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THE CONCEPT OF QUALITY OF LIFE

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SUMMARY

Background

The increasing need to assess the effects of various diseases on patients' psychological and social functioning has led to a number of initiatives aimed at quantitative evaluation of quality of life (QOL). Although for some this concept is a source of much controversy, it has now become an important indicator of health. Many definitions of QOL can be found in the literature. Numerous QOL studies have endeavoured to learn more about the wellbeing of different patient groups, and especially about the effects of various medical interventions which cannot be measured by quantitative biological parameters alone.

Material/ Methods:

QOL is usually assessed with self-report measures. Rating scales were initially introduced in order to observe disease aggravation or recovery, but then began to be used to assess patients' subjective experience of illness and its effects on various psychological, social and physical aspects of patients' lives.

Results:

QOL assessment is becoming a standard component of comprehensive clinical assessment of patients with chronic diseases that can have a negative effect on every aspect of life. Correct medical intervention involves not only accurate diagnosis of the disease and implementation of adequate and effective pharmacotherapy, but also correct evaluation of all the components of QOL and level of satisfaction of patients' various medical, emotional and social needs.

Conclusions:

QOL assessment in patients may affect the improvement of global treatment outcomes. It may also lead to the reduction of the social costs of treatment, both individual and global.

Key words: chronic illness, rating scales, psycho-social factors

INTRODUCTION

Awareness of the fact that one is ill and suffering has an important individual, subjective aspect. The range and content of difficulties experienced, restrictions in daily living and related anxieties are so heterogeneous and unique that we can confidently compare them, without fear of exaggeration, to the uniqueness of human finger prints. Physicians often equate helping patients with optimization of pharmacotherapy, and their basic criterion of treatment effectiveness is level of recovery in a strictly medical sense. It is important to remember that such focus on the biological aspect of disease and clinical outcomes of drug treatment seriously limits the doctor's thinking. Helping patients involves much more than this, and includes improving the patient's psycho-social functioning, teaching the patient to find satisfaction in daily life, or more generally, to improve patients' quality of life (QOL). QOL assessment helps us to see how seriously illness is interfering with normal functioning and affecting performance of social roles. It also helps us to see what is causing tension and stress in the patient. QOL assessment helps us to determine the reasons for poor treatment effectiveness and find the most effective methods of treatment for a given patient. Finally, it has a number of tangible, economic benefits as well.

THE CONCEPT OF QUALITY OF LIFE

The term QOL was coined in the United States after World War II. At first it meant "the good life," and was limited to having or not having typical consumer goods. Good QOL meant affluence – having a car, a house of one's own or other commodities. It was a "have" category. The concept gradually evolved and its range widened to encompass life satisfaction, realisation of one's needs and aspirations and modifying one's environment in order to cope with it better. In other words, the QOL concept gradually moved from "have" to "be." In those days, high quality of life was reserved for the healthy. Only a healthy society – the argument went – can produce material and cultural goods and enable people to use them and achieve the high level of development which is the mark of better quality of life. Attention was paid to the process of QOL assessment. Finally, general QOL began to be defined as an individual's appraisal of his/her own life situation within a specific time span (De Walden-Gałuszko 1997). In other words, it is the appraisal of a fragment of one's life which takes place between the human subject on the one hand and the factors which have an impact on him/her from the external environment and the internal environment (his/her own body) on the other hand. Observer ratings are viewed as additional, complementary information. One must remember that these ratings are not free of subjectivity in the perception of reality. The importance which people ascribe to various aspects of life partly depends on the role the rater is playing in the diagnostic process and the rater's profession. Physicians pay more attention to the somatic state and

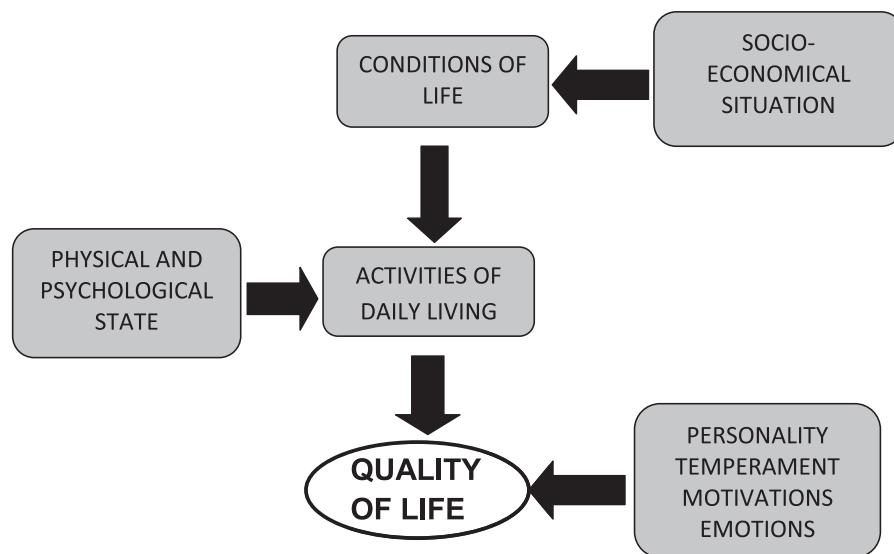


Fig. 1. Determinants of quality of life

to physical complaints which may reduce quality of life. Psychologists and the patient's family pay more attention to psychosocial dimensions. The subjective source – direct appraisal of one's situation by the interested party – is now considered the most important and most valid source of information.

So what are the determinants of one's appraisal of one's quality of life? Everyone takes several factors into consideration when appraising their quality of life. Some of these factors are objective, others are subjective.

External factors which are important for both healthy and unhealthy people include the economic situation, education, place of residence, work, family relations, and social relations. Appraisal of the life situation is mutable and depends on the rater's personality, which has been shaped by former experience and social status (Fig. 1). Temperament, which is largely genetically determined, also affects the appraisal of one's quality of life.

QUALITY OF LIFE IN MEDICINE

Researchers have paid attention to aspects of health other than biological and strictly medical since the mid-twentieth century. Karnofsky drew attention to this problem in the following words: "We can treat the cancer patient, prolong his life for months or even years, but treating prolongation of life as a measure of medical success is the critical issue" (Karnofsky & Burchenak 1949). This leads to the most difficult question of all: who wants to live in pain deprived of his most basic functions, completely dependent on the environment?

As interest in bio-psycho-social issues increased it became necessary to define and identify the criteria of evaluation of QOL in patients. Many studies

of QOL began to appear in the medical sciences in response to the shift toward a more holistic understanding of human nature, in which subjective states were also important. These subjective factors definitely affect the patient's life situation. From the medical perspective, not only is objective improvement of health very important but also the subjective quality of life.

The QOL concept began to appear in the medical sciences in the 1970s. Before that, attempts had been made to identify the various dimensions of QOL but not to associate these dimensions with QOL directly. For example, these dimensions were included in the definition of health formulated by the World Health Organisation's (WHO) in 1949. According to this definition, health was a state of complete psychological and social wellbeing. Later QOL was defined as the individual's experience of his/her own life situation in the context of his/her culture and value system, and also with respect to his/her goals, expectations and standards (World Health Organisation 1996). The authors of this definition also point out that QOL is a capacious concept and that it can be modified by many factors relating to physical health, psychological state, level of independence, and social relations, as well as personal beliefs and their relations with significant aspects of the external environment. Researchers began to refer to this definition and to equate good quality of life with subjective wellbeing, which they divided into cognitive wellbeing (judgement of life) and affective wellbeing (subjective happiness). Then they began to link quality of life, thus defined, with other variables (socio-demographic, personality and economic, life events etc.).

Efforts to define QOL more precisely finally led to the development of a new quality of life concept which could be applied in the medical sciences, health-related quality of life (HRQL). Schipper and collaborators introduced this concept to the medical sciences towards the end of the twentieth century and defined it as "the functional effect of illness and its treatment perceived (experienced) by the patient". HRQL has four aspects: physical state – somatic experience and motor fitness, psychological state, social situation, and economic conditions (Schipper et al. 1996).

These four basic dimensions are widely considered to be sufficient for the evaluation of basic components of QOL. In the broad sense, QOL means subjective appraisal of one's happiness and satisfaction with life.

Table 1. Determinants of health-related quality of life (Schipper et al. 1996)

Physical health	General state of health, effectiveness of coping with activities of daily living, frequency and severity of aggravation of illness, experiencing side effects of treatment
Psychological state	Appraisal of wellbeing, appraisal of one's fitness (depressive ideation, anxiety), problems with cognitive functioning (attention, memory)
Social functioning	Family, friends, social relations at work (superiors, subordinates)
Economic situation	Financial independence, personal income, employment

METHODS OF ASSESSMENT OF QOL

Assessment of QOL was made possible by the development of clinimetrics, the science of using rating scales to rate various clinical symptoms and phenomena (Feinstein 1987). QOL is measured by means of patient self-report instruments (questionnaires). There are two types of questionnaires – generic and specific. Generic questionnaires are universal and have a wide range of application. They can be used to study both patients and healthy individuals. They assess subjective well-being in the broad sense and the effects of illness on the patient's general functioning, unrelated to any specific disease or its level of advancement, independently of treatment methods or the demographic and cultural parameters of the studied group of patients. Generic questionnaires are used to assess and summarize patients' general health and to compare QOL in various diseases and various patient populations. These questionnaires can be used to compare QOL scores of patients with specific diseases with the healthy population and hence to assess the actual level of dysfunction.

Disease and dimension specific questionnaires are used to assess patients with specific diagnoses, and deal with aspects of life which, according to physicians and patients, are directly relevant for the disease in question or its treatment. Instruments containing combinations of items concerning both general health and specific symptoms of a disease and its treatment are very often used. The following four QOL dimensions are the ones most often studied: somatic state, psychological wellbeing, social relations and physical fitness. It is generally accepted these four dimensions are sufficient to describe quality of life (Kiebert 1997). According to some researchers, questionnaire scores do not really reflect the actual level of QOL (Leplege & Hunt 1997, Dziurowicz-Kozłowska 2002). This is because the QOL concept lacks sufficient precision and a good and generally accepted definition. They feel that the concept is too general and ambiguous. Its full range of meaning is fuzzy and imprecise. They also argue that QOL depends to a considerable extent on the socio-economic situation, the private sphere, culture, and other extra-medical factors. Overall, however, these writers admit that the concept can be useful and empirical research using this concept has its advantages.

QUALITY OF LIFE – AN IMPORTANT INDICATOR OF HEALTH

In the medical sciences the quality of life concept is used in the context of research into the health-related and non-health-related consequences of disease and also to assess the medical and extra-medical outcomes of health care and medical interventions. It is part of the broader concept of person-responsible medical care, both in the sense of prolonging life and making therapeutic efforts to ensure optimal vital activity. This is important because,

according to the WHO definition, health is more than just lack of disease or disability, it is also good physical, psychological and social wellbeing, capacity to perform social roles, ability to adapt to the changing environment and cope with change.

Quality of life is a function of the difference between the desired situation and the actual situation, i.e. it is the subjective satisfaction which a person experiences and which that person projects onto all aspects of their life (physical, psychological, social and spiritual). Irreversible deterioration of health and limited mobility lead to disabilities in activities of daily living and hence worse quality of life. The difference between the desired situation and the actual situation increases and the greater it is, the poorer the patient's ratings of his/her quality of life. This is because all activities which determine the range of independence have a direct and indirect effect on the extent to which the patient needs the help of other people and the health care system.

One of the reasons why we assess health-related quality of life is that we want to gain a deep understanding of the wellbeing of individual patients or a given patient group and to evaluate the advantages or disadvantages of specific medical procedures. By assessing QOL we gain valuable information about patients' health status, including its psychosocial aspects, and the effectiveness of our therapeutic interventions. QOL assessment also allows us to determine the clinical and economic effectiveness of medication, medical interventions and their effects on patients' lives, and to evaluate the legitimacy of costly medical procedures and the cost-effectiveness of the health care system (Dziurowicz-Kozłowska 2002).

QOL assessment can produce extremely interesting and useful results in the context of improvement of the economic effects and functioning of the health system. This system generates enormous costs. There is no limit to the amount of money the system is capable of absorbing, digesting and wasting. Hence the socially justified need to improve the economic legitimacy of the system's functioning as such. From this point of view it would be interesting and useful to take a closer look at the relations between patient QOL and the health care budget. By analysing the regression curves for these two variables we can make precise predictions concerning the limits to which pumping more money into the system is still rational and makes economic sense, and beyond which more money will not translate into proportionally more improvement in patients' quality of life. Patient self-ratings of QOL are reliable data for insurance companies, which use these data to estimate the effects of chronic illness on the cost of treatment (Pąchalska et. al. 2001). This is a legitimate application of QOL assessment. It rationalizes health system management and can help the state budget to save a great deal of money (Taylor 1995).

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