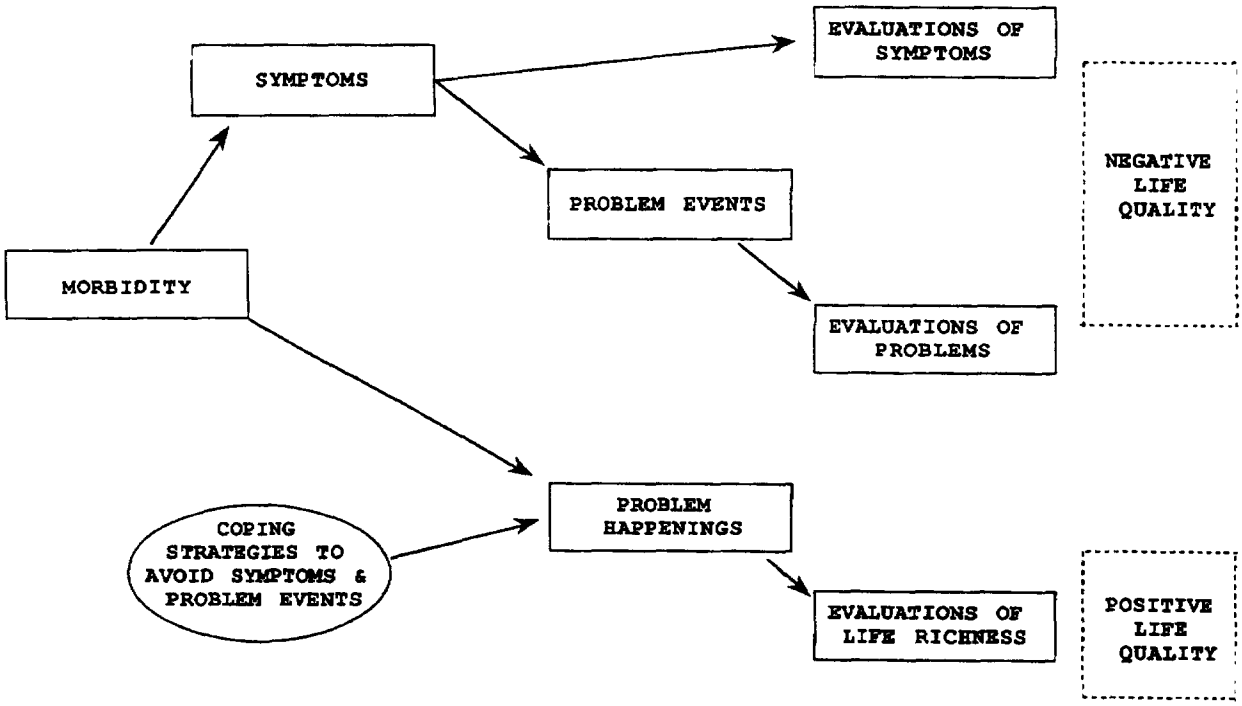

Figure 2. Different causal sequences for positive and negative life quality.

positive and negative evaluations may be affected by cognitive factors such as re-evaluations or cognitive re-appraisals.

Purpose-specific quality of life assessment

In order to understand the psychological reaction patients have to ill health it is necessary to conceptualise QOL as several causal sequences rather than as a multifaceted aggregation. If QOL is a causal process, what kinds of measurement are relevant to medical research?

First, let us suppose that researchers are interested in whether a new form of drug treatment improves QOL relative to some other treatment. Under such circumstances, the most direct, short term effect of a change in medication is a change in the frequency of symptoms and problem events. Thus the short term effect of morbidity reduction is a reduction in symptoms and problem events. In the longer term, reduction in morbidity may reduce the need for avoidant coping strategies and so lead to a reduction in problem happenings. However, any improvement in problem happenings depends on the patient altering his or her coping style, and as coping style is not affected directly by non-psychoactive drugs, this may take an as yet unknown length of time. Thus, for short term evaluations of drug treatments, greater sensitivity to the effects of treatments would be achieved by measuring symptoms and problems events, which can be measured either through questionnaires or, possibly more accurately, through symptom and problem daily diaries. For longer term evaluations it would also be useful to have a measure of problem happenings which could be assessed through a questionnaire.

The data reported by Evans[14] shows how evaluations can be poorly related to objective or subjective assessments of problems. The complex relationship between problems and evaluations suggests that evaluations are not a good outcome measure in clinical trials involving non-psychoactive drug treatments—though measures of happiness would be highly relevant to the evaluation of psychoactive drugs. On the other hand, improved styles of management on the part of the doctor may lead to greater perceptions of control by the patient, re-evaluations of life, or some other psychological factor which leads to improvement on evaluative dimensions. Thus, evaluations are a relevant outcome measure to assess the overall quality of care of a patient, and should therefore be included in patient audit. In particular, evaluations are relevant when making comparisons between patients having different diseases who have quite different types of problem. Comparisons of problems between types of patients is made difficult by the fact that like is not being compared with like, but it would be perfectly feasible to ask more general questions about the degree of happiness or unhappiness experienced by the patient across disease type. Thus, questionnaires which ask about the patient's general happiness and unhappiness with life—without referring specifically to disease related problems—may be a useful tool for cross-disease comparisons.

Guyatt *et al.*[22] have suggested that different instruments should be developed for cross-sectional (i.e., between types of patient) and longitudinal (e.g., clinical trials) research, but without suggesting that these different kinds of instrument should measure different kinds of QOL construct. The present proposal is consistent with Guyatt's in suggesting the need for purpose specific scales but goes further by suggesting that the different kinds of appraisal patients make about themselves vary in their relevance to different types of medical research. In general, cross-sectional research is best carried out with scales which measure evaluations whereas longitudinal research is best carried out with scales which measure problems and symptoms.

Conclusions

Existing QOL instruments measure a variety of psychological appraisals which are causally related. Although there may be merit in aggregating these different kinds of appraisal for economic purposes, such aggregations will not serve the purpose of medical science well. I propose that we should start a new chapter in QOL research where instruments are designed to measure specific constructs in the causal sequence that results from an interaction between morbidity and psychological factors.

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