

## EDITORIAL

### ΑΡΘΡΟ ΣΥΝΤΑΞΗΣ

#### The "social" quality of life

The historical roots of the term *quality of life* can be identified in the classical writings of Aristotle from 330 B.C. In his classical Nichomachean Ethics, he recognises the relationship between happiness-quality of life and the subjective values of individual:

"When it comes to saying in what happiness consists, opinions differ, and the account given by the generality of mankind is not at all like that of the wise. The former takes it to be something obvious and familiar, like pleasure or money or eminence, and there are various other views, and often the same person actually changes his opinion. When he falls ill, he says that it is his health, and when he is hard up he says that it is money".

The concept of quality of life has undergone various historical phases and has received many interpretations. It involves personal tastes, experience, perceptions, attitudes and beliefs concerning philosophical, cultural, spiritual, psychological, financial, political and interpersonal dimensions of everyday living. The multidimensional aspects of quality of life have often been analysed using the tools of multidisciplinary research. In the empirical literature different approaches have been developed by social scientists, politicians, administrators, economists, epidemiologists and other health scientists in order to measure and evaluate quality of life. In addition, different indicators have been used, based on both subjective and objective methodologies.

#### Subjective approaches

Theories on subjective well-being are prominent among a great number of behavioral science researchers. Psychological theories emphasise the relationship between subjective well-being, emotions and psy-

chological states. In quality of life research psychological well-being constitutes an important dimension. It is often analysed in terms of life fulfilment, mood, self worth, anxiety and depression.

#### Utility

Economists may also take a subjective view of health and they often examine the relationship between health status and health resources and draw implications on the efficiency, effectiveness and equity aspects of the health care system. Personal or subjective evaluation of health status is analysed with reference to utility. Jeremy Bentham introduced the notion of utility in the 18th century. He proposed the following definition:

"By utility is meant that property in any object whereby it tends to produce benefit, advantage, pleasure, good... Or to prevent the happening of mischief, pain, evil or unhappiness of the party whose interest is considered" (Bentham 1798) Stanley Jevons, Alfred Marschall, and other 19th century economists provided valuable theoretical and empirical contributions to the concept of utility. They argued that individuals choose among competitive goods and services. Their choice aims at the maximization of their pleasure or utility. An individual derives utility from a large number of social and economic actions, and a total utility which can be

measured in cardinal terms. At the run of the 20th century a new school of economic thought was established which argued that utility can be assessed in ordinal terms. Using the concept of ordinal utility, preferences can be measured on an interval or on a ratio scale.

In 1944, Von Neumann and Morgenstern developed the notion of expected utility and introduced the concept of uncertainty in individual choices. They argued that according to the expected utility theory individual preferences under conditions of uncertainty can be derived. The Von Neumann-Morgenstern (V-N-M) expected utility approach, because of its sound theo-



retical foundations, has been applied extensively in the literature of health economics. Torrance (1986) used the expected utility theory to develop the Standard Gamble (SG) and Time Trade Off (TTO) methods both of which are utility based approaches for measuring the health status of the population. Several variants of these approaches have been used by health economists to derive Quality Adjusted Life Years indicators, the so-called QALYs.

### QALYs

Reviewing the literature of health economics reference should be made to the classical contributions by Williams at the University of York and Torrance at McMaster University who enriched and expanded knowledge on health status measurement using QALYs methodology. Searching for a definition of what the QALYs indicators are all about, Weinstein and Stason can be quoted:<sup>4</sup>

“A health-status index is essentially a weighting scheme: each definable health status, ranging from death (...) to full health (...) is assigned a weight zero the corresponding weight, λ to yield a number λ<sub>s</sub>Y<sub>s</sub> that might be thought of as an equivalent number of years with full health – a number of quality-adjusted life years (QALYs).”

Using the above definition, several health economists attempted to combine quantity with quality of life. Quantity has been expressed as length of survival (L), e.g. number of healthy days or number of days after a transplantation, or days after a medical therapy. These measures can be easily defined in objective terms.

Quality of life has been expressed in subjective terms and it is defined as the value assigned to a day of life. Different values then can be assigned to health states U(H) concerning physical or mental states of health, or changes in treatments, or health policy decisions. The above relationship can be expressed as:

$$U(\text{Quantity, Quality}) = U\{L, U(H)\} = a L^r U(H)$$

Where: a=a constant scaling factor  
 r=a parameter showing attitude to risk  
 L=length of survival  
 U(H)=health state.

A societal perspective of quality of life measurement can be approximated by the following function:

$$W_{\text{societal}}\{L, U(H)\} = \theta \{U_A[L, U(H_A)], U_B[L, U(H_B)], U_C[L, U(H_C)], U_N[L, U(H_N)]\}$$

The societal function W depends on the quality of life measurement of all members of the society represented by A, B, C to N.

When dealing with societal values then inevitably some reference should be made to the issues of equity and social justice.

### Rawls' Social Justice

The moral philosopher John Rawls<sup>5</sup> introduced the concept of social justice and argued that:

“Justice is the first virtue of social institutions, as truth is of systems of thought. A theory however elegant and economical must be rejected or revised if it is untrue; likewise laws and institutions no matter how efficient and well arranged must be reformed or abolished if they are unjust” (Chapter I page 3).

Using utilitarian thinking he argues:

“The main idea is that society is rightly ordered, and therefore just, when its major institutions are arranged so as to achieve the greatest net balance of satisfaction summed over all the individuals belonging to it” (page 22).

Politicians and decision makers can then choose among alternative therapies or health status outcomes and compare them with their corresponding costs in order to maximize the expected welfare level of the citizens. Health outcome research in this way should not be restricted to medical parameters but should also incorporate both economic and social parameters (fig. 1).

The great challenge faced by politicians, administrators and decision makers is to make use of the available information in order to make arrangements satisfying the principles of equality and social minimum. The

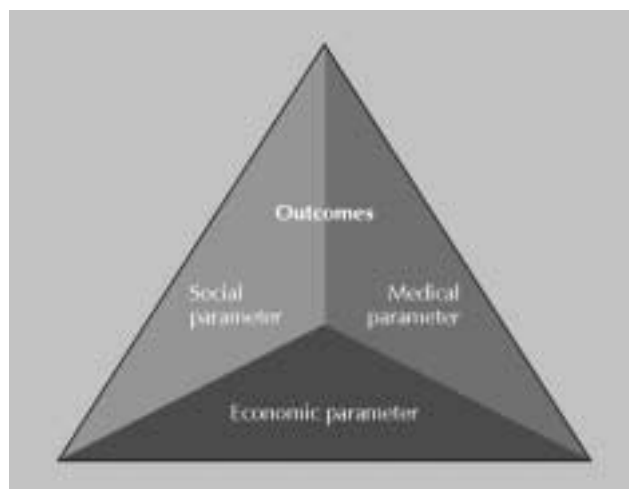


Figure 1. Health outcome parameters.

particular features of Rawls' thinking can be summarized as:

- a. He introduces the concept of "maximin" which promotes the idea of a "Just Society" when resources are allocated in such a way as to maximize (MAX) the benefits provided to the least advantaged (MINimum).
- b. There is a "veil of ignorance" in society regarding the position of each individual in the social system.
- c. His theory addresses social goods including: freedom of movement, choice of occupation, powers and prerogatives of office, set basic liberties.

Although health care is not explicitly mentioned, by taking into consideration the characteristics of health as have been described by Culyer<sup>6</sup> and Arrow,<sup>7</sup> health may be included in the list of primary social goods. Expanding this argument, different social decisions for good and bad health can be considered. Resources can then be allocated in such a way as to ensure the socially acceptable minimum health status of the poor and the needy. Despite the analytical virtues of Rawls' theory there are some important questions which seek an answer:

- a. How much priority should be given to the worst-off people in society?
- b. What indicators should be used?
- c. Who is going to define the "socially accepted" maximin?

There are many political and ethical challenges promoted by Rawls. Although fairness cannot be guaranteed, a minimum package of services distributed to all members of the society within the limits of the scarce resources could be pursued.

### Objective approaches

Objective approaches to quality of life have often been discussed in the literature of the social sciences. In anthropology and sociology quality of life has been examined with reference to social system. Here two broad schools of thought i.e. functionalism, and social quality may be distinguished.

### Functionalism

The analysis of functionalism as it was introduced by Durkheim<sup>8</sup> (1897–1951) involves the investigation of socio-cultural conditions within a social system. He perceived as "normal" a condition which was most widely distributed within the social system. Any other

unusual condition was then recognised as "morbid" or "pathological". In Durkheim's approach ill health generated by a disease is considered as a deviation from the ideal of general well-being.

The concept of normality/deviance or function/dysfunction was further expanded by Parsons.<sup>9</sup> In his thesis on "Social Systems" he defined ill health as: "a state of disturbance in the normal functioning of the total human individual including both the state of the organism as a biological system, and of his personal and social adjustments" (1951, p. 431). Health is considered in Parsons' thinking as the "optimum capacity" for the effective performance of all social roles.

Functionalism contributed significantly to the development of quality of life instruments. Many researchers have used extensively several aspects of health status measurement referring to social functionalism. Indicatively the concept of mobility may be considered, where the range function/dysfunction has been used in order to evaluate alternative states of mobility such as: "walking about freely", "walking with some help" or "being confined to bed". In addition socio-emotional aspects such as "being happy and relaxed most of the time", "being anxious and depressed some or a good bit of time" have been included in the quality of life literature.

Sen Amartya<sup>10</sup> developed an expansion to functionalism in 1982. He introduced the concept of capabilities i.e. the spectrum of activities that a person can carry out such as: "going to movies", "being in good health", "being socially integrated". Quality of life is assessed in terms of participation in the larger possible spectrum of capabilities.

### The European concept of social quality

The concept of social quality was introduced at the level of the European Union, on June 8th to 10th 1997, during the Dutch Presidency. A group of social scientists from various member states met in Amsterdam and discussed the relationship between European policy and social quality. They argued that social quality should be envisaged with the notions of fairness, social cohesion and social inclusion:

"We want a European society that is economically successful, but which, at the same time, promotes social justice and participation for its citizens. This would be a Europe in which social quality is paramount."

They proposed a common conceptual approach and supported the notion that social quality can be defined as the outcome of social, economic and political developments in Europe. They further considered the dimensions of social quality with reference to social conditions and social relations between groups, networks, organizations and the state. Finally it was argued that quality should be taken as a criterion or a “scientific yardstick” to measure the effectiveness of national and European policies.

In 1998, the same group of people decided to establish the European Foundation on Social Quality. Following research in this area they come forward with the following definition.

“Social quality is defined as the extent to which citizens are able to participate in the social and economic life of their communities under conditions which enhance their well being and individual potential. The level of social quality experienced by citizens depends on:

- The degree of economic security
- The level of social inclusion
- The extent of social cohesion or solidarity
- The level of autonomy or empowerment
- The health of European citizens”.

The interplay between social quality, health status and quality of life is clearly depicted in the above definition. The research potential to examine the theoretical foundations and to investigate these relationships empirically is paramount.

Recently the European Union addressed the issue of quality of life and attempted to investigate the factors influencing it. Figure 2 presents the findings of a Eurobarometre survey launched to 15,000 Europeans. As it is shown in figure 2, the principal factor influencing quality of life in Europe is “being in good health”. Income and family constitute the second group of factors followed by housing, friendship, job satisfaction, and stress.

### The structure of this special issue

The idea for this special issue of *Archives of Hellenic Medicine* on quality of life and QALYs grew out of several discussions with the editor-in-chief A. Germenis. The EuroQol group, with its three decades of experience on quality of life research provided the scientific environment in which the author had the opportunity to discuss relevant topics and to identify potential contributors for this special issue.

The purpose of this volume is not to present a “bible” on quality of life, but to explore the ways in which different techniques and measures are used in clinical research and population studies.

The term quality of life has many applications in different disciplines. Several scientists in different fields of applied research have attempted its conceptual justification. Inevitably, in this special issue plea Fries and Singh’s for the need for a more concise approach to quality of life measurement should be considered.

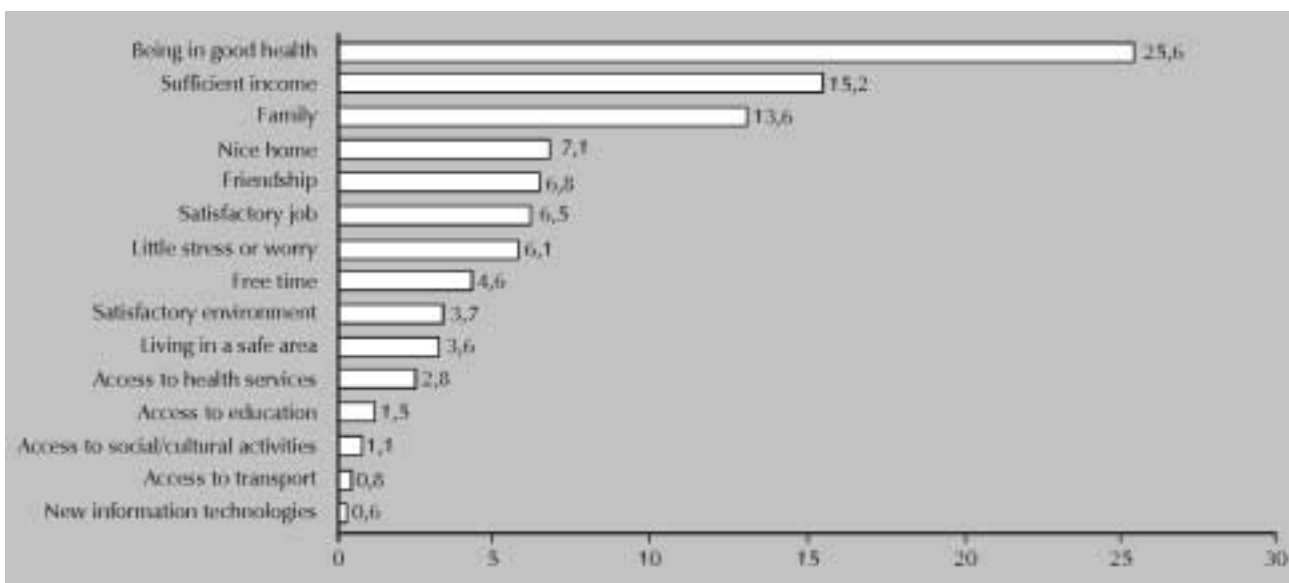


Figure 2. Factors contributing to quality of life in European Union.<sup>15</sup>

"Quality of life is a term at once pejorative and vague. The term as often used offers hope and meaning but lacks focus and precision. In the context of clinical studies, we have a restricted concept of quality of life in mind. We do not mean happiness, satisfaction, living standards, climate or environment. Rather, we are speaking topically of health related quality of life – those aspects of life quality that relate to health".

Research in this promising area is expanding at a very fast rate and it is still too early to resolve theoretical or empirical differences in perspectives, methods and techniques.

For this reason this volume was put together to introduce and expand the debate on quality of life measurement in selected countries such as Canada, Germany, Spain, Finland, Hungary and Greece.

The reader will find in the first paper a review by J. Yfantopoulos of different methods explored by various disciplines for quality of life measurement. Generic instruments used for population studies as well as disease specific techniques designed to assess the impact of alternative therapies or medical interventions upon individual health are discussed. Since the concept of QALYs has become a popular topic among doctors and economists during the last two decades, the alternative approaches to estimation of QALYs are explored and reference is made to simple rating methods such as the category and the magnitude methods as well as to utility based techniques such as the TTO and the SG.

In the second paper, authored by Roset M., Herdman M., Badia X. and Baro E., the use of Health Related Quality of Life (HRQoL) instruments is discussed with reference to Spain. HRQoL instruments measure the burden of illness in terms of quality of life. The authors strongly suggest that when a HRQoL questionnaire is developed in any country, its psychometric properties must be tested in that country in order to ensure that the questionnaire is measuring what it is intended to measure (validity). It should be shown that the scores are reproducible when the questionnaire is administered in the same circumstances (reproducibility) and that it is sensitive to real changes in health status (responsiveness).

The issue of health status inequalities and inequities in the delivery of the health care system in Hungary is discussed by Szende A. and Molnar L. They pool five interview surveys conducted in two typical Hungarian cities and three districts of the capital. Their overall sample consists of 4,083 individuals. Socio-economic inequalities in the health status of the population and

inequity in the delivery of health care in Hungary is analysed by use of the EQ-5D instrument. The authors provide evidence that despite the findings that rich people in Hungary use health care less than the poor, their use of health care is proportionally too high compared to their level of ill health.

A population based study launched in Alberta, Canada is discussed by Johnson J.A. and Pickard A.S. The authors argue that for population surveys, instead of the most commonly used health status profile of SF-36, its abbreviated version containing only 12 items (SF-12 Health Survey) can be effectively used. A postal survey was mailed to 4,200 subjects in Alberta and 1,555 completed questionnaires were returned. The instruments contained in the questionnaire were the EuroQol (EQ-5D) and SF-12. The analysis revealed that significant differences in the SF-12 composite scores were identified according to age, gender, marital status, educational and income levels.

The methodological issues concerning the translation and validation of the EuroQol in Greece is discussed by J. Yfantopoulos. The translation process from English into Greek was conducted according to the EQ-Net published guidelines. A pilot study of 30 individuals showed that the EQ-5D Greek version was comprehensive and applicable to the Greek cultural environment. A valuation exercise was conducted using a sample of 487 individuals from different demographic profiles and socio-economic backgrounds, the results of which exercise revealed that as many as 76.6% of the sample population found the questionnaire either easy or very easy to answer. The Greek values were compared with similar valuation exercises conducted in Germany, the UK, Spain, and the Netherlands and the estimated correlation coefficients revealed a high level of association between the Greek values and those of the above countries. The findings of this study confirm the EuroQol instrument as a reliable and valid measure for use in the future in clinical and population studies in Greece.

Greiner W., Obermann K. and Graf v.d. Schulenburg present J.M. the findings from a disease specific study on transplantation in Germany. They point out that during the last decade, kidney transplantation technology has reached a very high standard in Germany and other industrialised countries but the number of transplantations is very limited due to the scarce graft supply. Given the fact that health care budgets are limited, advanced and costly medical technologies need to

prove their cost-effectiveness. The study focuses on the interplay between cost, quality of life and cost-effectiveness of kidney transplantation in Germany. The sample consists of 1,149 patients with end-stage renal disease (ESRD) who were on the waiting list of the Hannover Medical School (MHH). Quality of life values were obtained using the EuroQol (EQ-5D) and the Nottingham Health Profile (NHP) questionnaires. Of this sample only 199 patients were transplanted during the 16 month study period. The cost of 77 patients was fully documented for their hospitalisation period. Comparison of direct and indirect cost for dialysis and indirect cost for dialysis and kidney transplantation and cost utility analysis (QALYs approach) was conducted. Kidney transplantation was found to be cost saving in the period of two years after operation and in addition quality of life values were higher for transplanted patients.

At the University of Helsinki H. Sintonen investigated the properties of two quality of life instruments: the EQ-5D and the 15D. Various psychometric criteria were taken into account such as feasibility, reliability, validity and sensitivity. Two data sets were considered, one from a population study and the other from a disease specific group. The first sample consists of 359 Finns people who were asked to complete EQ-5D and the 15D instruments. Correlation coefficients, multi-trait-multimethod matrices and regression techniques were explored to investigate the psychometric properties. In addition 59 patients suffering from chronic pulmonary disease were examined and their quality of life was assessed using the EQ-5D and the 15D instruments. Spearman's rank correlation was explored. The results of the study show that 15D and EQ-5D are equally acceptable for assigning values to health states but 15D is considered superior in terms of its reliability, discriminatory power and responsiveness to change.

Athanasiadis C. and colleagues report their findings from a prospective, open label, multicenter study conducted on 308 patients undergoing hip replacement in three major general hospitals in Athens. The objective of the study was to measure subjective pain using a Visual Analogue Scale (VAS). Effectiveness was measured in terms of units of pain relief via a linear VAS and effectiveness was measured in terms of units of pain relief. The clinical significance of the scores was first tested, based on an expert opinion of a 5% clinically

meaningful difference, then the statistical significance of the results was tested using one-way analysis of variance tests. Sensitivity analysis was carried out with particular emphasis on the extent of clinically meaningful differences. The results revealed that absolute pain levels in the analgesia period of patients with continuous epidural infusion were significantly lower than pain levels with per os and intra-muscular analgesic technique. It was shown that pain measurement via a linear VAS is a reliable measure which can be easily incorporated into routine pain management processes.

Skapinakis P. et al present a framework for critical appraisal in the area of evidence-based medicine (EBM). They discuss the principles and they argue that four major criteria should be taken into account: (a) study design in the epidemiological research, (b) statistical methodology used for data analysis, (c) causal inference and (d) health outcome assessment in clinical practice.

Finally this special issue addresses the development measurement of quality of life in Greece. It lends credence to the observations from European and international literature that quality of life is complex and requires rigorous scientific research. It also shows that quality of life measurement has proved to be a useful instrument for assessing the effectiveness, efficiency and equity of health care systems.

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