

# Quality-Of-Life Issues in Mental Health Care: Past, Present, and Future

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## Abstract

*With progress in medicine, it gradually became apparent that the ultimate purpose of health interventions is to enhance the quality of life (QoL) rather than to simply prolong life. Over the last two decades, this concept has been applied to almost all aspects of health care. Despite debates on definition and components, it is now widely agreed that QoL issues are central to health care, including mental health care. Quality definition in mental health and its measurement poses special problems. However, QoL has been assessed in many psychiatric disorders, and serial QoL assessment now forms an essential part of research protocols in therapeutic trials. QoL issues in relation to mental health care is especially relevant with regard to: baseline assessment of severity of the disease condition; part of evaluation of treatment outcome; identification of high-risk population; setting goals for psychosocial therapies and rehabilitation; and finally, health education, prevention and policy making. Research conducted in QoL aspects of severe mental disorders are summarized and their implications highlighted. Conceptual and methodological questions in such research are also discussed (German J Psychiatry 2004; 7 (3): 35-43).*

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## Introduction

For years, the major concern of our numerous scientific advances has been an improvement in the physical aspects of life – for example, amelioration of specific symptoms and signs of disease. Over years, the major breakthroughs in the medical science have been able to drastically change the outcome and prognosis of almost all the broad categories of diseases – inflammatory, infective, traumatic, and even neoplastic. In fact, even in some degenerative diseases, medical science has been able to provide a degree of symptom relief that was unthinkable a few decades ago. This is no mean achievement. Every significant advance in the science and technology of medical science – vaccines, analgesics, antibiotics, anti-cancer agents and therapies, so many other important categories of medicines, and various surgical and non-surgical interventions, indeed, the list is almost endless – has been a signpost on our roadmap to conquer disease and infirmity.

These masterful advances, however, have not been without blemishes. Often, in its quest to control diseases, medicine

has focused inordinately on the symptom control and neglected the patient as a person. As a result, years have been added to the life of the patient who would not have lived otherwise, but, paradoxically, the patient might have felt that those added years were not really worth living! Consider the case of the patient with a severe degree of chronic kidney failure whose life hangs in balance on lifelong haemodialysis, an expensive and cumbersome procedure. Or the case of the child with thalassemia who depends on his frequent and very prolonged schedule of blood transfusion to increase the number of years to his life. Or the case of the cancer patient whose life was saved by the miracles of surgery and chemotherapy but who has to suffer a lifelong of disfigurement, pain, and severe side effects of chemotherapy. The list here too is almost endless... a different kind of signpost, a grim reminder that medical science has certainly enhanced the *quantity* but not necessarily the *quality* of life.

In a reformative step, the last few and especially the last two decades have witnessed a surge of interest by the medical professionals in the quality-of-life issues. A PubMed search revealed more than 61,000 references to this keyword till date. Whereas the first few citations, starting in 1960, were few and far apart (e.g., Long, 1960; Elkinton, 1966; Beard,

1971), the frequency of publications picked up exponentially in the 1980s and the vast majority of the publications were in the last two decades. In this article, we shall have an overview of this concept and its application in one of the more recent and challenging areas of medicine, i.e., mental health care. Rather than enumerating studies (of which there are hundreds), an effort will be made to understand the basic issues regarding the concept and measurement of quality of life in the medical field and especially the mental health applications. The achievements, difficulties, and challenges will be highlighted in a broad-based manner, so as to gain a direction for future research.

## Historical Evolution of the Concept

### The beginning

As mentioned above, the quest for paying attention to the quality of life of patients arose historically as a perceived need to counterbalance, or at least supplement, the successes of modern medicine to increase the quantity of life in case of serious, chronic, debilitating or fatal illnesses. In other words, it was an instance of ‘reaction formation’ against the modern medical science, which, it was feared, could become unduly mechanical, gadget-dependent, technology-oriented, and, in a way, de-humanizing. Thus, it was ‘humanistic medicine’ pitted against ‘mechanistic medicine’. To quote Sir Robert Platt at the Linacre Lecture 40 years from now (Platt, 1963), “...How often, indeed, do we physicians omit to enquire about the facts of happiness and unhappiness in our patients’ lives.” Yet all this is just as much the live fabric of medicine as biochemistry and applied physiology. And so the trend of clinical science which I regret is that which tends to divorce its teaching from appreciation of human values in the practice of medicine...” Although this lecture did not use the specific term ‘quality of life’, yet this contained the seed and the spirit of the concept. An early editorial published in the *Annals of Internal Medicine* (Elkinton, 1966) that perhaps brought the term in the medical field cited this lecture and asserted, “This is nothing less than a humanistic biology that is concerned, not with material mechanisms alone, but with the wholeness of human life, with the spiritual quality of life that is unique to man.” Borrowing from a quotation of Francis Bacon, made some four hundred years ago, that compared the man’s body as a ‘curious harp’ and delegated the duty of medicine ‘to tune...and reduce it to harmony’, this editorial defined quality of life as “the harmony within a man, and between a man and his world”. Thus, this initial definition was clearly a conceptual and not an operational one, drawn from the moral-ethical and spiritual-humanistic dimensions of medicine. The editorial, with great farsightedness, anticipated this later difficulty in operationalizing the concept but stuck to the concept nonetheless: “Just what constitutes this quality of life for a particular patient, and the therapeutic pathway to it, often is extremely difficult to judge and must lie with the conscience of the

physician, but surely such quality of life is the harmony of which Francis Bacon spoke” (Elkinton, 1966, p.713).

### The seventies

During the seventies, the concept and application of quality of life gradually picked up, though sporadically. It was becoming clear that only measurement of symptoms and longevity was inadequate for the comprehensive assessment of a patient, the disease, or the outcome of a therapeutic intervention. In other words, the quality of care could only improve if that care finally brought about a change in the patient’s quality of life. Thus, the latter was slowly gaining recognition as something that needed to be assessed. This was initially limited to only chronic debilitating or life-threatening physical diseases such as cancer, renal failure, etc. However, this recognition did not come about suddenly. For example, in 1978, Bardelli and Saracci reported that less than 5% of papers in major cancer journals measured any aspect of quality of life (cited by Maguire & Selby, 1989). Other than the lack of widespread awareness of the need for such assessment, another very important reason could have been the lack of adequate assessment instruments. The issues related to the measurement of quality of life are discussed later.

### The eighties

The 1980s ushered in an era of change with respect to both the awareness and the formulation of many such instruments (mostly questionnaires, checklists and inventories, (e.g., Spitzer et al., 1981; McEwen, 1988; Bergner, 1988). By the end of the 1980s, there were dozens of ‘scales’ purportedly measuring patients’ quality of life. At one point in time, it became somewhat confusing as to who was measuring what for whom, when, and most importantly, how. Hence, detailed assessment criteria were developed to evaluate the instruments (Maguire & Selby, 1989). The importance of such assessment was underscored in the Shattuck lecture in 1988 whereby it was proclaimed, “The centrepiece and unifying ingredient outcomes management is the tracking and measurement of function and well-being or quality of life”, while at the same breath apprehension was voiced because “this sounds like a hopelessly optimistic undertaking” (Ellwood, 1988, p. 1552).

Another important event of historical importance in the 1980s was the application of the concept of quality of life in severe and chronic mental illnesses. Till such time, with rare exceptions (Lebensohn, 1972) the quality-of-life studies were limited to physical diseases only. However, this was an era when mental hospitals or ‘asylums’ as they were called were being closed in many western countries (a process christened as ‘de-institutionalisation’), and patients suffering from chronic severe mental illnesses were being released into the community. An understandable concern was their ‘quality’ of living in the community. The earliest studies to examine this issue were from USA (Lehman et al., 1982; Baker & Intagliata, 1982) and Sweden (Malm et al., 1981; Skantze et al.,

1992). These were also the earliest to frame specific assessment instruments for quality of life in patients with severe chronic mental illnesses, typically chronic schizophrenia. These studies were followed by others, which also ventured a similar assessment in other psychiatric illnesses as well. However, there were problems in defining and measuring the construct in an operational fashion. In view of the increasing importance of the issue, the World Health Organization (WHO) began a project in 1991. Its aim was to define and create a measure for quality of life in such a way as to allow inputs from a broad range of cultures around the world (Orley et al., 1998; The WHOQOL Group, 1995). This instrument, along with many others developed for assessing quality of life in psychiatric illnesses (reviewed by Lehman, 1996), firmly established the subject.

## Definition and Characteristics of QoL

### Definition of QoL

Although easier to conceive in an abstract manner, quality of life (variously initialised as QoL or QOL) has been notoriously difficult to define. It is one of those words like 'happiness', 'love' or 'peace' that everybody grasps intuitively, but problems arise the moment one tries to formally define them. However, numerous attempts have been made in this regard. Of the several available, the most widely used and comprehensively derived definition is that by WHO (Orley et al., 1998; The WHOQOL Group, 1995):

"Quality of Life is defined 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, incorporating in a complex way individuals' physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationships to salient features of the environment. This definition highlights the view that quality of life is subjective, includes both positive and negative facets of life and is multi-dimensional." [The WHOQOL Group, 1995, p. 1405].

Another, rather simple if somewhat simplistic, informal definition has been provided by Lehman (1996): "...patients' perspectives on what they have, how they are doing, and how they feel about their life circumstances. At a minimum, QoL covers persons' sense of well-being; often it also includes how they are doing (functional status), and what they have (access to resources and opportunities)" (p. 78). Lehman's model suggests that "(1) ultimately QOL is a subjective matter, reflected in a sense of global well-being, and (2) this experience depends on at least three types of variables: (a) personal characteristics, such as age and sex; (b) objective QOL in various domains of life, such as income level; and (c) subjective QOL in these same life domains, such as satisfaction with income.

In contrast to the above, according to WHO perspective, 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 of one's social and material world. The facets (of QoL) 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. .... 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." (Orley et al., 1998, p. 291).

### Characteristics of the QoL construct

Although there is no consensual definition of QoL, there are areas of considerable agreement among QoL researchers about some of the central characteristics of the QoL construct. These are:

*Patient-centeredness:* As opposed to an 'observer' or 'external rater' approach, the QoL construct, by definition, is oriented towards the experience gathered from the perspective of the consumer, client, or in our case, the patient himself/herself. Thus the final arbitrator or evaluator of the 'quality' of the life is the person who lives that life, not some external expert. In other words, it is not what the doctor thinks he does to improve the quality of the patient's life but what the patient thinks about himself/herself.

*Subjective nature:* As a corollary of the first characteristic, it follows that such an evaluation has to be subjective. This has been a problematic area in the past, with some authors arguing that only subjective reporting and self-rating by the patients may not be sufficient to do justice to a complex concept like QoL, due to various factors that may distort or bias such self-evaluation, such as medication, cognition and emotional functioning of the individual and motivation for life improvement (Sainfort et al., 1996; Atkinson et al., 1997). However, this 'subjective' defining feature of QoL can be broken down into levels (The WHOQOL Group, 1994; 1995). Perceptions of objective conditions (e.g., material resources) have to be distinguished from subjective conditions (e.g., *satisfaction* with resources). The WHOQOL Group proposed that questions concerned with the individual's perception can ask for:

- Information about functioning (e.g., 'How many hours do you sleep usually?')
- Global evaluations of functioning (e.g., 'How well do you sleep?')
- Highly personalized evaluations of functioning (e.g., 'How satisfied are you with your sleep?')

Although the person's report of functioning is important health status information, the WHOQOL Group argued that it is questions about the person's global *evaluations* of behaviors, states and capacities and *satisfaction/dissatisfaction* with behaviors, states and capacities that inform about quality of life.

*Multi-dimensional nature:* Another area of broad consensus is the multi-dimensional nature of QoL. At minimum, quality of life includes the following dimensions: physical (individuals' perception of their physical state), psychological (individuals' perception of their cognitive and affective state), and social (individuals' perception of their interpersonal relationships and social roles in their life). There are variations of this theme, depending upon conceptual, pragmatic or empirical reasons of the particular group that developed the assessment instrument. Such further dimensions can be 'usual activities' (Brazier et al., 1993), 'role functioning' (Ware et al., 1993), 'work' (Bergner et al., 1981), or even 'spirituality/religion/personal beliefs' (The WHOQOL Group, 1995).

## QoL in Health Care: Applications and Assessment Issues

### Applications of QoL

Interest in measuring quality of life in relation to health care has increased in recent years. The purpose is to provide more accurate assessments of individuals' or populations' health and of the benefits and harm that may result from health care. QoL measures can be used in many ways in health care (Fitzpatrick et al., 1992; Fletcher et al., 1992; Spiegelhalter et al., 1992). These include: screening and monitoring for psychosocial problems in individual patient care; population surveys of perceived health problems; medical audit; outcome measures in health services or evaluation research; outcome measures in clinical trials; cost-utility analyses, etc. Serial QoL assessment now forms an essential part of research protocols in therapeutic trials. QoL issues in relation to mental health care is especially relevant with regard to: baseline assessment of severity of the disease condition; part of evaluation of treatment outcome; identification of high-risk population; setting goals for psychosocial therapies and rehabilitation; and finally, health education, prevention and policy making.

The best-understood and most widely used application of QoL measures is in clinical trials, where they provide invaluable evidence of the effects of interventions. Since late 1980s, many trials have included QoL as an important outcome measure. However, application of QoL in other areas, especially in routine clinical care, medical audit or similar health care evaluation has lagged behind. In order to focus better on these issues, it is important to realize that QoL assessment instruments that have proved useful when applied in one context may be less appropriate elsewhere. A good research tool may be impractical or too lengthy for routine clinical care or health care outcome evaluation.

## Types of QoL assessment instruments

There are two basic types of instrument, disease specific and generic. *Disease specific* instruments have been developed for one particular disease or a narrow range of related diseases, e.g., arthritis impact measurement scale (Meenan et al., 1982). They are useful for clinical trials or outcome assessment for specific diseases, but comparability is compromised when studying different diseases. On the other hand, *generic* instruments are intended to be applicable to a wide range of health problems. They have a broad perspective and are applicable across different types and severity of diseases, across different medical treatments and interventions, and, importantly, across cultural subgroups. Some of the important ones used in the context of mental illness are summarized and critically evaluated by Lehman (1996). The best recent example of a generic scale for measuring QoL is the one developed by the WHO, named WHOQOL (The WHOQOL Group, 1994; 1995). Developed as a multinational, multicultural and multilingual generic instrument, WHOQOL places emphasis on subjective evaluation of respondents' health and living conditions rather than on their objective functional status. It produces a multi-dimensional profile of scores across six broad domains and 24 sub-domains (facets) of quality of life. These 6 domains are: physical domain; psychological domain; level of independence; social relationships; environment; and spirituality/religion/personal beliefs. Within each domain several sub-domains (facets) of quality of life summarize that particular domain of QoL; e.g., the 'physical domain' includes the facets 'Pain & discomfort' and 'Energy & fatigue'.

## Requirements of QoL assessment

Other than a multidimensional construct as mentioned above, the other important requirements of a good QoL instrument are reliability, validity, responsiveness (sensitivity to change), appropriateness, and practicality (Fitzpatrick et al., 1992).

**Reliability:** instruments must produce the same results on repeated use under the same conditions. Various types of reliability estimation procedures include interrater reliability, test-retest reliability, and internal consistency.

**Validity:** the validity of quality of life measures is more difficult to assess because instruments are measuring an inherently subjective phenomenon. Informally face validity can be assessed by asking various concerned persons (patients, doctors, nurse, family members, and social workers) regarding the extent of coverage of the area by the items. Formal approaches include testing agreement between related measures (convergent validity) and disagreement between unrelated measures (divergent validity).

**Responsiveness:** this is a crucial requirement for most applications, especially in clinical trials, evaluation research, or cost-utility analyses, i.e., in situations where some intervention is thought to bring about an improvement in the patients' life. Generic instruments may be less responsive to change due to intervention than disease-specific instruments.

Appropriateness: to ensure that the QoL measure used is the most appropriate in a given situation, the health problem and likely range of impacts of the treatment being investigated need to be carefully considered. Obviously, one disease-specific instrument is inappropriate for another disease or treatment.

Practicality: as mentioned above, for regular routine use in clinical care or medical audit the QoL instruments need to be brief, easily understood and easily scored, and, most importantly, clinically meaningful. Otherwise, even the best-formulated instrument (as often used in clinical trials) would lose its practical use.

## QoL Assessment in Mental Health Care

As mentioned earlier (*vide* 2.3), the need to study QoL in relation to mental health care arose in the wake of 'deinstitutionalization', i.e., discharge of patients with severe, persistent mental illness from 'institutes' (mental hospitals with long-stay and often involuntarily admitted patients under strict and often dehumanizing conditions) into the community, usually to some form of community living with varying degrees of supervision, shelter and structure. It became important for the health care providers to understand whether this move led to an increase in life satisfaction of the patients.

### QoL assessment in psychiatric patients

Given the subjective nature of QoL, there are special considerations in its assessment in psychiatric patients whose mental functioning is affected by the mental disorder. The credibility of patients' self report, which is usually not questioned in patients suffering from physical diseases, is doubted in case of psychiatric disorders, specially the serious or psychotic disorders such as schizophrenia, mania or severe depression (Lehman et al., 1993; Sainfort et al., 1996; Atkinson et al., 1997; Voruganti et al., 1998). In schizophrenic patients especially, it has been repeatedly shown that patients subjectively report a quality of life *better than* what their objective living conditions would predict (Lehman et al., 1996; Sainfort et al., 1996; Atkinson et al., 1997). In fact, while comparing schizophrenic patients with severely depressed patients on both subjective and objective QoL measures, it was seen that compared to the depressed patients, the schizophrenic patients had significantly higher scores on satisfaction ratings. But when compared on objective QoL indicators, schizophrenics had experienced more aversive life experiences than the depressed patients (Lehman et al., 1993; Trauer et al., 1998; Voruganti et al., 1998). The authors concluded that, in case of psychiatric illnesses, subjective reports of life quality poorly reflect substantive environmental conditions, and suggested that in self-report methodologies, the biases introduced by affective, cognitive, and social factors must be examined. Thus, these authors

again rekindled the 'subjective-objective' issue in QoL assessment when applied to mental disorders. However, the WHOQOL group maintains, "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" [Orley et al., 1998, p. 292]. However, they grant that only in the case of brain-damaged or demented patients may the subjective QoL rating be considered invalid. "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."

### QoL assessment as part of outcome assessment in mental health care

Measuring and interpreting outcome is more difficult in mental health services than in some other areas of health care, for at least four reasons (Slade, 2002). First, the effect of treatment may be to slow decline or to maintain the current level, so the score on the outcome measure itself may not improve despite best quality clinical care. Second, different types of outcome are desynchronous, changing at different rates during an intervention. Third, there may not be agreement regarding what is a positive change in outcome – the patient who has fewer episodes of mania as a result of treatment may see this as a negative outcome. Finally, three levels of mental health service can be differentiated: treatment (i.e., specific interventions), program (i.e., combination of different treatment components), and system (all programs for a defined target group in a given area) (Burns & Priebe, 1996). The outcome data needed to evaluate each level will be very different.

The solution to these issues that has evolved in research studies has been to assess a wide range of treatment and program-level outcomes, from multiple perspectives. This approach has led to the identification of several consistent findings. The most important outcome is quality of life, and the best predictor of QoL is level of unmet need (UK700 Group, 1999). Mental health outcomes research indicates that care should be provided on the basis of need so as to improve the quality of life.

It should be noted that QoL forms only one of several outcome measures in mental health care delivery evaluation. In their conceptual framework for mental health services, Tansella and Thornicroft (1998) have proposed the 'matrix model' that has two dimensions: the geographical, which refers to three levels (country, local, and patient) and the temporal, which refers to three phases (input, process, and outcome). Using these two dimensions a nine-cell matrix is constructed to bring into focus critical issues for mental health services, especially in a public health framework. In this nine-cell matrix, quality of life is mentioned as a key issue to be considered in the cell formed by the 'patient' level and 'outcome' phase (Tansella & Thornicroft, 1998). Similar point has been stressed upon by Hansson (2001).

Barry and Zissi (1997), in their review on QoL as an outcome measure in evaluating mental health services, noted that the majority of the studies were cross-sectional in nature

or had involved comparison between groups in different care settings. Repeated-measures (longitudinal) and randomized (experimental) designs were far less in number. Although difficult to generalize or compare between the various studies, the indications were that the majority of studies reported improved quality of life for patients following their discharge into supported community schemes. No study reported deterioration in QoL following discharge. The majority of patients living in the community reported high levels of satisfaction with their living situation, increased freedom and independence, and despite having problems with finance, health and social relationships, few desired to return to the hospital. The quality of the immediate living environment emerged as a very important concern for them, specifically the extent to which it was physically comfortable and allowed for a sense of independence and behavioural autonomy. Indeed, improved living conditions appeared to be one life area where community residential programs scored heavily over institutional care. However, lack of money, concern over health matters, poor social and family relations, and personal safety issues consistently emerged as factors that adversely affected patients' quality of life. There are clear implications from these findings for the development of programs capable of addressing at least some of these aspects of patients' lives.

It is also clear from these studies that these patients frequently reported the high levels of life satisfaction against a background of economic disadvantage and restricted social and employment opportunities (the 'counterintuitive' paradox referred to earlier). The fact that impoverished life conditions are not necessarily reflected in life satisfaction measures raises major concerns about their use as evaluation outcome indicators (Barry & Zissi, 1997). The other concern raised by this review is the apparent lack of responsiveness (sensitivity to change) of many QoL measures to specific interventions.

## Does QoL change following specific mental health intervention?

If quality of life of patients is to serve as an indicator of the quality of care, then ideally the patients' QoL should improve following good-quality care. As reviewed above, often it is so. However, it is important to note that two recent well-designed controlled studies from UK provided mixed support to confirm this finding. In the so-called PRiSM Psychosis Study, patients with psychosis residing in South London received either standard routine mental health care or an intensive care package aimed to offer acute home-based care, decrease hospital admissions, provide assertive outreach, and develop primary care liaison (Taylor et al., 1998). QoL was measured at baseline (Time 1) and after the intervention (Time 2) in both the groups using a standardized measure that provides a self-reported objective and subjective appraisal of eight life domains (finances, work, leisure, family, social relationships, living situations, safety, and health), along with a global well-being rating. It was seen that at Time 2, the QoL of *neither group* improved with respect to that at Time 1, and there was no inter-group differ-

ences as well. Thus, from the perspective of the service users, the quality of care was apparently not reflected in any improvement in their own QoL, irrespective of whether they received the standard care or intensive care. The possible reasons discussed by the authors included small sample size (resulting in a low power to detect true differences), insensitivity of the QoL instrument to detect true changes, or a true lack of effect of the interventions on improving the quality of life of the patients.

In the second, more recent and high-powered and randomized study named the UK700 trial (UK700 Group, 1999), a total of 708 patients with severe mental illness were randomly assigned to intensive or standard forms of case management in four sites in the UK. QoL was assessed using the same instrument as in the PRiSM study. The outcome after 2 years was examined using univariate and multivariate analyses. In contrast to the previous study, significant improvement in QoL over the 2 years was observed in both groups in this study (Huxley et al., 2001). However, even in this study, the QoL outcome did not differ significantly by case management treatment conditions (intensive vs. standard care). Interestingly, a better outcome was associated with improvements in depression rather than the type of primary psychotic illness.

Thus, it is not sacrosanct that improved quality of care will necessarily lead on to an improved quality of life, at least as reflected in the QoL score. An important related question then is: how far does this information on QoL can actually help the treating team to improve their quality of services?

## Role of routine administration of QoL instruments to improve quality of care

Routine administration of QoL instruments has been advocated as part of clinical care to aid the recognition of psychosocial problems, to inform clinical decision making, to monitor therapeutic response and to facilitate patient-doctor communication; in short, to improve the health care. However, their adoption also involves cost, logistics, manpower and other resources. Thus, the use of such instruments in routine health care has to be justified. In a recent systemic review, Gilbody et al. (2002) identified nine randomized and quasi-randomized studies conducted in non-psychiatric settings that studied the use of QoL measures in improving aspects of health care. It was observed that the routine feedback of these instruments had little impact on the recognition of mental disorders or on longer-term psychosocial functioning. While clinicians welcomed the information these instruments imparted, their results were rarely incorporated into routine clinical decision-making. Interestingly, no studies were found that examined such issues in mental health care settings. The authors concluded, "Routine QoL measurement is a costly exercise and there is no robust evidence to suggest that it is of benefit in improving psychosocial outcomes of patients..." (Gilbody et al., 2002, p. 1345).

It is possible that benefit cannot and will never be demonstrated for the routine use of QoL measures in individual patient decision-making, since this is a purpose for which the

instruments were *not* developed. In particular, it has been argued the psychometric properties of the generic QoL measures are such that their scores are un-interpretable at an individual patient level. Generic outcome measures are essentially designed to evaluate healthcare and to identify needs at a population level, and extrapolation of use beyond this to an individual level may be unwise (McHorney & Tarlov, 1994; Dunn, 1996). Even then, however, the need of developing an individual-level instrument remains.

## QoL Issues in Mental Health Care: *quo vadis?*

The review above has outlined the areas in which QoL issues have been studied in mental health care. Where do we go from here?

### Theoretical issues

Despite the increasing importance of quality of life in the mental health field, the theoretical conceptualization of the construct remains poorly developed. Much of the QoL research has relied heavily on a two-part QoL model that includes objective life circumstances and subjective satisfaction with these. However, as has been mentioned above, there is only a very weak correlation between the objective and subjective aspects of QoL, and even ‘counterintuitive’ findings of reported high life satisfaction in spite of adverse objective life circumstances. Moreover, the best available evidence in the UK indicates that clinical and social variables predict no more than 30% of the variance in an individual’s quality of life (UK700 Group, 1999). These and other ambiguities (some of them reviewed above) suggest that there is a need for theoretical models that link these objective indices (external conditions) with more psychological factors (internal states) that may be more central to the structure of QoL. In this context, Barry (1997) and Zissi et al. (1998) have proposed and empirically tested a “mediational model of quality of life”. In essence, this model proposes that there are ‘mediating variables’ that mediate (and modify) the link between objective life conditions and the perceived quality of life. These mediational variables are various self-related constructs (e.g., self-efficacy, self-esteem, and other personal characteristics) and clinical characteristics. These variables influence the appraisal process of the individual. However, limited research is available to study this model. More such attempts should be made in this direction.

### Linking QoL to quality of care: use of QoL in two different ways

Summarizing the review above, it can be seen that the QoL construct has been used in two different ways: as a dependent variable and as an independent variable. The context and

values of these two usages are different and this distinction should be kept in mind in future applications.

### QoL as a dependent variable

This is the more traditional use of the QoL construct, e.g., in clinical trials. Here QoL is used as an outcome measure to examine the effectiveness (and adverse effects) of a particular therapeutic intervention. Thus, QoL itself is an indicator of quality of health care. This can be done either in a research setting, where more detailed and sound instruments should be used, or in a routine care setting (e.g., as part of a medical audit) where the instrument used should be brief and easy-to-use, both for the patients and for the staff who score the report. However, in both these settings the QoL measure is usually interpreted at an aggregate (population) level and not at an individual level. In other words, here we work with the mean, standard deviation, standard error of the mean, and overall *pattern* of distribution of the QoL scores of the patient group as a whole, rather than individual characteristic.

### QoL as an independent variable

This is a less used, more controversial but potentially very useful application of QoL. Here the QoL data gathered from a particular patient is used as an independent variable in predicting other outcomes, e.g., in quality of *individual health care* or quality of care. In this usage, QoL is not in itself an outcome measure but influences it. This is the type of research reported earlier by Gilbody et al. (2002). As noted there, currently there is very weak support to use QoL measures in routine clinical care as an individual feedback to improve quality of patient care. However, the types of QoL instruments presently in use are perhaps not suitable for this purpose. This is another area of future work.

## Conclusion

Over the years in our society, there has been a slow but gradually increasing interest in listening to the consumer’s voice in all aspects of service; in health care sector, one of the ways to do this is through the quality of life assessment. On an abstract, conceptual level, this is fairly well established. In the area of mental health service, one of the ways to demonstrate improved quality of treatment or other forms of care is by demonstrating improved quality of life of the recipients of such care. On the other hand, evaluation of patients’ quality of life can potentially serve as a feedback information source to guide specific areas of improvement of care. In spite of several issues and problems outlined above, overall there can be little doubt that attention to QoL rather than only symptoms and signs of disease can enable the health care provider to truly “add life to years and not only years to life”.

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