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QUALITY OF LIFE AS A CONCEPT AND MEASURABLE ENTITY

(Accepted 14 February, 1994)

ABSTRACT. This chapter proposes that "quality of life" (QOL) is a multidimensional concept, the measurement of which must contain objective elements of a person's life. It is further suggested that in the development of QOL measurement instruments the selection of items must be influenced significantly by the views of the population under study. Instruments to measure quality of life have been flawed owing to their inadequate conceptual bases and the attempts to utilise general measures which are often the "broad brush" to detect changes in disease specific situations. The chapter outlines conceptual approaches to quality of life and provides an analysis of a range of definitions. It provides an overview of a number of approaches to measure QOL in specific populations. Finally, it addresses some of the potential uses and abuses involved in the measurement of QOL.

> *The whole of science is nothing more than a refinement of everyday thinking.*
>
> (Albert Einstein, 1950, p. 59)

As the concept of quality of life is increasingly being used a quality assurance index of the effectiveness of medical and rehabilitation services, it is appropriate to explore in some detail just what the concept means and to examine whether it is a construct that can be measured with any precision. This chapter will provide an overview of conceptual approaches to the study of quality of life in the health and rehabilitation fields and will investigate a number of efforts that have been made to operationalize the construct. Various approaches to measurement will be examined, highlighting some of the hazards involved. Specific examples of the used of scales to evaluate the effectiveness of interventions

Social Indicators Research **33:** 9–46, 1994.

in a number of disease areas will be given. A concluding section will address a number of practical and philosophical issues concerning the use of QOL scales.

A. CONCEPTUAL APPROACHES

While the use of the term"quality of life" as a scientific concept is relatively recent, it has been used colloquially in the fields of medicine and health for some time. Engel's (1978, 1980) development of a biopsychosocial model of medicine possibly heralded the emergence of the scientific application of psychosocial concepts in medicine. Applying systems theory as a framework for his formulation, Engel suggested that medicine could become a more "scientific" enterprise by the inclusion of psychosocial information in the development of medical concepts, in research and in patient care, especially when compared with the more narrow biomedical or the "nonscientific" "holistic" models. Engel's work gave a strong impetus for the broader biopsychosocial model to be incorporated into medical training and has led to medical research embracing the quality of life concept as a legitimate avenue of study.

Definitions of quality of life have ranged from unidimensional to multidimensional approaches. In the range of approaches there are some commonalities, but some quite distinct differences, particularly in terms of comprehensiveness, levels of specificity and theoretical rigour. For instance, Levine and Croog (1984) have noted that a single variable of human behaviour, such as employment, general happiness, or sexual functioning, has been used as an *ad hoc* indicator of quality of life by medical researchers. Van Dam (1986) took a somewhat similar view in suggesting that there is no clearly accepted definition of quality of life as it may refer to a variety of issues such as physical and psychological complaints, feelings of well being, sexual functioning and daily activities.

On the other hand Wegner *et al.* (1984) have proposed a more detailed three-dimensional definition (functional capacity, perceptions and symptoms) that is broken into nine subdimensions (daily routine, social functioning, intellectual functioning, emotional functioning, economic status, health status, well-being, life satisfaction, and symptoms related to the disease under study as well as other diseases). Comprehensive rationales have also been provided to justify the inclusion of each of these quality of life criterion.

However, before proceeding to analyse further the plethora of definitions and approaches to quality of life it may useful in the context of health services to discuss more closely the concept of health. Ware (1991) has suggested that we should begin by looking at the two dimensions of life, namely its quantity and its quality. Quantity can be indicated in terms of the length of one's life, life expectancy and mortality rates, but Ellinson (1979) has pointed out that these indices have little value in capturing the quality of years lived in developed countries.

What is required are more qualitative indices. Consequently a comprehensive view of one's health has often been equated with the quality of one's life. But is this a valid assumption? Quality of life surely encompasses much more that the status of one's health. For instance, issues such as standard of living, quality of housing, the district in which one lives and job satisfaction are frequently included in quality of life definitions and scales.

However, contemporary approaches to defining health go beyond objective states such as death and the extent of morbidity. Broader conceptualizations of health include how well a person functions in everyday life, his/her emotional well-being, and self-reports of health in general. Hence "quality of life" has been adopted as a way of summarizing a set of qualitative indices that go far beyond the traditional clinical approach to defining health status. This approach is not without its problems, because it is obviously too inclusive. While jobs, housing, schools and the neighborhood are related to one's functional status and overall well-being, they are not strictly components of one's health.

Nevertheless, the multidimensionality of health is recognized in the definition of health suggested by the World Health Organization (WHO, 1948, 1958). The WHO defined health as a "state of complete physical, psychological and social well-being and not merely the absence of disease or infirmity". This definition goes beyond the traditional medical model which seeks only the cure or the palliation of disease. In an endeavour to restrict the breadth of the quality of life concept and to make it more amenable for use in clinical trials Fries and Spitz (1991) developed a hierarchical model which concentrated upon "health status" and "patient outcome." An assumption is made that these constructs constitute "quality of life." Health status is seen as a measure of quality of life at a particular point in time while patient outcome refers to a final health status measurement taken after the application of treatment(s) and/or the passage of time. In this model health outcomes have been restricted to five dimensions; a patient's desire to be alive as long as possible; to function normally; to be free of pain and other physical, psychological or social symptoms; to be free of iatrogenic problems from the treatment regimen; and to remain economically viable.

In this model five dimension (death, disability, discomfort, drug side-effects, and dollar cost) are seen as mutually exclusive and collectively exhaustive; together defining patient outcome. It is obvious that this approach does not fit comfortably with the broader biopsychosocial approach suggested above. Furthermore, it is apparent that the health outcomes approach is predicated upon the assumption that quality of life indices should be restricted to strictly objective rather than subjective dimensions in order to satisfy scientific rigour.

Another way of approaching the conceptual framework for studying quality of life is to ask the question why should it be studied or used. From a patient's perspective the obvious answer is to improve the effectiveness of his/her treatment. From the therapy level quality of life trials may differentiate between the effects alternative therapies have upon survival or upon different types of disease. Studies may also be conducted to compare two different treatment approaches, for instance using either surgery or a drug to treat a disease. Other uses include commercial interest, especially those of pharmaceutical companies. The prescribing habits of physicians are affected and these in turn impact upon the drugs carried by individual pharmacies. In the area of cancer treatment, in particular, quality of life data, especially the patient's reporting of his/her own perception of level of function, has been used to monitor the palliative and curative effects drugs and their toxic side-effects (Schipper *et al.*, 1984). Quality of life assessments are also being considered as indices to accelerate the approval processes for the use of new drugs (Shoemaker *et al.*, 1990). From the perspective of a country quality of life data are being used to determine the allocation of the health dollar.

A factor which leads to confusion when one addresses the way quality of life has been conceptualized in the health field is the tendency by some to treat specific domains within a multidimensional model as though that domain represented a good index of quality of life. For instance, if one were to adopt Spilker's (1990) suggestion that quality of life generally includes the four categories of (a) physical status and functional abilities, (b) psychological status and well-being, (c) social interactions, and (d) economic status and factors, it is apparent when analysing the literature that many authors who claim to be dealing with quality of life issues are, in reality, only studying one of these domains.

It is obvious that the concept of quality of life in the health field, and indeed in other fields, has been used very loosely without a clear definition and without a coherent theoretical base (Parmenter, 1988, 1992). For instance, Andrews and Withey, as early as 1976, noted that the notion of measuring quality of life could include the measurement of practically anything of interest to anybody. Schipper *et al.* (1990, p. 11) have suggested that "the rubric has become a catcall for inconsistently designed trials, many of which have unclear goals". Schipper *et al.* cited as an example of conceptual confusion a case where an investigator may focus on the rate of wound healing, or sexuality or financial concerns, and then correlate those variables directly with quality of life. While these individual variables may be important factors in a patient's quality of life, without a sound conceptual basis for quality of life, it is very difficult to draw any firm conclusions about his/her overall function when analysing a specific variable.

The paradigmatic shift in the way society is thinking about issues and solving problems related to people with disabilities provided an underpinning for Schalock's (1991) development of his model of quality of life. Schalock suggested that a model of quality of life should encompass both aspects of the macrosystem that represents cultural trends and factors in society and aspects of the microsystem that relate to the individual (e.g. family, schooling, rehabilitation programs). In the health field a similar paradigm shift may be noted. For instance, Schipper *et al.* (1990, p. 11) have argued that a conceptual formulation has emerged, "which defines quality of life functionally by patients' perception of performance in four areas: physical and occupational function, psychologic state, social interaction and somatic sensation". This is quite a dramatic shift in emphasis for the medical world that formerly operated under what might be termed a "beneficence model" of health care, which assumed that health professionals are best placed to determine what promotes or protects the best interests of the patient. McCullough (1984) has contrasted this model with the "autonomy model" which acknowledges that patients can provide knowledge about what is in their best interests.

This approach is reminiscent of George Engel's tribute to the work of Arthur Schmale, Professor Emeritus of Onclogy in Psychiatry at the University of Rochester School of Medicine and Dentistry. Schmale, suggested Engel (1991, p. 64)

> ...exemplifies the scientist who seems always to have sensed the appropriateness of looking inward as well as outward. And in no scientific endeavour is the necessity to look inward so obvious, and so ignored, as in clinical medicine. After all, gaining information about a patient's state of health depends not only on having the patient look inward, but also on the doctor's looking inward to evaluate what the patient is reporting.

It is somewhat ironic that medicine from its very beginnings in the clinical study of one person by another depended upon the triad of observation, introspection and dialogue. The advent of 17th century natural science, suggested Engel (1990) relegated introspection and dialogue to a nonscientific status. However, current qualitative approaches to scientific enquiry emphasis the standards of accuracy, completeness, and reproducibility. Increasingly, the exclusive application of the methodologies of the "hard sciences" to answering questions raised in the complex interactions that occur in the study of the human condition is being critically examined.

The inclusion of subjective variables within the formulation of quality of life indices, while more readily accepted in the nonmedical world, have not been received as enthusiastically in the medical arena. Historically physicians have viewed with suspicion the subjective assessment of treatment outcomes by the patient. While the reasons for this are varied, one of the major reasons is the view that the process of medical research should be in keeping with the rigorous application of the Scientific Method.

Early approaches to the concept of quality of life as an outcome parameter in the health sciences were solely empirically driven. Schipper *et al.* (1990) have observed that efforts have been made to develop a conceptual definition of quality of life. They have proposed that five concepts have emerged which add to our current understanding: the psychological approach; the time trade-off or utility concept; Ware's (1984) community-centred concept; the reintegration concept; and Calman's (1984) Gap Principle.

The Psychological View

The psychological view is best epitomized by the call by Engel (1978, 1980) for the inclusion of psychosocial parameters when considering the effects of disease. From a psychological perspective quality of life represents the patient-perceived effects of disease (e.g. "I feel ill"). Here a distinction needs to be made between illness and disease. Illness is what the patient experiences as a result of a particular disease. Physicians concentrate more upon the process of the disease, although there is growing evidence for a direct relationship between the patient's psychosocial response to symptoms and the etiology and treatment of some diseases. Even where this relationship is not evident, physicians are increasingly taking into account the patient's psychosocial response to disease in their treatment regimen.

The Utility Concept

This concept refers to the trade-offs we might make between quantity and quality of life, an approach derived from decision theory. When given the choice between treatments, one which may prolong life, but with an attendant loss of function or impairment; and another which may retain that function, but at the cost of a shorter life, many people with serious diseases will opt for the latter course. The utility concept is somewhat like an accident insurance policy which places a monetary value on a limb or any eye, etc. Good examples are found in McNeil *et al.* (1981) and Torrance (1987).

The utility approach can also be used within an economic framework, especially when there is a need to discriminate between individuals when making clinical judgements about the withholding or withdrawing treatments. For instance quality of life data could tip the balance when the physician is faced with a decision based on the scarcity of resources. At present while there is still debate as to the reliability and/or validity of quantitative quality of life measures it may be somewhat premature to use these data when making decisions between individuals.

The ethical rather than technical concerns the use of such data in clinical decision-making was highlighted in an Ontario study by Till (1986) and Ciampi *et al.* (1982). In this study, 226 females in two Ontario cities were asked their opinions about a hypothetical medical decision concerning whether to use a radical or conservative treatment for a form of malignant lymphoma. The results indicated that the majority of respondents advocated the more radical treatment for those patients who came form a vulnerable group such as those with either disabilities, social isolation or lacking a motivation to improve their situation. The disturbing implication is that this finding is reminiscent of those situations in the past where vulnerable groups in the community (e.g. institutionalized people such as those with mental retardation, mental illness or prisoners) have been exploited by being exposed to risky radical treatments.

Another ethical implication is that marginal groups in society who are not valued highly could have treatments withheld while others whose situations are assessed more favourably could be given the treatment. The social justice implications of this approach will be taken up later.

The utility approach has found more favour among program educators and health policy decision makers. Here the questions revolve not around individuals, but groups requiring especially expensive treatments. Cost-utility analysis is used to relate the cost of an intervention to the number of quality-adjusted life-years (QALYs) gained through the application of intervention. A QALY assumes a year of healthy life expectancy to be worth 1, but regards a year of unhealthy life expectancy as less than 1. As Lee and Miller (1990) have pointed out, QALYs essentially measure the cost effectiveness of specific medical interventions for decision-making at a macro or micro level. Torrance (1986) provided an example (in 1983 dollars) where it was estimated that the cost per QALY gained is $4500 for neonatal intensive care for 1000 to 1499 gram neonates and $54 000 for hospital hemodialysis. Ethical and methodological issues surrounding the use of QALYs will also be raised later.

Ware's Community-Centred Concept

Ware (1984, 1991) has proposed a model which organizes health status and quality of life variables in such a way that a sense of the impact an illness has upon the broader community is given. In this approach Ware has grouped specific variables in concentric circles starting with biological functioning and spreading out in turn to general well-being and behaviour or social/role functioning. He suggested that measures of biological phenomena cannot alone be used to portray human phenomena. In his explication of the model Ware has indicated that it may be possible to use differential weightings for the component parts of the model quality of life construct. Also implicit in the model is the notion that an individual's illness impacts upon the general community. The economic aspects of this proposition have been long recognized, but the impact serious illness or trauma through accident has upon family functioning is often overlooked by health professionals.

The Reintegration Concept

Wood and Williams (1987) building on a model which they referred to as "reintegration to normal living", developed a scale which included the following domains: mobility, self-care, daily activities, recreational activities, family roles, personal relationships, presentation of self, and general coping skills. Underpinning this model was the concept that a person with a chronic disease for which no cure is expected would learn to live with that fact and would get on with their life. There was also a strong element of self-determination implicit in this model. They suggested that for the individual there would be a recognization of his/her physical, psychological, and social characteristics into a harmonious whole, so that after an incapacitating illness or trauma normal living can be resumed.

Two subscales which were developed were found to correlate moderately with Spitzers' Quality of Life Index (Spitzer, *et al.*, 1981), a popular quality of life scale used in the area of oncology. This finding is not surprising for the Spitzer Index samples the domains of activity, daily living, health, support and outlook which coincide fairly closely with those of Wood and Williams.

Calman's Gap Principle

One way of viewing quality of life is to estimate the gap between a patient's expectations and his/her achievements, a position adopted by Calman (1984) whose study of the quality of life of cancer patients revealed that the gap between expectations and achievement varies over time. As the patient's health improves or digresses as a result of treatment or the natural progression of the disease so does their expectations of how they might function. Calman further suggested that "the impact of illness" on patients varied according to how they perceived their quality of life at the time. Thus a person whose illness had caused debilitating effects may have reduced their expectations accordingly.

This approach has value for it introduces the notion of comparing quality of life against some standard, in this case the patient's own expectations. Another way of looking at the gap principle is to compare the patient's actual achievements with his/her potential achievements as estimated by a third party. A number of studies have shown that despite assessments of good potential achievements, patients' estimate of their quality of life have been negative (Andrews and Stewart, 1979; Powell and Powell, 1987). In this respect it is necessary to attempt to increase the patient's awareness of their potential so they may enjoy a higher quality of life. It must be recognized, however, that there is a great variation in the way individuals react to serious illnesses and consequently their perception of their quality of life.

Schipper *et al.* (1990) have rejected a definition of quality of life based upon the World Health Organization's definition of health as being too inclusive 'of elements that are beyond the purview of traditional, apolitical medicine' (p. 16). Instead they have proposed that "Quality of Life" represents the functional effect of an illness and its consequent therapy upon a patient, as perceived by the patient' (p. 16). It is their contention that this definition reflects the goal of medicine which is to reduce and possibly eliminate the morbidity and mortality of a particular disease.

Shumaker *et al.* (1990) have defined quality of life 'as individuals' overall satisfaction with life and their general sense of personal well-being' (p. 96). They have suggested somewhat similar dimensions to those of Schipper *et al.* (1990) and have proposed that six dimensions determine a person's quality of life; the first four including cognitive, social, physical and emotional functioning. Personal productivity or the degree to which a person is able to contribute to society (e.g. through a meaningful paid or unpaid activity) is postulated as a fifth dimension. The final dimension is intimacy, including sexual functioning, but also the giving and receiving of a broad range of behaviours that underlie the presence of a strong relationship with significant others.

This latter dimension is often ignored in other conceptual approaches to quality of life. However, it is one of the central features of the definition proposed by Powers and Goode (cited in Goode, 1990) who have suggested that 'quality of life is primarily a product of relationships between people in each life setting' (p. 43). The importance of the environment or the immediate macrosystem surrounding the individual to his/her quality of life has been strongly emphasized by Goode (1987), and highlights the narrowness of the definitions employed in medicine.

The approach adopted by Fretwell (1990) in her analysis of standards of care for the frail elderly has captured aspects of the "person-environmental fit" approach adopted in the psychological and sociological literature. For instance she has suggested that, 'as human age, there is a continuous interaction of environmental and genetic factors that accentuates the uniqueness of each person' (p. 225). This is consistent with Lipowski's views (1969) who remarked that 'how a person experiences the pathological process, what it means to him (her), and how this meaning influences his (her) behaviour and interaction with others are all integral components of disease viewed as a total human response' (p. 1198).

In discussing the quality of life in the context of persons with a congenital physical or intellectual disability Parmenter (1988, 1992) suggested that the theory of symbolic-interactionism could profitably form a conceptual basis. Fundamental to this approach is the principle that human experiences are mediated by interpretation (Bogdan and Kugelmass, 1984). Another basic element is that the "self" arises and is maintained in a symbolic and interactive world. For people with a congenital disability, and, it is suspected , for those with a serious disease, the development of the self or their identity as a person is influenced from two sources. One comes from outside and proceeds from the social order. The other comes from within and relates to what they can or cannot do. Thus as the same time they have to deal with the negative aspects of their personal condition and cope with the possible negative effects of how they are viewed by significant others. From a philosophical point of view there is a conflict between the existential nature of the person and the social nature of human experience. Using this framework Parmenter (1988) suggested that 'quality of life represents the degree to which individuals have met their needs to create own meanings so they can establish and sustain a viable self in the social world' (p. 15).

This approach is in sympathy with Fava (1990) who saw quality of life as a common pathway for the 'various interlocking mechanism at the neurophysiological, biochemical, experimental and behavioural levels' (p. 71). Fava urged a holistic approach in considering quality of life in relation to disease; one which shifted from a purely biomedical approach that included parameters such as psychological distress, illness, behaviour, and social functioning to one which included the additional psychosocial correlates of illness. Fava made an extremely cogent contribution by stressing the need to consider a person's quality of life *before* the full-blown onset of disease. Such consideration, he suggested, should include issues such as environmental factors associated with the disease, life changes or life events prior to the onset of illness and the occurrence of psychological distress in the preliminary stages of illness.

Siegrist and Junge (1990) in their conceptual approach towards the social dimension of treatment-related subjective health have argued for a stronger recognition of the importance of the social dimension in measures of subjective health, despite Torrance's (1987, p. 594) assertion that 'social functioning is "beyond the skin" and ... is not an appropriate aspect of health-related quality of life'. Siegrist and Junge have highlighted the social performance and social well-being as being critical aspects of the definition of subjective health. Social performance includes role performance and social skills; the former may be related to formal roles such as resumed vocational activity or informal roles such as membership of clubs or social groups. Social skills are those personal requirements for successful role performance and include sociability, empathy and social interactions. Their description of social well being which includes the four conceptual scales of 'sense of belonging', 'intimacy and trust', social approval' and 'meaningful contribution' has significant parallels with the argument proposed by Parmenter (1988, 1992) above concerning the palpable role that the development of one's identity plays in the conceptual basis of quality of life.

One of the difficulties experienced in most attempts to conceptualize and quality of life is the omission of any consideration of the individual meaning of illness. Few scales of QOL include the opportunity for respondents to rate the significance of particular items to their perception of their quality of life.[1] This highly individualistic phenomena concerning a person's well-being and general life satisfaction almost ensure that most conceptual approaches will be invalid for some people. Mayou (1990) working in the context of cardiovascular disease has stressed this weakness in most approaches to the measurement of quality of life. He cited the example of the uncertain significance of rates of return to work, especially for those of late middle-age. Return to work can be seen by some as a good outcome whilst others may see failure to return to work as an excellent outcome. The use of scales which do not accommodate these individual differences will invalidate much of the findings in quality of life research. This issue will be taken up in more detail in the next section.

An examination of the conceptual bases for much of the study of quality of life in relation to disease has revealed a fairly pragmatic and empirical approach. There is little in the way of solid theory that can be used to generate research hypotheses that might allow one to expand the boundaries of our knowledge base. The most fruitful approaches are those that recognize the interaction between the person with the disease with his/her environment. The recognition of the need to study quality of life from the perspective of the patient is well established as is the need to include psychosomatic aspects. However, there has been an illusion of simplicity that has caused many researches to believe that the measurement of quality of life is simple and feasible. What is required is a more comprehensive and broadened conceptualization of quality of life, one that recognizes the significance of individual meaning. It is essential that models be established that include specific measures of quality of life that are chosen as being of particular importance to patients.

C. SPECIFIC POPULATIONS AND APPROACHES TO MEASUREMENT OF QUALITY OF LIFE

This section will review the use of a number of assessment approaches that have been developed to estimate quality of life in the context of specific populations with serious health problems. The areas covered do not purport to represent the wealth of research and literature available. However, a number of methodological and conceptual problems will be raised that do reflect the current status of quality of life research.

Selection of Quality Of Life Measures In Clinical Trials And Practice

Before selecting an appropriate QOL scale a useful strategy is to ask a number of questions concerning why the assessment is required. Osoba *et al.* (1991) have proposed an algorithm, or set of guidelines, that will help in the selection of the most appropriate measure for assessing quality of life in specific clinical situations. Their algorithm contains four basic questions:

(i) Will the measure be used for screening or case finding?
(ii) Will the measure be used for the obtaining quality of life health profiles?
(iii) Will the measure be used for the assessment of preferences?
(iv) Will the measure be used in clinical decision making?

Hence the purpose for which the data are required will influence to a great degree the nature of the scale adopted.

Among additional questions raised by Osoba *et al.* (1991) concerning scale selection were the following:

(i) Which method of measurement is most appropriate for the purpose?

 Here the options are between structured or unstructured interviews and questionnaires that may be either self-assessment or observer-assessment.

(ii) What is the scope of the assessment?

 This refers to whether the issues to be covered are general or specific regardless of the method adopted. General assessment contains several dimensions of quality of life while the specific approach focuses upon a single dimension or social aspect within one dimension.

(iii) Are reliable, valid measures available?

 Having chosen the purpose of the exercise one needs to explore the psychometric properties of available scales. If none is appropriate a decision has to be made as to whether it is cost effective to design and validate a new instrument.

The major properties of a psychometrically sound instrument are its reliability and validity. In terms of reliability the scale should be internally consistent, have sound test-retest stability and have high inter-rater reliability.

Validity is tested in variety of ways. An instrument should be responsible to changes in quality of life over time. It should also be able to detect differences between groups of patients in differing situations. It is important that a scale have face validity; that is the item should logically apply to the group being assessed. For instance, a number of scales have been developed for specific populations such as those with chronic illnesses (e.g. cancer) and those with psychiatric disorders. It would be unwise to use a scale for a population where the items are logically inappropriate.

There are rigorous statistical techniques available that can be applied to assess the reliability and validity of instruments. These have traditionally been used to demonstrate the scientific rigour of this area of research. For instance Osaba *et al.* (1991) have provided a comprehensive psychometric analysis of a selection of QOL measures developed for cancer patients. The trends towards a more qualitative approach to QOL assessments does not preclude the need, as suggested by Engel (1990, p. 67) for data 'to satisfy standards of accuracy, completeness and reproducibility; claims of proof must conform to rules of evidence and procedures (must) meet the requirements for consensual validation and public accountability.'

(iv) Are the results or outcomes of the assessment meaningful?

Here one has to distinguish between statistical and practical significance. A result may be statistically significant, but have little meaning in a clinical sense. A typical example of this is when large sample sizes are based in randomized clinical trials. Very small group differences in quality of life outcomes will often reach the standard levels of statistical significance, but these results may have little clinical relevance.

Osaba *et al.* (1991) have suggested that researchers should specify the nature of quality-of-life outcomes that will be considered clinically meaningful at the beginning of a study rather than in a *post hoc* manner. They have also highlighted the very important need for researchers not to dismiss findings that have been acknowledged with sound instruments and that are counter-intuitive on a clinical basis. They cited cases in cancer studies where results have run contrary to *a priori* expectations, requiring a serious reappraisal of conventional thinking. Medicine is not the only area where scientists need to reexamine existing paradigms.

The following examination of a approaches to quality of life assessment in the areas of cardiovascular disorders, oncology, and rehabilitation, is illustrative of the conceptual and measurement difficulties that surround this topic.

Cardiovascular Disorders

In this area research has explored five main issues: (a) description and understanding of the effects of different types of cardiac disorder upon all aspects of quality of life; (b) the relationship between effects on quality of life and physical impairment; (c) individual variation in response to cardiac disorder; (d) the design of interventions to prevent and treat medically unnecessary psychosocial problems, and (e) the evaluation of interventions; medical, surgical, educational and psychological.

As in other illnesses, two approaches may be utilized in the measurement of quality of life. One can use *general (or generic) measures* which are standardized and are applied widely to these without different types of illness for purposes of comparison. These measures usually provide either a health profile with subscales for different aspects of social functioning which can be aggregated. Alternatively the scales produce a single figure index which is often used in cost benefit analyses.

Mayou (1990) has argued that these general measures have a role 'as long as they are not seen as a simple unconsidered answer to the need to be seen to be measuring quality of life' (p. 103). General measures will often not reveal important clinical changes because they are usually too 'broad brush' to detect specific problems of particular illnesses. A related problem is irrespective of whether one uses general or specific measures, quality of life research has overly concentrated upon overall changes within groups of patients and has obscured the significance of individual variation. This highlights the need to use quality of life instruments as process measures as well as an index of final outcomes. What are required are well-chosen *specific measures*. In this case it is best to start asking basic questions of the patients and their families as to what they feel is important in their life quality. For instance, what are their particular problems? What are their expectations concerning treatment? These aspects of quality of life seldom appear in the popular general measures of health status.

As a result of the popularity of general measures, Stewart *et al.* (1989) pointed out that there has been an underestimation of the clinical and economic significance of including psychological aspects of quality of life in both acute and chronic heart disease. Studies have concentrated on "common sense" measures of functional status and on employment outcomes while ignoring in large measure the mental state of patients. This raises the issue of the reluctance of researchers to accept the validity of "soft" psychological measures.

Nevertheless, there has been a perceptible trend towards a greater inclusion of patient involvement in studies concerned with cardiovascular disorders. For example, in a comprehensive review in 1984 of those areas of psychological and social functioning which should be assessed in trials of cardiovascular treatment elements, Wenger *et al.* (1984) did not include aspects which related to a patient's feelings of satisfaction, frustration, anger, excessive caution, expectations, etc. By 1990, however, Wenger and Furberg (1990) had moved their position to that of strong support for the inclusion of patient life satisfaction factors such as well-being, emotional state, perceptions and expectations. They argued strongly, too, that the impact of the disease upon the family and significant others should be taken into account. They noted that 'the perceptions of the patients and their families reflect their personal value system and judgments regarding general health status, well-being, and life satisfaction' (p. 337)

The importance of assessing patient and family expectations is of particular importance where those expectations are excessively limited. The effectiveness of new therapies which can improve the outlook for both morbidity and mortality may be curtailed because of limited expectations brought about by the course of the illness.

A popular outcome index for cardiovascular treatments has been return to work, so much so that it has almost become a 'surrogate for quality of life' (Wenger and Furberg, 1990, p. 338). As noted above, Mayou (1990) found return to work as an unreliable quality of life index for arterial surgery. In those severely impaired or elderly, return to paid work is an unreasonable goal of most interventions and should not be seen as an aspect of quality of life. A patient's perceptions of health status and his/her ability to work, rather than objective measures of functional capability, are more often the determinant of whether the person returns to paid employment.

Returning to the question whether to use general or specific measures of quality of life it can be argued that even disease-specific indices are not sensitive to the variations in the stages or severity of the illness. For example, attributes of quality of life for coronary patients may be different across the various stages of the treatment and subsequent recovery. There would also be different areas of concern for a patient with a stable angina pectoris compared with one who has acute myocardial infarction.

There is a large body of literature on the psychological consequences of treatment following myocardial infarction. The seminal work by Hackett and Cassem (1984) at The Massachusetts General Hospital in the 1960s gave rise to much of this work. There is evidence that the major consequences for social functioning in areas such as leisure activities, social and family life and sexual activities are not closely related to ongoing physical problems (Mayou, 1979). Further, these various areas of mental and social functioning are not necessarily highly related either. This calls for a broader approach to evaluation.

In the heart transplant area there have been reports of the considerable benefits to quality of life for patients in addition, of course, to their life expectancy (Buxton *et al.*, 1985) as assessed by the Nottingham Health Profile. Mayou (1990) has suggested, however, that the complexity of the consequences of a heart transplant are not revealed by a very simple measure of quality of life. For instance, Mai *et al.* (1986) and Shapiro and Kornfeld (1989) have highlighted the presence of significant psychiatric, social and family problems in this population. Such studies do not question the success of heart transplants, but they do alert us to the psychological and social support needs of patients and their families. This is further support for the need of a more comprehensive assessment of quality of life and health status.

Raczynski and Oberman (1990) have summed up the position admirably with their suggestion that one of the key factors that mediates the disability effects on quality of life of people with cardiovascular problems is the patient's learning the disability role. In the majority of QOL assessment scales little attention is paid to the effects disability may have upon the individual's definition of him/her self as a person and his/her role in the social environment. There is a clear need to shift the focus in this area from longitudinal research that uses overly simplistic outcome indices, to research that seeks to maximize and maintain the many facets of quality of life. This will require a wider range of instruments which include interview-based as well as self-report approaches. Mayou (1990, p. 107) has put the case rather pungently in his suggestion that 'such changes in methodology will be impossible without acceptance that quality of life is not a simple, cheap and dubious extra, but a subject deserving as much attention as physical outcome measures'.

Quality Of Life In Oncology Patients[2]

Of all diseases cancer possibly invokes the most profound fear in persons so inflicted (in more recent years, however, AIDS may have eclipsed the fear that a diagnosis of cancer evokes). Not only do the majority of the 100 or more separate disease identified as cancer result in a significant threat to life, but many are accompanied by severe pain and suffering. Further, there are often disastrous side effects associated with any of the treatments which have led to a focus on'quality of survival'.

The main themes that have merged in quality of life research in oncology have been: (a) the evaluation of therapies, including psychosocial criteria; (b) the provision of a better basis for decisions between competing treatments by including criteria of quantity and quality of survival, and (c) the development of more focussed and more efficient ways of psychosocial support for patients with malignant diseases.

The types of quality of life assessments used in cancer studies have included: (a) population-based assessments, such as the Quality of Well-

Being Index (Bush, 1984) and the Sickness Impact Profile (Bergner *et al.*, 1981); (b) psychosocial assessments of coping (Derogatis, 1986) and depression (Beck *et al.* (1961); (c) global measures such as quality of life adjusted years (QALY) (Weinstein, 1983) and time without symptoms or toxicity (TWIST) (Gelber and Goldhirsch, 1986); (d) functional indices including the Karnofsky Index (Karnofsky *et al.*, 1948) and the World Health Organization Scales (WHO) (Zubrod *et al.*, 1960); and (e) multidimensional instruments such as the Functioning Living Index for Cancer (FLIC) (Schipper *et al.*, 1984), Quality of Life Index (Spitzer *et al.*, 1981) and the Padilla Quality of Life Index (QLI) (Padilla *et al.*, 1983).

The low correlations found between objective and subjective indices of quality of life outlined by Lewis and Ryan (1986) in their community studies are supported by the findings of Muthny *et al.* (1990) that there is not a high relationship between medical parameters and quality of life scores. The low psychophysiological correlations found in persons who are chronically ill may be explained by their coping behaviours that include cognitive, emotional and behavioural efforts to overcome the stress and achieve adaptation to the sequence of the illness. It has been observed that cancer patients report better qualities of life than would be expected for an independent assessment of the impact of their disease and its treatments. De Haes and von Knippenbert (1985) have suggested that a patient's response may be a reflection of perceptual restructuring where the patient who expecting less, feels that he or she is doing well. The adaptation theory of Helson and Bevan (1967) would account for this phenomenon. Alternatively, a more psychopathological stance taken by Hurny *et al.* (1987) suggests that patients tend to respond in a socially desirable way, especially as they age.

An early, yet significant, contribution to the quality of life literature by Campbell *et al.* (1976) was their observation that a quality of life judgement contains both cognitive and affective components, each of which can change independently of the other. For example, when patients indicate that they remain satisfied they may be masking the negative affective changes which are occurring concurrently. This will require further independent assessment. The role that cognition plays and the independent effects of the effective components of quality of life require further intensive study, particularly in the context of providing adequate psychosocial support for patients with cancer, or indeed other illnesses that are surrounded by severe emotional stresses.

For instance, in the area of chronic obstructive pulmonary disease, Jensen (1983) found that social support and life stress predicted the number of hospitalizations better than did the patients's demographic characteristics, the severity of the illness, or previous hospitalization. Several studies have revealed the significance of instrumental and emotional support provided by spouses, friends and relatives to a person's quality of life and their response to treatment. Economic security has also been found to predict better adaptation (Sexton and Munro, 1988; Young, 1982).

A fruitful avenue for further studies is an examination of the effects an individual's coping strategies may have upon quality of life outcomes with respect to physical functioning, family/partnership relationships, emotional well-being, and social and occupational functioning. The role that social support may play in this process also requires investigation. These questions would obviously involve an interdisciplinary approach involving oncologists, psychologists and psychotherapists. It is anticipated that the quality of life cancer patients can be improved not only by medical interventions, but also by more effective doctor-patient relationships wherein diagnosis and possible treatments are better communicated to the patient. A further important consideration is the improvement of psychosocial care including the effective support of an individual's coping processes. This calls for an individual-specific approach to the assessment of quality of life.

Rehabilitation

Despite the shift of emphasis from a narrowly focussed compensatory program to one which seeks to reintegrate persons with disabilities into community life, assessment of rehabilitation outcomes rely heavily upon objective functional indices which ignore to a large extent the subjective aspects of a person's life. While the term rehabilitation is used generically in the disability literature, encompassing programs for people with congenital impairment, usually referred to as developmental disabilities, and for those whose disabilities have been acquired through accident or disease, this review will be restricted to programs for the latter group.

In any examination of rehabilitation outcomes one is struck by the absence of references to theory. As in other areas of health services this omission reflects the lack of well-elaborated theories of rehabilitation and disablement. Having its genesis in medicine, rehabilitation has been overly influenced by the need to define outcomes specifically and objectively within the rubric of the "hard" sciences. A related influence has been the need to restrict outcomes or goals to those aspects that the rehabilitation professional can directly control. The nature of much of the rehabilitation industry, relying heavily on third-party sponsors, also does not encourage the evaluation of the long-term effects of rehabilitation services. These factors, together with the difficulties of assessing the influence of environmental variables, often beyond the control of rehabilitation professionals, may explain the absence of a sound conceptual base for the rehabilitation process. This in turn has retarded the development of research programs which address the broader, and often more subjective, elements of quality of life.

The pervasive influence of the independent living paradigm (De Jong, 1981), the growth of disabilities studies in which people with disabilities are speaking out (Finkelstein, 1980; Stoddard, 1978; Vash, 1984); and the influence of the literature on the social construction of disability (Barton, 1989; Fulcher, 1989; Söder, 1984), have all contributed to a broader perspective on the outcomes of rehabilitation programs.

The paradigm that has led to the development of a more integrated model of rehabilitation than the earlier emphasis upon observable pathology and dysfunction is the World Health Organization classification of impairment and handicap (Wood, 1975). Grange and Gresham (1984) have presented a model wherein concepts are organized across three levels: organ, person and society. Within each of these the condition results directly or indirectly, in either impairment, disability or handicap. This framework allows for functional assessments of physical performance, mental performance, emotional performance, and social performance (Jette, 1984).

While there have been conceptual advances in the delivery and assessment of rehabilitation programs, the field has been slow to incorporate the impact of disability upon the psychosocial functioning of the person. One gains the impression from a review of the literature that the rehabilitation field is still dominated by the various professional groups which deliver the services, despite Turner's (1990, p. 249) suggestion that measurement of rehabilitation outcomes is moving from 'situation and institution-specific scale development to broader-based, coordinated, interdisciplinary work.' Ellwood (1988), for instance, called for the development of an outcome management system which would have quality of life assessment as its core.

However, rehabilitation counselling has made a significant contribution to the study of quality of life. For instance, Roessler (1990) has presented a quality of life perspective on rehabilitation counselling which integrates competing program goals such as client independence or employment into higher order, multidimensional rehabilitation outcomes. He noted that counsellors committed to the quality of life orientation work from a wellness and holistic position that addresses both the development of the individual and the environment in which the person lives.

An interesting study by Scherer (1988) illustrated an important aspect of quality of life for people with spinal cord injuries or cerebral palsy. She compared the use or nonuse of assistive devices by these two groups. The users of both disabilities saw their quality of life as being within their control, whereas nonusers believed otherwise. Despite numerous methodological problems in assessing locus of control, persons assessed as having an internal locus of control appear to have more than a coincidental power over their disabilities. It seems that it is this power that can make the difference in a person's prognosis and quality of life (Evans, 1991). It would appear that an important dimension in rehabilitation outcome studies is the degree to which the persons feel in control of their lives.

A related issue is professionalism which defines the hierarchical relationship between the health care worker and the patient. The traditional dominance of the former over the latter is giving way to a more equal partnership, or indeed in some situations, a complete reversal of power. An interesting study by Lomas *et al.* (1987) illustrated the differences in values between clinicians and a group of patients with language disabilities. Clinicians and patients generated lists of important functional communication situations to develop a measure of quality of life. Results indicated that the clinicians underestimated the patient's focus on social needs. The clinician-generated items were not fully representative of patient values.

The trend in quality of life studies in the area of traumatic brain injury (TBI) has been toward the assessment of psychosocial variables such as those related to family relationships (Brooks, 1992) and empowerment (Jacobs *et al.*, 1990). It is essential, too, for longitudinal studies which can assess changes in quality of life over time. Such assessments can be used for adaptations to lifelong living programming. Indeed the use of quality of life assessments as process as well as outcome measures is to be encouraged. The ultimate success of such programming is measured by lack of institutionalization and by improvement of individual control and quality of life. Increases noted in passive behaviours by people with TBI over time are a cause of concern and require specific attention (Diller and Ben-Yishay, 1987).

In conditions such as TBI and other impairments where recovery to pretrauma states is unlikely, the provision of environmental supports has increasing relevance, especially where the efficacy of treatments is questionable. The inclusion of the concept of support in the recently promulgated definition of mental retardation by the American Association on Mental Retartdation (1992) is a model worthy of consideration for other impairments where handicaps can be reduced through appropriate community support. The roles that friendship networks and close personal relationships play in enhancing quality of life also need to be considered more urgently by rehabilitation services (Knox and Parmenter, 1993).

The life-experience difficulties experienced by people with TBI are not dissimilar to those experienced by people with mental illness. Both groups, because of their emotional and behavioural disorders feel discriminated against and frustrated because of the lack of respect they receive from the community. In a study of 204 persons with serious mental illness, drawn from eleven rehabilitation and mental health centres, Coursey *et al.* (1991) found that the majority of consumers wanted more help with quality of life issues than symptom reduction. They were concerned by their powerlessness and feelings of rejection. Rehabilitation programs that provide an enhancement of economic resources and an empowerment approach to service delivery have also been found to be significantly related to overall quality of life. Perceptions of mastery accounted for the impact of these components of life satisfaction (Rosenfield, 1992).

The diversity of the players in the rehabilitation system and their associated values will continue to influence the types of variables that will be included in outcome studies. Increased emphasis upon the quality of life of people, both in the short and long-term after traumatic injury or illness, may result in the development of a more coherent theory of rehabilitation; one that may lead to new treatment methods which are based upon a more holistic appreciation of human functioning.

D. USES AND ABUSES

Research into the quality of the lives of people who have serious illness or who have experienced traumatic injuries offers a rich area of investigation that can lead to dramatic improvements in the way we deliver health and rehabilitation services. The paradigmatic shifts in the field of disability generally are having profound effects upon service delivery and the way we view the nature of illness and disability and its subsequent amelioration by the various professional groups. In order that"quality of life" as a concept does not become maligned because of its vagueness and/or because it poses supposedly insuperable problems in its accurate measurement, a number of questions will be explored in this concluding section. These questions include the rationale for measuring quality of life; discussions concerning who should measure it; how should it be measured; and what are some of the ethical issues surrounding its measurement?

Rationale

Quality of life indices have been used to assess outcomes of clinical trials, to compare the efficacy of different treatments, to evaluate the cost-utility and cost-effectiveness of health care programs, to assist quality assurance and to assist in the marketing and regulation of drugs.

Assessments of outcomes of clinical trials in cancer patients provide an excellent rationale for including quality of life assessments in addition to biological data such as overall survival, disease-free survival, end-response rates, in addition to haematological and other indices of toxicity. With current interventions there is no guarantee that curing the patient‘s cancer will return him/her to the same level of quality of life as in the precancer state. Relief of physiological symptoms is not necessarily accompanied by an improvement in quality of life. Taking quality of life considerations into account may allow the patients to make decisions as to whether they wish to undergo specific forms of treatment. Pretreatment states of quality of life may also have prognostic value especially as a stratification variable when designing clinical tests. If quality of life measures used are sensitive to clinically important changes, then the resulting information can alert clinicians to the onset of morbidity associated with a disease. This may allow appropriate preventative measures to be taken.

Health economists have used cost-effective analysis as a means of quantifying the relative benefits of medical procedures. With a cost-effectiveness analysis approach, medical outputs are equated with the number of lives or life-years saved. Thus, a redistribution of funds to projects with a low cost per life can be seen as a means of increasing the total number of life-years that may be gained (Drummond, 1991). A major weakness in the approach was that it treated all life-years as having equal value irrespective of the quality of life (Richardson, 1991). This has raised obvious ethical issues, especially in the treatment of neonates with severe abnormalities (Zaner, 1986).

Perceived weakness in the cost-effectiveness analysis approach has led to the development of the concept of quality-of-life adjusted years (QALYs) (Williams, 1979, 1985).

Administration Of Scales

There are conflicting opinions concerning who should complete QOL scales. Many of the more popular scales are of a self-report nature for ease of administration. Another approach is to use proxy raters. Fava (1990), for instance, have maintained that observer-rated methods, especially when the interviewers are properly trained, provide a far more reliable assessment than self-rated instrments. Another view is that it is the patients who are in the best position to set the standard by which they will assess their present status (Osaba, 1991). Studies have indicated that observers' ratings are consistently lower than patients' ratings. The patients's perception of what is an acceptable standard also changes with time. A case in point is where one patient expects a cure as against one who knows the illness is incurable. The former patient probably has a much higher standard than the latter whose primary concern may be comfort. The optimum path would be to conduct structured interviews where the patients can elaborate upon their responses . Reputable forms of qualitative data analysis techniques can be used to provide both reliable and valid information.

How Should QOL Be Measured?

One of the problems observed in quality of life research is the elusive search for a 'gold standard' scale; one that can be used across populations and one that can be used for a variety of purposes. A good example is the Quality of Life (QL) Index developed by Spitzer *et al.*, in 1981. The authors set out to develop a simple, quantified instrument that would reflect the different dimension of quality of life, somewhat similar to the Apgar scale used with neonates. The scale has proven to be a reliable and valid assessment of an individual's health related quality of life and is responsive to changes in life's quality over time. It has been used extensively with patients with cancer in addition to those with other debilitating disease. It has been administered as a self-report or by proxy raters such as significant others, the physician, or other health care providers. Its prominence and reputation is such that it is frequently used as a validating tool by other investigators developing instruments with similar theoretical bases.

In their initial development of the Index Spitzer and colleagues set up three advisory panels, each of 43 people representing the patients' relatives, health professionals, clergy, and the general public. From structured and unstructured questionnaires, factors that comprised quality of life were determined, together with information on the relative importance of each factor. Draft forms of a scale were developed and tested on a sample of 339 subjects. A final index emerged with five dimensions; activity, daily living, health, support, and outlook. In addition a linear analog scale which assessed the global attributes in quality of life was incorporated plus a ten-item questionnaire (Multiscale) which also assessed quality of life.

Its simplicity of administration and its global nature has resulted in its widespread use across a wide range of objectives. These have included comparisons between continuous and intermittent chemotherapy in cancer patients (Coates *et al.*, 1987); comparisons between patients with end-stage renal failure receiving continuous ambulatory peritoneal, home or self, or hospital dialysis (Churchill *et al.*, 1987); comparisons of day hospital and in-patient management for cancer patients (Mor *et al.*, 1988).; the value of intensive care for critically ill patients (Sage *et al.*, 1986); and the validation of utility assessment (Churchill *et al.*, 1987). A problem with the QL Index is that the domain "social support" may be a correlate, rather than an outcome measure of quality of life. A difficulty experienced here is the lack of clarity of how "social support" is defined. It may include social contacts, which is closer to performance of social rules; as well as social resources which are more analogous to the concept of social support. The former has quite subjective dimensions, while the latter can be assessed more objectively.

A number of conceptual and methodological problems arise when one approaches specific questions using a global measure. For instance, there is evidence in the case of the QL Index that it correlates better with instruments containing elements of physical performances as opposed to psychosocial functioning. Rather than attempting to use a single index as a measure of quality of life it would seem more reasonable to first ask the question 'for what purpose will the data be used' and to design an instrument that does not purport to come up with a single score. As discussed above, many of the global scales fail to take into account the differential weightings individuals place upon certain aspects of their lives.

Whether one gathers "hard" (i.e. objective) data or "soft" (i.e. subjective) data, measurement tools should have the characteristics of reliability, precision, responsiveness and validity. Gathering independent data to establish concurrent validity and demonstrating the reproducibility of results help to establish the validity of quality of life measures. One of the most serious omissions in much of the scale developments has been the paucity of studies that have tested their construct validity against a sound theoretical base.

Ethical Considerations[3]

Two important principles must be borne in mind when assessing the quality of life of patients. The first is that the long-term goal should be to improve the care of patients. This is consonant with the beneficence principle of a physician's obligation to improve the patient's welfare and well-being. The second principle is that one must always respect the autonomy of the patient. Hence the patient's views and priorities must always be paramount. This will require the active participation of the patient in the quality of life assessment process (Beauchamp and Childress, 1989). Bioethical principles should also have a pervasive influence upon the design; review, conduct, interpretation and reporting of the research instruments for assessing quality of life (Till, 1991).

In the area of 'utility-based' quality of life assessments which have their origins in the decision making theory of von Neumann and Morgenstern (1947) a number of possibly unwarranted assumptions are made. This approach which forms the basis of the concept of QALYs relies upon the aggregation of the duration of survival with the quality of survival into a single variable. Two caveats may be made. The first is that the selection of the algorithm to determine the precise aggregation of scores is an arbitrary one. For instance, different weights can be given to the elderly, or the young or people suffering a particular disease. The crucial question is who decides? The second is that people who decide the trade-offs between quality versus quantity decisions are usually not the people suffering the disease.

It is natural that health economists, faced with ever increasing "blowouts" in health care budgets, seek measures which can ration these services in an equitable manner. However, as currently used, measures of QALYs underestimate the significance of disability and handicaps as compared with life expectancy. Harris (1987) argued that QALYs fallaciously value time lived, instead of individual lives; taking an excessively narrow view of what quality of life might be.

E. CONCLUSION

The literature on quality of life in the medical area reveals a tension between those who would wish to focus on the biomedical aspects of disease and those who take the broader approach; an approach that seeks to open a dialogue between physician and patient. The power of dialogue and introspection has the potential to elucidate more effectively the meaning of quality of life and to enhance the accuracy and validity of information reported. Criticism of the conceptual bases of quality of life research, including overemphasis upon general concepts; the neglect of mental state; the failure to recognize the range of individual responses; the neglect of individual meaning of quality of life; and the neglect of consequence for the family may be ameliorated by a more equal partnership between instrument developers and those being assessed.

Goode (1991) has suggested that addressing what quality of life actually means from an epistemological perspective may be of more value than developing more indices that may manifest theoretical, definitional, operational, and methodological problems. Interestingly, the quest for effective quality of life measures may forge a closer link between those who emphasize the application of biomedical concepts and techniques and those who wish to include psychosocial aspects normally studied by the behavioural and social sciences. This rapprochement and consequent shifts in attitudes may have a greater impact upon health services than quality of life assessments *per se*.

NOTES

[1] A recent Australian scale developed by R. Cummins (1991) provides respondents with the opportunity to weight the significance various items have in respect to their perceptions of QOL.

[2] The reader is referred to Osaba (1991) for a comprehensive analysis of the effect of cancer on quality of life.

[3] For a comprehensive discussion of ethical issues in the disability field the reader should consult Duncan and Woods (eds.) (1989).

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