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Quality of life and mental illness

Reflections from the perspective of the WHOQOL

JOHN ORLEY, SHEKHAR SAXENA and HELEN HERRMAN

The quality of life (QOL) of the mentally ill has been a matter of concern for centuries. The great reforms to the madhouses were prompted by this, so too was the creation of asylums and most recently, the move from institutional to community care. Despite these humanitarian concerns, little effort was made to define or measure such changes in QOL. QOL is now becoming a more valued assessment, not just in psychiatry but in many branches of medicine, particularly those dealing with patients who suffer or are disabled over relatively long periods of time. Of particular note has been its use in the assessment of those being treated for cancer (Maguire & Selby, 1989). Over the years, QOL assessment came to mean taking account of anything beyond mortality and symtom levels. Even noting side-effects of treatments has been put forward as a QOL assessment. More and more, however, QOL has come to embody the justified concern for patients as people and not just cases. It has also come to reflect the rise of a more consumer-oriented approach to medical care, in which the patients' own opinion of what is happening to them is taken as important, rather than patients being the objects of expert attention from professionals who themselves judge the effectiveness and relevance of what they do (Gill & Feinstein, 1994). The interest in QOL also reflects a more serious concern for that broad definition of health as "a state of complete physical, mental and social well-being and not merely the absence of disease" (World Health Organization, 1948). Virtually all the efforts of the health sector are directed towards creating an absence of disease, by prevention or treatment, with well-being as a secondary product. Without definitions and measures of well-being, however, there can be little progress towards including it as an objective in the creation of a more healthy society. QOL measures provide one step towards such a goal.

WORLD HEALTH ORGANIZATION

With these ends in view, the World Health Organization began a project in 1991 to define and create a measure for QOL (the WHOQOL) in such a way as to allow inputs from a broad range of cultures around the world. At the start, the WHOQOL group defined QOL as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad-ranging concept affected in a complex way by the persons' physical health, psychological state, level of independence, social relationships, and their relationship to salient features of their environment (WHOQOL Group, 1995).

The emphasis within the definition is first, on the subjective nature of QOL and second, on the need to explore all those parts of life considered as having a significant impact on QOL. Twenty-four such aspects of life (facets) have been identified in the WHOQOL project. The facets are grouped into the broader domains mentioned in the definition. This article will treat QOL as it has been defined and used within the WHOQOL project (WHOQOL Group, 1995).

QOL differs from subjective well-being, in that the latter concerns itself primarily with affective states, positive and negative. A QOL scale is a much broader assessment and although affect-laden, it represents a subjective evaluation of oneself and one's social and material world. The facets are largely explored, either implicitly or explicitly, by determining the extent to which the subject is satisfied with them or is bothered by problems in those areas. The WHOQOL bears some similarity to life-satisfaction scales. It differs from these, however, in that it carefully defines 24 facets of life, which it then explores, determining the subject's satisfaction (or lack of it) for each.

QOL AS AN ASPECT OF MENTAL STATE

QOL is thus an internal experience. It is influenced by what is happening 'out there', but it is coloured by the subjects' earlier experiences, their mental state, their personality and their expectations. This need not be considered as an obstacle to assessing it.

By defining QOL as subjective (internal), this brings a degree of unity to the evaluation. If it were purely objective, QOL would be constituted by a whole range of possibly disconnected and uncorrelated items and there would be little point in putting them together in a single instrument. There is, after all, no obvious reason for there to be a correlation between the number of hours one sleeps and the number of people one meets in a day or one's income. If, however, one is looking more at subjects' level of satisfaction with each of these areas, it may be influenced by a kind of overall 'satisfied with life' factor, and indeed the WHOQOL shows that there are correlations between the ratings on these different facets, greater within the broad domains, but also between domains (WHOQOL Group, 1998).

With regard to the presentation and use of the results, a question arises as to the validity of pooling together the scores obtained from the various facets to create a 'domain score' or even a single score of overall QOL (Patrick & Erickson, 1993). For many purposes, it is more useful to keep the various sub-scores separate and produce a profile, just as one normally does with data from an IQ assessment, for example. As indicated, there seems to be an underlying 'general factor' of QOL, and it should be possible to produce a single index score of QOL, which can be useful for making certain comparisons, even if considerable information is lost in the process.

Because QOL is influenced by a very broad range of facets, it is unlikely to change markedly from day to day or to be influenced by a change in one facet (e.g. relief of pain) unless that in turn affects many other facets (e.g. improves sleep, increases mobility, allows more social contact). It is unlikely that all illnesses markedly affect QOL in this broad sense, or that all treatments, even if effective in alleviating symptoms, necessarily improve it.

QOL AS A SUBJECTIVE ASSESSMENT

The fact that the WHOQOL is a subjective evaluation makes it much easier to have an internationally comparable instrument. It is easier to compare people's degree of satisfaction with their living space than to try and find some way of comparing the actual living space of a pavement dweller in Calcutta with that of a psychiatrist in New York.

The WHOQOL then sets out to be a purely subjective evaluation, assessing perceived QOL, and in this way differs from many other instruments used to assess QOL. The SF36 (Ware *et al*, 1993), for instance, includes a question on whether the subject is limited in climbing one flight of stairs or walking 100 yards (although the word 'limit' may allow some subjective evaluation; the question does not ask "can you climb one flight of stairs?").

The Nottingham Health Profile includes such items as "I lie awake most of the night" and "I am in pain when I am sitting" (Hunt *et al*, 1980). Lehman's (1988) scale for those with mental disorder asks "Is it sometimes very noisy here?", but the assumption is perhaps that only those who are bothered by the noise will endorse it as 'very noisy'. The Lancashire QOL Profile (Oliver, 1991/2), again for those with mental disorders, asks "In the past two weeks, have you been out to play or watch a sport?". These can all be considered as more or less 'objective' questions, although most instruments are a mixture of both the subjective and the objective.

This is not to say that objective questions are not useful in an assessment of a patient. Any good assessment of a patient requires a combination of instruments, but each needs definition, so that it is clear as to whether it is following an objective or subjective approach, or whether it is dealing with QOL or with disabilities or with symptoms.

GENERIC VERSUS DISEASE-SPECIFIC INSTRUMENTS

Some instruments for assessing QOL have been developed for those with particular diseases or conditions, whereas others are generic, applicable to virtually all people. The rationale for disease-specific instruments is that there are particular issues that contribute to a much greater extent to the QOL of people with certain diseases. Another point made is that a more specific measure will be more sensitive to changes in that condition (Patrick & Deyo, 1989). If, however, an objective is to assess the influence of a disease (or its symptoms) on QOL, then to include items closely related to say, symptoms, in the assessment of QOL serves only to confound the dependent with the independent variable. To take the example of pain, this is just one of 24 facets in the WHOQOL. The QOL of a person with arthritis must be assessed by inquiring into all 24 facets. The QOL of such a patient is adversely affected to the extent that the disease and the pain affect many of the facets. An instrument which focuses on assessing pain is not exploring the effect of pain on QOL. Similarly, to assess the QOL of a person with a depressive illness, requires an instrument that assesses all aspects of life, not just negative affect. For this reason, there are strong arguments for using generic instruments. These also have the advantage of allowing comparisons between disease groups, to inform decisions, for instance, on resource allocation.

Focusing an instrument on a single issue (e.g. pain) will increase the sensitivity of that instrument to changes brought about by the relief of pain. Such changes, however, should not be taken necessarily to imply that the overall QOL of the subject has improved.

QOL ASSESSMENT IN PSYCHIATRIC PATIENTS

Given the subjective nature of QOL, there may be special considerations in its assessment in psychiatric patients whose mental functioning is affected by the disorder. There are two main issues that need to be addressed. One concerns the institutionalisation of patients in hospital, and the other is the effect of disturbed affect or thinking on the evaluation, which might be considered to affect its validity.

With regard to institutionalisation, this is an example of where a patient may have an apparently good QOL because of lowered expectations. The WHOQOL definition of QOL allows that expectations are a valid influence on QOL, and therefore the patient's assessment must be accepted. The argument has been made that discharging such patients to the community lowers their QOL, certainly their subjective QOL. If the hypothesis is that community care does not, in fact, lower QOL, then a subjective assessment of QOL therefore should be perfectly adequate to test this. It might not be possible to demonstrate that a move to community care improves patients' subjective QOL (Barry & Crosby, 1996). One could argue that the first step in moving patients into the community would need to be to raise their expectations for their lives, which by definition will lower their perceived QOL in hospital.

The other issue with regard to QOL assessment in psychiatric patients is that of the questionable validity of their judgement because of mental disorder. There is no doubt that a depressed mood is likely to affect thinking in a generally negative sense, leading to a tendency to express dissatisfaction with most aspects of life. Again, however, if QOL is accepted as subjective, then logic dictates that a patient's viewpoint is accepted as valid. Depression will affect QOL, but it does not 'distort' it or make the assessment invalid. It may be true that effective treatment for depression will dramatically improve QOL, although only research can indiate the extent that this is so. The delusional thinking of those with schizophrenia is also likely to affect QOL, but beliefs which may be bizarre by certain standards, cannot be discounted in their influence on QOL, whether these are schizophrenic delusions or the beliefs of certain cults or religions, shared among a group of people. Only research which tracks the QOL of people with schizophrenia during various phases of the disease can provide information to illuminate this issue.

In the case of those whose mental processes are impaired by brain damage or dementia, it may be true to say that subjective QOL has little validity. Nevertheless, it is still true to say that the health care provider must listen to what the patient is saying and not discard it as nonsense. Proxy measures for such patients may provide useful information for planning and evaluating care strategies, but these should not be taken as a measure of perceived QOL. The limitations of data obtained from proxy raters as compared to self-report need to be appreciated (Sprangers & Aaronson, 1992).

The same would be true for young children, but measures using the parents, say, as proxies should not be considered to be of perceived QOL, useful though such proxy measures may be. It seems possible, however, to have reasonably stable measures of perceived QOL, at least in older children (Pal, 1996).

NEED FOR QOL ASSESSMENTS

It can of course be argued that perceived QOL should not have a prominent position among the assessments of patients. Health professionals are trained to be sensitive to their patients' needs, and a professionally objective assessment of a patient's QOL may be perfectly adequate. What is more, the major advances in medical treatment and care during this century have been founded upon objective assessment and diagnosis together with the use of scientifically proven treatments. Most attention should perhaps be given to promoting these successes of relieving symptoms and prolonging life, expecting that improved QOL will follow with no direct, or only minimal, attention. Such an attitude, however, does not fit with the most recent trends, which even veer towards seeing health care (not meaning medical treatments) as a marketable commodity.

QOL assessment puts patients at the centre of inquiry, and gives due weight to their opinions. Its rising popularity is in some measure due to the increasing emphasis placed on the patient as a consumer. QOL assessment responds to patients' concerns not to be treated as cases but as human beings, who have lives with many facets not connected directly to their disease. In many instances, a disease and its symptoms may not be the central concern of the patient. Physicians at times have a tendency to re-frame all problems as being related to a presenting disease. A QOL assessment helps identify any part of life with which a patient has problems or difficulties. In the case of long-term illness, including psychiatric disorder, by helping the patient overcome these difficulties (even if they are not directly related to the presenting disease) the patient may make less demands on the health sector, and indeed feel a healthier individual.

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JOHN ORLEY, MD, Division of Mental Health and Prevention of Substance Abuse, World Health Organization, Geneva, Switzerland; SHEKHAR SAXENA, MD, Department of Psychiatry, All India Institute of Medical Sciences, Ansari Nagar, New Delhi 110029, India; HELEN HERRMAN, MD, Department of Psychiatry, St Vincent's Hospital, Fitzroy, Victoria 3065, Australia

Correspondence: Dr John Orley, Programme Manager, Programme on Mental Health, Division of Mental Health and Prevention of Substance Abuse, World Health Organization, CH-1211 Geneva 27, Switzerland

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