

Estimating quality of life

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A candle in the dark may add more information than a floodlight at noon. Malm et al (1981)

Enoch Powell's famous 'Water Tower' speech, in which he described mental hospitals as, "Majestic, imperious, brooding institutions . . . rising unmistakably and daunting out of the countryside", inaugurated the policy of successive governments to close the large mental hospitals and care for the chronically mentally ill "in the community".

Further impetus was provided by descriptions of institutionalism, Goffman's *Asylums*, hospital scandals and public enquiries, and the combined provocation of the ascendant anti-psychiatry movement. Central to this process was the belief that chronic patients were to some extent created by institutions, linked to the, largely untested, assumption that their quality of life (QOL) could be greatly improved by discharge from hospital.

A succession of White Papers have reiterated this policy, culminating in the long awaited *Caring for People* which requires Local Authority Social Services Departments to play a far more active role in caring for those with long-term psychiatric disabilities.

The recent and rapid changes in psychiatric services have given rise to many novel and experimental forms of health care. The justification for these changes, beyond mere economic considerations, has been to improve the quality of life for those patients who cannot be cured. However there have been remarkably few studies of QOL in those with chronic mental illness and fewer that attempt to demonstrate changes in QOL with intervention, e.g. before and after discharge.

The few surveys of discharged long-stay patients that do exist appear as a retrospective response to anxieties over community neglect, e.g. *Where Have All the Patients Gone?* (Cheltenham and Gloucester Health Authorities, 1988). In addition there is a major and unresolved debate as to what constitutes a 'good quality life' and how it can be measured.

Quality-of-life indicators

Zautra & Goodhart (1979) divide the numerous approaches in evaluating QOL into those based on social and psychological indicators.

Social indicators of QOL are potentially unlimited and each list is idiosyncratic to the author. They tend to cluster around social welfare, education, public safety and health. There is a clear link between poverty and most morbidity indices, such that an international Gallup survey of QOL concluded that "nations with the highest *per capita* income invariably top every test of psychological wellbeing" (Zautra & Goodhart, 1979).

QOL models based on these data characteristically produce a numerical score which is aggregated as an indication of the wellbeing of the community. The major problem with social indicators concerns their uncertain validity for individuals. Schneider (1976) used 25 social indicators as predictors of residents' ratings of life satisfaction across 12 communities and found no clear relationship.

Psychological indicators attempt to assess QOL by studying subjective reactions to life experience or psychopathology. Wellbeing has been measured indirectly using objective and subjective ratings of symptomatology and directly using life-satisfaction and happiness inventories which cover domains such as: family, work, leisure, relationships and health.

Avowed happiness is viewed as a short-term affective state whereas satisfaction represents a cognitive process in which the current situation is evaluated and contrasted with external standards. Zautra & Goodhart (1979) note that whereas satisfaction increases with age, happiness decreases and comment that the elderly may have less favourable present circumstances but are more likely to have realistic aspirations and expectations.

Psychological indicators, while appearing to give a more direct impression, are vulnerable to the bias of social desirability and idiosyncratic reporting of feelings, as both happiness and dissatisfaction may be reflections of abnormal mental state.

The problem of validity

The World Health Organization produced, in 1980, a consensus statement of the following dimensions to be covered in any QOL description: physical, cognitive, affective, social and economic, with levels of

departure from health in each category defined as: impairment, disability and handicap.

By 1987 more than 100 QOL tests had been developed, mostly applied to physical illnesses, notably cardiovascular disease, rheumatoid arthritis and cancer. Researchers commonly dealt with the problem of validity by combining several tests from different perspectives, producing unnecessarily complex and largely invalid results (Joyce, 1987).

Further advice on the construction of new tests has been offered by Guyatt *et al* (1986) who review the construction of 'disease specific' QOL tests in clinical trials and point to the choice between rigorous time consuming approaches and more efficient less costly strategies, matching the sophistication of the test with the hardness of data and confidence in the conceptual basis, "a choice between the Rolls Royce and Volkswagen models".

Malm *et al* (1981) developed a simple and practical QOL test (from a Volkswagen garage service sheet!) which consists of a comprehensive checklist of life domains which can be used by patient or staff to judge how satisfactory they rate each area to be. The items were selected to provide a description of the needs of recovering out-patient schizophrenics, and by making the evaluation process overt, rather than implicit within the test, the results can be suitably qualified as the judgements of those conducting it with reference to various concepts of normal or desirable.

In contrast Leonard (1989) designed an "environment specific" QOL test by asking users (staff, patients and relatives) to generate relevant QOL dimensions and then evaluate their relative significance. It is of great importance to note that each group considered different QOL dimensions to be "most significant" and that individuals varied in detail of what was considered central to their quality of life.

Flanagan (1978) offers an impressive example of the problem of validity. He reported the preliminary findings of an extensive programme designed to define and improve the quality of life of American people. In an attempt to achieve a valid, embracing definition of QOL, 3,000 individuals were interviewed to discover what they considered would influence their quality of life. The 6,000 reports were eventually reduced to 15 QOL dimensions in five categories which were formulated into a three hour structured interview, and administered to three samples in different age groups, each consisting of 1,000 adults.

Despite this huge investment and enormous collection of data, Flanagan concluded that the only valid unit of study is the individual, that this methodology can provide a structure for gathering data, but the results are meaningless unless accompanied by intense individual study to enable interpretation of the responses made.

Complex methodologies yield huge amounts of data but the basic problem of validity has yet to be resolved. Therefore a crude estimate of an important variable is preferable to a precise but irrelevant measure.

Objective or subjective?

Studies are divided between objective measurement of the individual's setting and circumstances, and subjective evaluation of satisfaction and fulfilment. The relationship between the two is unclear.

Joyce (1987) reflects the view of many recent authors in regarding assessment of QOL as unavoidably involving a value judgement. However, he regards QOL as experiential and therefore only amenable to self evaluation, which leads him to conclude that the patient's own definition of QOL and estimation of change is the only valid one.

This produces results that are individualistic, idiosyncratic and unamenable to comparison; hence the development of standardised interviews and schedules. These impose restricted choices to be made from a standard set of responses which are often then combined to produce a global score. However he warns that in producing results that are orderly enough for hypothesis testing there is a considerable risk of losing the meaning of the responses and hence the validity of the test.

He concludes that an adequate QOL test must "enter the black box of individual patient perception". For, as William (1988) has demonstrated, doctors may not know what aspects of ill health cause patients most distress and professional preconceptions can be misplaced.

Robertson (1985) further questions the validity of judging the quality of a person's life through a set of more or less objective criteria, and asks whether departures from QOL norms similarly signify a downward progression in quality of life experience. If not, are our judgements of the quality of another's life invalid?

Would for example the possible contentment of a person of Quietist religious beliefs living in squalor and poverty disqualify us from commenting on his quality of life?

In posing the question he raises a provocative parallel to the predicament of the chronically deluded – content in their delusions, which is further stimulated by his own response to the question:

One way out of the dilemma would be to resort to the Marxist concept of 'false consciousness', arguing that an individual's values bind him to the reality of his situation; and that if he could be made aware of it he would certainly desire to change it.

He considers this approach raises "sinister connotations" of state, and hence psychiatric, imposed

conceptions of QOL standards with efforts to impose these, rejecting subjective satisfaction as a QOL criterion.

Quality of life and value systems

Robertson (1985) emphasises that there are no value-free QOL indicators, and claims to objectivity are a pretence. The value judgement resides with the individual who forms an evaluation of the quality of his own life; or is explicitly or implicitly that of the observer who selects particular criteria by which to evaluate the lives of others; or is that of a political or service delivery system which selects QOL indexes as a means of policy or goal setting and as a way of evaluating the impact of intervention.

However the necessary ethical debate to clarify the values by which society and the 'helping professions' determine what constitutes 'the good quality life', and therefore valid QOL indicators, has scarcely begun.

This may be overtaken by the ascendancy of the consumer movement, strongly representing the subjective position of customer satisfaction.

Potential problems of this approach include determining who the consumers are, as a self-appointed articulate minority may misrepresent majority opinion, recognising that relatives and staff may possess different QOL values and be inaccurate advocates (Leonard, 1989) and the possibility of pathological satisfaction and dissatisfaction among the chronically mentally ill population.

Quality of life in chronic schizophrenia

There have been few attempts to study the quality of life of those diagnosed chronic schizophrenic, despite the fact that they constitute the majority of the chronic patient population and are those most affected by hospital closures.

Baker & Intagliata (1982) reported a study involving 118 patients who were "chronically mentally ill", 55% diagnosed schizophrenic, and part of a community support system in New York State. They used a self report measure of life satisfaction and the Global Assessment Scale of mental health status, and compared this with a national survey group. They found QOL to have little relationship with demographic measures, and from their own results and a review of the literature, they concluded that the most significant and consistent relationship was between psychiatric morbidity and subjective QOL.

Lehman *et al* (1982) examined the life experience of 278 chronically ill residents in 30 board and care homes in Los Angeles using objective and subjective measures of life satisfaction and found that strongest correlation was with the presence of a close friend or intimate relationship.

Lehman (1983) later re-analysed the same data and emphasised that ultimately QOL was subjective but that the personal evaluation of QOL was dependent on several interacting variables: personal characteristics (structural and demographic features), objective QOL in a range of life domains and subjective evaluation of these same domains reflecting satisfaction. However he found no relationship between personal characteristics and wellbeing, except educational level which was negatively correlated, and concluded that there was a need to delineate the impact of psychopathology on subjective QOL.

Simpson *et al* (1989) sought to evaluate the consequences of a community care policy resulting in the placement of chronic psychotic patients in group homes and a hospital hostel as a means of improving their quality of life. These were compared with a group of long stay (>6 months) patients who remained on a District General Hospital (DGH) ward. Each group was given Lehman's structured interview (above), the Patients' Attitude Schedule, selected scales from the Present State Examination (PSE) and each setting was evaluated using a staff attitudes and practices questionnaire.

Results were consistent within each group and varied between them. Greatest global wellbeing, subjective QOL and least psychological deficits and dissatisfaction were found in group homes whereas the opposite was found in the DGH group. Least victimisation and greatest leisure activity were found in the hostel ward.

The results initially appear to vindicate the policy of placing patients in as normal a setting as possible but in interpreting these results they observed that each of these facilities was clearly different in aim and function, and in a well resourced service, placement in spectrum of care corresponds to severity of psychopathology, which was therefore the major determinant of QOL.

This re-emphasises the need for caution in interpreting the complex interaction between life experience, location in a specific health care setting and quality of psychiatric morbidity. It is unacceptable to generalise from length of stay in hospital to severity of illness, and discharge does not mean recovery; both are dependent on patterns of service utilisation and available alternatives.

Gibbons & Butler (1987) present a more careful study of the same process. They observed 15 'new long-stay patients' in wards in a DGH and mental hospital and again when they had lived for a year in a new hospital-hostel. These were compared with six who remained on the wards. Their QOL measures were constructed with reference to the value system of Normalisation, and therefore included a comparison of the living situation and degree of integration with community resources together with structured

observation of time spent in activity and work. This combined both objective descriptive comparisons and semi-structured interviews to gather residents' own perceptions of changes in their QOL.

The mental hospital was found to be the least "normalising" setting and the hostel the most. The hostel residents made much more use of community resources, expressed a greater sense of freedom and were more active. However, the majority also felt "lonely and cut off" but none wished to return to the wards. The six remaining patients showed no such changes and all wanted to live elsewhere.

On the basis of the assumed values they concluded that the change represented a significant improvement in QOL for those moved to the hostel. The problem here as elsewhere is in validating the value system used to interpret the results and the need for caution in accepting the comparison group. Those remaining may have been a 'sicker' residual group, as no comparison was made of levels of, or changes in, psychopathology.

Comment

It follows that any future attempt to evaluate QOL in a mentally ill population must include both objective and subjective measures. There may be merit in designing tests to be both disease specific and environment specific, and involving the subjects in selection of relevant QOL indicators.

Each QOL investigation is inevitably made with respect to a value system, either the individual's or a system such as Normalisation, which needs to be clearly articulated to interpret results.

The different interested parties (researchers, planners, staff, relatives, and patients) can usefully make separate QOL evaluations to continue the debate over the range of perspectives and whose values count.

Where questions are being asked concerning the effect of an intervention, e.g. discharge from hospital, it is clear that studies can only be interpreted with confidence if conducted prospectively with adequate baseline measures and appropriate controls, which must include reliable indicators of the quality and severity of psychopathology.

The present naturalistic studies, comparing groups in different settings, provide valuable and interesting descriptive accounts but cannot produce QOL data to inform planning decisions because the groups are selected for these different settings according to severity of psychopathology, which has so far emerged as the major determinant of quality of life.

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A full list of references is available on request to the author.