

Measuring the quality of later life

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SUMMARY

This paper examines quality of life as a scientific construct with a wide range of applications. The assessment of patients' quality of life is assuming increasing importance in medicine and health care. Illnesses, diseases and their treatments can have significant impacts on such areas of functioning as mobility, mood, life satisfaction, sexuality, cognition and ability to fulfil occupational, social and family roles. The emerging quality of life construct may be viewed as a paradigm shift in outcome measurement since it shifts the focus of attention from symptoms to functioning. This holistic approach more clearly establishes the patient as the centre of attention and subsumes many of the traditional measures of outcome. Quality of life assessment is particularly relevant to ageing populations both for healthy elderly and for those who develop chronic diseases where maintenance of quality of life rather than cure may be the primary goal of treatment. This paper introduces the concept of quality of life and describes the significant difficulties in definition, measurement and interpretation that must be addressed before such measures can be used as reliable and valid indicators of disease impact and treatment outcomes. It is argued that approaches to quality of life assessment in the elderly should incorporate advances in knowledge about the psychological adaptation to ageing. Consequently, the unique perspective of the individual on his or her own quality of life must be incorporated into outcome assessments aimed at improving the quality of health care. Incorporating measures of subjective outcome such as quality of life into policy decisions on resource allocation in health care will prove one of the major challenges for health services over the next decade.

1. THE AGEING OF THE POPULATION

For the first time in our history we are confronted with the reality that humanity as a whole is growing older. Never before have so many people lived for so long. According to Olshansky *et al.* (1993), the demographic ageing of the population began early in this century and will end near the middle of the next century when the age composition of the population stabilizes and the practical limits of human longevity are approached. The coming change in population structure is enormous and has potentially far reaching consequences for society. In 1900 there were 10–17 million people aged 65 or older constituting less than 1% of the total population. By 1992 there were 342 million people in that age group, making up 6.2% of the population. By 2050, the number of people aged 65 years or older will expand to at least 2.5 billion—about a fifth of the world's projected population (Olshansky *et al.* 1993). Previously ageing was regarded as an emerging trend mainly in industrialized countries but it is now recognized as a global phenomenon. In 1990, more than half (55% of 176 million) of the elderly were living in the so-called developing world; by 2025, the proportion is expected to be 65% (Darnton-Hill 1995).

Three epidemiological scenarios may result from this demographic change (Fries 1992). First, the average period of morbidity experienced before death may

increase if medical interventions do not affect the onset of chronic disease but only delay mortality (the 'failure of success' scenario). Second, the average age for the onset of chronic disease as well as mortality may increase, resulting in no change in the average period of morbidity. Third, the average age for the onset of chronic disease may be postponed, due, for example, to changes in lifestyle, with no change or a slow increase in longevity resulting in an average decrease in the period of morbidity (the 'compression of morbidity' hypothesis).

There is considerable debate about which of these scenarios is most likely to occur and the consequences for medicine and health care of each are significant. If the average period of morbidity remains static or is compressed, an increasing proportion of the elderly will spend an increasing proportion of their old age in good health. This will require some adjustments in attitudes to old age since healthy ageing will be the norm and pathological ageing the exception. A widespread paradigm in the behavioural and medical sciences is that old age is a time of deficiency rather than a natural component of the life-span. Thus, health and physical, cognitive, social and sexual functions are assumed to decline inevitably with age resulting in decreased quality of life (Schmid 1991; Browne *et al.* 1994). If the average period of morbidity remains static or compressed, then old age will be increasingly

seen as a time of good quality of life and social and health-care policies will be aimed at maintaining or enhancing quality of life.

The compression of morbidity hypothesis has been challenged by many scientists who posit an expansion of morbidity (Olshansky *et al.* 1993). It is argued that behavioural factors such as changes in diet, exercise and daily routines, which are known to reduce the risks from fatal diseases, do not change the onset or progression of most debilitating diseases associated with ageing. Reductions in the average age of mortality could therefore extend the time during which the debilitating diseases of ageing can be expressed resulting in a proportionate rise in the untreatable diseases now common in the very old. Some data indicate that the average number of years that people spend disabled has grown faster than those that they spend healthy. Although people are enjoying more healthy years while they are young and middle aged, they may be paying the price for those improvements by spending more time disabled when they are older (Olshansky *et al.* 1993). Furthermore, as new medical technologies are developed, which seek to postpone death, increasing numbers of people will live longer periods in states of disability. If this happens, a major shift in resources will be required to ensure that, for such people, cost-effective interventions aimed at maintaining function and ensuring maximum quality of life, will be available. This would require a significant refocusing of health care, which is currently largely oriented towards expensive acute care interventions, to the provision of chronic long-term care, the need for which will rapidly increase as the population ages. A critical element in evaluating the effectiveness of such interventions will be the availability of measures which reflect as many dimensions of outcome as possible.

2. MEASURING HEALTH OUTCOMES

Health outcomes are classically defined as 'changes in a patient's current and future health status that can be attributed to antecedent health care' (Donabedian 1985). Outcome indicators have traditionally included the following: avoidable mortality, standardized mortality ratios, hospital re-admission and other service-use indicators, laboratory investigations, diagnostic tests, morbidity, case severity, adverse reactions, complications, technical success, symptom relief, pain and cost-effectiveness. All of these are of course important and provide relevant information. However, while those who deliver health care are concerned with the broad range of such outcomes, those who receive it are usually more concerned solely with the impact on their longevity and on the quality of their lives.

The goals of the medical and health sciences are to add years to life *and* life to years. When the condition is chronic and cure is not possible, the goal is to ensure the best possible quality of life for the patient. There are many examples of studies that have reported low levels of agreement among doctors and between doctors' and patients' judgements. Broadening outcome assessment to include subjective patient-based health outcomes refocuses efforts on a more holistic set of

treatment goals and provides a patient-centred baseline for assessment of treatment. Consideration of patient quality of life promotes improved clinical interventions, assists in treatment comparisons and will prove increasingly important in the identification of services and facilities and in resource allocation. The various methodologies derived to measure quality of life offer the potential for a final common pathway for assessing the multidisciplinary inputs of basic scientists and clinicians to diagnostic and treatment processes. As such, quality of life could become the dominant criterion by which medical decisions are made and treatment advances are judged.

3. WHAT IS QUALITY OF LIFE?—THE PROBLEM OF DEFINITION

The first problem that anyone interested in this field has to address is the problem of definition. The traditional biomedical model considered disease as an objective pathological state and the role of treatment was seen as the reversal of the pathological process in order to effect a cure. Outcome measurement was largely concerned with objective indicators such as mortality and morbidity and, latterly, cost (O'Boyle & Waldron 1997). Over the past two decades, however, there has been a significant shift in emphasis. An emerging alternative model of patient care has been labelled the biopsychosocial model and this focuses on the biological, psychological and social dimensions of illness as experienced by the patient. This model reflects more faithfully the original World Health Organization (WHO) definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. In 1984, the WHO added 'autonomy' to the list of health pre-requisites (WHO 1947, 1984). The quality of life paradigm, focusing as it does on the subjective measurement of effects in a range of domains, fits neatly into this paradigm.

There has been an explosion of interest in the concepts of quality of life and health-related quality of life and the novice is likely to be confused and overwhelmed by the lack of standardization and the multitude of measures available. Quality of life has become important both as a focus of clinical concern and as an outcome measure in research and evaluation studies (Schipper *et al.* 1996). It has become an important outcome measure in clinical trials, a criterion for the licensing of new medicines in some jurisdictions, the focus of a specific journal *Quality of Life Research* and the subject of a growing number of texts. A useful recent guide to information sources is that by Hedrick *et al.* (1996). Important resources are those by McDowell & Newell (1987), Smith (1988), Spilker (1990, 1996), Bowling (1991, 1995), Patrick & Erickson (1993), and Walker & Rosser (1993). Books covering specific areas such as cancer (Aaronson & Beckman 1987), epilepsy (Trimble & Dodson 1994), and renal disease (McGee & Bradley 1994), are also available as are texts covering specific populations such as children (Christie & French 1994), the elderly (George & Bearon 1980; Kane & Kane 1988; Birren *et al.* 1991; Abeles *et al.* 1994), or dealing with philosophical issues underlying

quality of life (Nussbaum & Sen 1993; Walter & Shannon 1990; O'Boyle *et al.* 1997). Computerized bibliographic systems and an on-line guide to quality of life assessment (OLGA) have also been developed (Hedrick *et al.* 1996).

Despite the burgeoning literature on the subject and its application in many disciplines—geography, literature, philosophy, economics, politics, advertising, health promotion, medicine and the social sciences—the concept of quality of life is difficult to define and operationalize. There are a variety of definitions including crude attempts at quantification. Because quality of life is such a vague concept, with such a multitude of usages, the definition is often more dependent on the user and in particular his or her understanding and agenda. Like happiness, it is a term which we all understand but for which adequate definitions do not exist. A recent critical appraisal of quality of life measurements (Gill & Feinstein 1994) highlights the problem of conceptualization and definition. Investigators defined what they meant by the term quality of life in only 11 (15%) of the 75 articles reviewed, identified the targeted domains in only 35 (47%) and gave reasons for selecting the chosen quality of life instruments in only 27 (36%). No investigator distinguished 'overall' quality of life from health-related quality of life. The measures used focused on predefined areas rather than allowing patients to define the areas that they themselves considered to be important. Patients were invited to give their own specific rating of quality of life in only 13 studies (17%), were asked to supplement the stipulated items with personal responses in only nine (13%) and to rate the importance of individual items in only six (8.5%). One is reminded of Humpty Dumpty informing Alice that: 'when I use a word it means exactly what I want it to mean, nothing more and nothing less' (Carroll 1871).

4. OPERATIONAL DEFINITIONS: HEALTH-RELATED QUALITY OF LIFE

Because of the global nature of quality of life and the myriad factors that can influence it, many researchers restrict its definition to health-related quality of life. This is distinct from quality of life as a whole, which would also include such components as adequacy of education, housing, income and perceptions of the immediate environment. Patrick & Erickson (1993) define health-related quality of life as 'the value assigned to the duration of life as modified by the social opportunities, perceptions, functional states and impairments that are influenced by disease, injuries, treatments or policy'. There is broad agreement that in measuring health-related quality of life we should assess a number of crucial areas including physical function, psychological state, somatic symptoms such as pain, social function including relationships, sexual function and occupational function and possibly financial state. We should include some assessment of the patient's level of general well-being and of satisfaction with treatment, outcome and health-status and with future prospects.

The concept of health-related quality of life owes much to the original WHO definition of health as a

state of complete physical, mental and social well-being and not merely the absence of disease (1947). The WHO established a working party on quality of life, which is undertaking a ten-country study of quality of life. The WHOQoL group has provided the following useful definition of quality of life:

'Quality of life is defined as the individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by a person's physical health, psychological state, level of independence and their relationships to salient features of their environment'

WHOQoL Group (1993)

5. HOW SHOULD QUALITY OF LIFE BE MEASURED?

The concepts underlying quality of life are complex and multidimensional and this has resulted both in differing conceptualizations and a wide variety of measurement techniques that reflect the lack of agreement on definition. In general, measurement of quality of life in medicine and health care is guided by two principles, multidimensionality and subjectivity. Most authors recommend that a comprehensive evaluation should cover several key domains: physical symptoms, physical role and social functioning, psychological distress, cognitive function, body image and sexual functioning (Bowling 1991, 1995). These are assessed usually by asking the patient to complete subjective questionnaires or by a health-care professional or relative making a proxy assessment.

In choosing a measure, or set of measures, the key questions are whether a disease-specific measure or a generic measure is needed and whether either requires supplementation with single-domain measures that are important to the study aims. Examples of generic measures are the well-known Sickness Impact Profile, The Nottingham Health Questionnaire, the McMaster Health Index and the SF-36, which are now very widely used. The Nottingham Health Questionnaire, for example, provides the patient with the opportunity to rate symptoms such as fatigue, pain, anxiety and depression and also the extent to which their health is causing problems in work, social life, sex life and so on. Such measures can provide important information about the impact of medical and surgical interventions. One problem with general measures such as these is that they may not be specific enough to capture small but significant changes in health status or levels of disease severity. This has led to the development of a host of disease-specific quality of life measures (Bowling 1995). A combined approach in which a generic measure such as the SF-36 is used together with a disease-specific measure is increasingly the norm.

6. DIFFERING PERSPECTIVES

It is important to understand the limitations of health-care professionals in making an accurate judgement of

the patient's concerns (Presant 1984). Spangers & Aaronson (1992), in a review of the literature on proxy ratings of quality of life, concluded that agreement between patients self-ratings and those of health-care providers and of relatives was generally poor. Early so-called quality of life measures such as the Karnofsky Scale and the Spitzer scales were rated solely by the doctor. Slevin *et al.* (1990) showed that agreement between doctors and patients ratings on these scales was poor. With the emergence of data such as these showing discrepancies between doctors, nurses and patient ratings, the importance of patient ratings increased. Agreement between ratings has been shown to depend on a number of factors: level of concreteness and visibility of the domain rated; type of rater; relationship to patient; closeness of living arrangement with patient.

In the context of health outcomes, it is becoming increasingly clear that the professional's definition of successful outcome is often quite different from that of the patient, particularly that of an older patient. Professionals rely on objective, easily quantifiable functional criteria whereas older people are more concerned with issues of self-identity and the preservation of meaning in their lives (Clark 1995; Koch *et al.* 1995; Porter 1995). It has been suggested that the search for scientific measures of quality of life should be abandoned as the models produced are inappropriate to the individual and fail to capture the complexity of caring for the elderly (Ebrahim *et al.* 1993).

7. THE ELDERLY

As is the case for quality of life generally, there is as yet no consensus regarding the measurement of quality of life in the elderly (Arnold 1991; Bowling 1995; Lundh & Nolan 1996*a,b*). Arnold (1991) proposed that quality of life assessment in this population should include assessment of the following: physical functioning and symptoms, emotional, behavioural cognitive and intellectual function, social functioning and the existence of a support network; life satisfaction; health perceptions; economic status; ability to pursue interests and recreations; sexual functioning and energy and vitality. Darnton-Hill (1995) has highlighted the importance of socioeconomic factors, particularly income in determining both life expectancy and quality of life in the elderly.

8. MEASURES OF QUALITY OF LIFE IN THE ELDERLY

Quality of life and health status measures are becoming increasingly important in assessing the elderly and a number of reviews are available (Kane & Kane 1988; Fletcher *et al.* 1992; Williams 1996; Fretwell 1996; Stewart *et al.* 1996). Disease-specific measures have obvious applications in particular groups of elderly patients. In addition, the domains that may require measurement among older people include health problems that can cause handicap or impairment and that are potentially remediable (e.g. hearing and eyesight problems, incontinence and foot

problems, which may impair mobility (Bowling 1995)). Measures of cognitive function and mood, functional ability and broader health status, life satisfaction, sense of control and degree and adequacy of social support systems are also likely to be important. Fletcher *et al.* (1992) have identified scales that are appropriate for use in assessing quality of life as an outcome measure for purposes of audit.

9. PROBLEMS OF MEASUREMENT OF QUALITY OF LIFE IN THE ELDERLY

Much of the research, to-date, on quality of life in the elderly has consisted of applying measures developed for application in younger populations or in specific patient groups (Kutner *et al.* 1992; Fletcher *et al.* 1992). Furthermore, populations studied have often been institutionalized and the generalizability of findings may be limited. For example, Noro & Aro (1996) investigated health-related quality of life and functional ability in a stratified, systematic sample of 1097 patients in public resident homes in Finland, compared with the general population. Only a few patients in residential care had HRQoL or functional ability at a comparative level to the non-residential population.

Older populations include many who have remained healthy and many whose health has deteriorated significantly. A common population pattern is that of decreasing average health but increasing variability in some of the more subjective components of health-related quality of life such as psychological well-being (Stewart *et al.* 1996). The heterogeneity of the elderly population makes it unlikely that any single measure will be suitable for all applications. Furthermore, measures developed to assess the impact of disease are inappropriate for assessing healthy populations and reflect a somewhat ageist view of such populations. Different types of measures are needed for different types of application. Applying particular measures to populations for which they are not designed is likely to result in floor and ceiling effects respectively. For example, many scales for measuring depression include somatic items, which may give an inflated score in those suffering from functional limitations associated with age. Given the origins of many scales in assessing patients, they are of little value in assessing healthy elderly people many of whom consider their quality of life to be very good indeed (Browne *et al.* 1994).

10. NEED FOR THEORY BASED ON PSYCHOLOGICAL AND SOCIOLOGICAL MODELS OF AGEING

Quality of life research is multidisciplinary and, to-date, the focus has been largely on developing measures that can be applied in clinical trials or in policy development. Little theoretical development has taken place and very few attempts have been made to construct a psychological theory of quality of life. One approach (Lundh & Nolan 1996*a,b*) has been to incorporate the model of ageing proposed by Brandstadter & Greve (1994). Here, successful ageing is seen as dynamic process of balancing assimilative (maintaining current

activities), accommodative (flexible goal adjustment) and immunizing (selective filtering) strategies in order to maintain a realistic and serviceable sense of self. Similarly, the model of successful ageing proposed by Baltes & Baltes based on the Berlin Aging Study (Baltes & Baltes 1990; Baltes *et al.* 1996*a,b*), focusing on the strategies for selection, optimization and compensation, has important implications for the study of quality of life in the elderly. In particular, such theoretical models highlight the role of the adaptive nature of the ageing person. Using these strategies, individuals can contribute to their own successful ageing. While the biological nature of human ageing limits more and more the overall range of possibilities in old age, the individual can adapt by selecting and concentrating on those domains that are of high priority and that involve convergence of environmental demands and individual motivations, skills and biological capacity. Among the important implications of theoretical models such as these is the conclusion that any assessment of quality of life in older people must concern itself with the unique concerns of that person and their own subjective assessment of their circumstances.

11. QUALITY OF LIFE: THE NEED FOR AN INDIVIDUAL PERSPECTIVE

Questionnaire approaches to the measurement of quality of life provide important information but suffer from the important limitation that they may not reflect the priorities of the respondent. Someone other than the respondent has decided which questions to ask, which areas should be explored and which areas should not be addressed. Furthermore, the relative importance assigned to the answers as reflected in the weightings that must be applied to obtain a score, may not, indeed are likely not to be, those that the patient would use (Cohen 1982; O'Boyle *et al.* 1995). Individuals are active agents, involved in a continuous search for meaning and constantly striving towards the goal of self-actualization. We have previously proposed a phenomenological approach to quality of life, that is, one which focuses on the individual's personal view of life and of its quality (Joyce 1988; O'Boyle 1992; O'Boyle *et al.* 1992, 1993, 1997). We have suggested that quality of life should be defined as what the individual determines it to be. Similarly, Hayry (1991) has proposed that 'the quality, or value, of an individual's life is no more and no less than what she considers it to be'. Calman (1984) proposed an important model for the assessment of quality of life which again places the emphasis on the perspective of the individual. Quality of life is the difference, at a particular period in time, between the hopes and expectations of the individual and their present experience. It depends on the individual's past experience, present lifestyle and personal hopes and ambitions for the future. The gap between hopes and realities may be narrowed by improving the patient's functions (reality) through treatment or by reducing expectations through informed understanding of the limitations of their disease and acceptance of the risks involved in treatment in relation to expected benefits.

12. THE SCHEDULE FOR EVALUATION OF INDIVIDUAL QUALITY OF LIFE (SEIQoL)

The phenomenological perspective has resulted in the development of a number of measures that seek to incorporate the unique views of the individual. Normative data for a UK sample have recently been collected and national population norms on pertinent domains of quality of life and the relative importance of these domains to people with long-standing illness are available (Bowling 1996). One of the most widely used measures adopting this approach is the Schedule for the Evaluation of Individual Quality of Life (SEIQoL) (O'Boyle 1994; O'Boyle *et al.* 1992, 1993, 1995, 1997). This is based on judgement analysis and measures three elements of quality of life: what areas of life are important to the respondent, how are they currently doing in each of these areas and what is the relative importance of each of these areas to them. Using the SEIQoL, we found that, contrary to ageist expectations, the quality of life of healthy elderly community residents was significantly higher than that of a sample of healthy adults below 65 years of age (Browne *et al.* 1994). We have also reported preliminary findings from the first study applying the SEIQoL in palliative care (O'Boyle & Waldron *et al.* 1997). An important finding was the very high validity and reliability outcomes that indicate that elderly patients receiving palliative care have a particularly deep insight into their quality of life. While the SEIQoL was found to be acceptable in the palliative care setting, it is likely to be too complex for routine use. A simpler direct method of measuring cue weights (Browne *et al.* 1997; Hickey *et al.* 1996) has recently been developed. Other measures have been designed that seek to incorporate the unique perspective of the individual (O'Boyle *et al.* 1997). These include the Patient Generated Index (Ruta *et al.* 1994), the Repertory Grid Technique (Thunedborg *et al.* 1993; Dunbar 1992), the Quality of Life Index (Ferrans & Powers 1985), and utility measures of quality of life, which, although having a different emphasis, incorporate the individual perspective (Bennett & Torrance 1996).

13. QUALITY OF LIFE AND HEALTH POLICY

Assessment of quality of life and health status is playing an increasing role in the development and implementation of health policy in an increasing number of countries (Williams 1996). In the US the 1989 Congressional legislation, creating the Agency for Health Care Policy and Research (AHCPR) and its Centre for Medical Effectiveness Research, mandated the agency to undertake research on the effectiveness of medical care in terms of its impact on patient outcomes including health status and quality of life. The US Food and Drug Administration encourages the collection of quality of life effects of experimental drugs before final FDA approval. In the UK, the Department of Health (1992) suggested the following should be included in outcome assessment: survival

rates, symptoms and complications, health status and quality of life, the experiences of patients and their carers, and the costs and use of resources. Similarly, the Irish Department of Health (1994), in planning health care for the 1990s, stated that the concepts of health gain and social gain would be used to focus the prevention, treatment and care services more clearly on improvements in health status or the quality of life. Such developments suggest a new vision of the future in which the value of health care services is measured from the patient's perspective in terms of how services make a difference in day-to-day living, complementing traditional metrics based on disease status and mortality.

Quality of life data are likely to contribute to health policy in a number of areas by providing:

1. policy-relevant information for audit on the effectiveness of medical care and methods to improve it;
2. information to inform consumers (patients) regarding choices and their likely impact on outcomes;
3. information relevant for policy makers facing issues involving insurance coverage, design of benefits, organization of health-care providers and reform of payment systems.

14. HEALTH POLICY AND THE ELDERLY

Olshansky *et al.* (1993) have predicted that the demographic evolution of the population will impact on many aspects of society including the job market, housing, transportation, energy costs, patterns of retirement, nursing homes and hospice care. Some of these changes will be positive and one would expect an ageing population to be in a position to make a continuing and increased contribution to society. However, an ageing population will face a number of significant social problems. Most social security programmes are based on a pyramid structure in which large numbers of younger workers fund the system for the beneficiaries. The ageing of the population will place increased burdens on such systems.

Health-care programmes will need to be refocused. Currently the focus of the health-care system in most countries is largely on providing expensive acute care with little restraint because it is necessary for the treatment of potentially fatal illnesses. Such systems cover almost none of the expense of chronic long-term care—the need for which will grow rapidly as the population ages (Olshansky *et al.* 1993). With limited resources such a required shift in focus could have major implications not only for the funding of acute care programmes but also for other non-health related programmes such as education.

Quality of life outcomes will assume increasing importance in health for a number of reasons associated with the ageing of the population. We have already seen a tremendous increase in chronic diseases such as heart disease, hypertension, various forms of cancer, stroke, diabetes and arthritis and this trend is likely to increase. In such conditions, where cure is often not possible the focus is on relieving pain and maintaining the best possible quality of life for the

patient. The development of new technologies which are capable of prolonging the life of a dying patient raise important questions about how widely such measures should be applied, what limits should be placed on their use, and what criteria should apply in making such decisions. Quality of life considerations are central to such decisions and there is an increasingly urgent need to place such measures on a sound empirical footing (O'Boyle 1996; O'Boyle & Waldron 1997).

There is renewed interest world-wide in successful ageing, partly due to the policy concern of how to maintain people in the community for as long as possible and also to higher expectations of old age as standards of living, health and health-care increase (Bowling 1993). Darnton-Hill (1995) proposes that efforts to meet the needs of elderly people should focus on three factors: their economic security, their psychosocial well-being and their perceived health. Policy responses to the challenge of ageing populations have been remarkably consistent across countries and are underpinned by three aims: to maintain older people in their own homes, wherever possible; to provide support for family caregivers; to reduce/contain the cost to public funds. Carers are important in planning. Jones & Peters (1992) studied 256 informal carers and the elderly people they support and examined the impact of caring on quality of life. The findings indicated that community services and future policies should be oriented towards the needs of carers and their families and not solely to the needs of older people. In particular, there is a need to consider an increase in the provision of planned respite care.

Resources are finite and quality, value for money, cost containment and the evidence base for interventions are increasingly important considerations in funding health care (Muir Gray 1997). Levine (1987) points out that many patients expend more medical resources in the last few months of their lives than they do in their entire lifetime and asks the question of how much cost and effort should be expended for patients who have lost the capacity for social interaction. Measuring the outcomes of health care is essential to providing quality services at the lowest unit cost, yet current models of outcome measurement present considerable difficulties when applied to frail elderly people. The traditional medical model in which cure is the desired outcome is often inappropriate for many older people and this has resulted in the use of a functional model of health as an alternative framework. In this approach, success is primarily based on achieving maximum levels of functioning within the activities of daily living (ADL). Therefore although quality of life has become one of the principal outcome measures used in evaluating services for older people, difficulties in definition and measurement of this concept have resulted in the use of functional ability as a proxy measure of quality of life. However, ADL based criteria often fail to reflect older people's perceptions. The measurement of health-related quality of life has properly become a central concern of those responsible for health-care policy at all levels and we are still in the early stages of development, from a methodological

point of view, and still at a minimal stage of systematic application from an empirical standpoint. The establishment of orthodoxy or standardization at this delicate stage would doubtless be counterproductive in the long run, despite its attractions in the short run to those who understandably feel overwhelmed and somewhat bemused by the proliferation of such diverse approaches to this important task.

15. QUALITY OF LIFE AND QUALITY OF CARE

Williams (1996) has pointed out that the quality of life paradigm has a number of implications for the provision of high-quality care for older people. High-quality care may be defined as 'care that is desired by the informed patients or client (and family); is based on sound judgement of the professionals involved, from scientific studies and/or experience; and is agreed upon and carried out in a relationship of mutual trust and respect'. Applying such a model to the care of older persons involves a number of factors. First, since an older person's highest priority is likely to be to regain and maintain as much independence as possible, the emphasis of care must be multidimensional and fundamentally rehabilitative. Second, the involved professionals must start by recognizing that multiple complex problems (medical, functional and psychosocial) are almost always present simultaneously. Therefore, a comprehensive, multidimensional assessment and development of a comprehensive care plan are essential first steps in achieving high quality care. The third component, that of mutual respect, must recognize and respect the fundamental individuality and right to autonomy of the disabled person. Caregivers, professional and lay, often talk about and make decisions for a disabled elderly person rather than talking with and making decisions with the individual concerned. Many nursing homes institutionalize rather than individualize care, although Williams (1996) offers evidence from Scandinavia that individualization is possible. The application of quality of life and health status scales would significantly increase the contribution of patients to decisions on their own care. The potential of individualized measures such as the SEIQoL, Patient Generated Index or utility measures in this context is obvious.

16. FUTURE DIRECTIONS

Quality of life has heretofore been considered solely as an outcome measure. However, developments in psychoneuroimmunology and evidence from a number of clinical studies raise the possibility that the quality of life might influence pathological processes (Coates *et al.* 1987; Ganz *et al.* 1991; Maltori *et al.* 1995; Spiegel 1989). If this were to be the case, then interventions aimed at maximizing quality of life might also influence biological processes.

In health care, the phenomenological perspective complements the increasing emphasis on patient autonomy and informed consent. Competent and autonomous patients need to, and will make decisions

including end of life decisions based, *inter alia*, on their evaluation of the implications for their quality of life. Ideological struggles can occur between providers of care who adopt a rational objective approach to quality of life and recipients of care who view quality of life in terms of their unique personal situation.

The major social movements of our time (feminism, recognition of minorities, consumer rights, the information revolution) have initiated a serious critique of health systems and a growing concern to humanize health care (Levine 1987). This has accentuated the importance of the patient not only as the biological target for intervention but as a sentient partner in a process, the outcome of which is not only to prolong life but to maximize its quality.

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