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HEALTH-RELATED QUALITY OF LIFE: THEORY AND MEASUREMENT

INTRODUCTION

The various goals that we set ourselves, be it a purchase of some material goods, getting education or a change of a health-damaging habit, have an instrumental value for us. This means that the pursued goals and the values related to them – material, educational, aesthetic, etc. – are only a means to other remoter and more general ends. The ultimate motives for our activity determine the way we live; the goals we strive for are to ensure us a better quality of life. Although 'quality of life' also has an instrumental value, it makes it possible to capture the unity of subjective and objective, individual and collective aspects of human existence. The concept of 'way of life' consisting in the evaluation of its quality enables a thorough, comprehensive treatment of essential, enduring aspects of human life regulated by various moral, ethical, praxiological or aesthetic principles.

People have always sought such a way of life that would be good for them. This manifests itself in striving for happiness, commonly believed to be particularly desirable. Science, however, is expected to explain what, if not happiness, then at least satisfaction with life depends on, as well as to determine what conditions are conducive or detrimental to it, and how these can be influenced. Quality of life comprises a number of objective factors such as state of health, level of education, income, property, relationships with others or economic situation of the country. Also, more popular terms, its measure is a subjective evaluation of one's situation expressed in particular beliefs and emotional states.

This paper points at the multi-dimensionality of the concept of quality of life, its various aspects and focuses on health-related quality of life, main fields of research and ways of measurement.

THE MULTI-DIMENSIONALITY OF THE CONCEPT OF QUALITY OF LIFE

The multi-dimensional character of human life and the uniqueness of each individual make defining 'quality of life' extremely difficult. As a result, each scientific discipline dealing with these issues introduces its own approaches, criteria and ways of measurement (Zalewska, 2003).

The concept of quality of life appeared after the Second World War in the USA. Initially, it meant 'a good life' in its consumer sense only i.e. denoted material status, and possession of goods and property such as a house, its furnishings, a car, etc. It was not until the second half of the 20th century that the category of 'have' was supplemented by that of 'be', which embraced such values as education, personal freedom or satisfaction found in various spheres of life (Tobiasz-Adamczyk, 1996).

There are many reasons for the multi-dimensionality of the concept of quality of life. Basically, the concept comprises a wide range of physical, psychological and social phenomena – virtually anything that falls under the general heading of 'happiness'. Happiness, in turn, can be approached from a naturalistic or humanistic standpoint. The former focuses on biological and mechanistic processes and views happiness in terms of pleasure, whereas the latter accentuates the conscious role of the individual, happiness being a concomitant of creativity and self-actualization. Thus, the two approaches – naturalistic and humanistic – see happiness as hedonism and eudemonism respectively (Beckmann, Ditlev, 1997).

Currently, quality of life is accepted to have two principal aspects: internal, referring to certain personal traits and skills that enable the human being to take individual, autonomous actions, and external, referring to the environmental conditions of the individual's life. According to R. J. Rogerson (1995), the internal factors are responsible for the feeling of satisfaction with life while the external ones affect internal mechanisms at the level of the individual or the community.

The concept of satisfaction or contentment with life poses a multitude of methodological problems. These concern among other things, the following areas: its semantic meaning (general quality of life, satisfaction, happiness), its scope (satisfaction overall or differentiated in various areas), making comparisons (individual or inter-personal), the perspective of evaluation (based on the whole life, focusing on past, or present), the objective of research (individual counselling, therapy, or social studies), the method of evaluation (self-evaluation or a questionnaire) (Fahrenberg et al., 1986).

VARIOUS APPROACHES TO THE CONCEPT OF QUALITY OF LIFE

The many features that recur in different definitions of quality of life make it possible to describe it as an extent to which material and non-material needs of individuals, families and communities are satisfied. Quality of life is closely related to the motivational sphere of the individual and the ability to satisfy his or her needs. According to S. Hunt and S. McKenna (1992), the needs that decide quality of life are as follows:

- eating, drinking, sleeping, activity, sex, avoidance of pain;
- warmth, safety, absence of anxiety, stability;
- love, physical contact, intimacy, communicating, sharing each other's experiences, working towards mutual goals;
- curiosity, exploring the world, approval, respect, feeling of usefulness, self-esteem, professionalism, power, independence, freedom;
- self-actualization.

The level of quality of life depends on the effective satisfaction of one's needs. Physiological needs such as eating or sleeping require absolute satisfaction while the needs of higher order can remain unaroused in some people. It is therefore necessary to compare an individual's resources with the standards that he/she aspires to.

According to A. C. Michalos (cited Kowalik, 2001), the general quality of life is the result of the discrepancies perceived by an individual in the following six dimensions between:

1) what they presently own and what they would like to own;

2) what they presently own and what they should own in an ideal situation;

3) what is available in their environment for the achievement of their objectives and what is necessary for the attainment of them;

4) the quality of their life at present and the best quality in the past;

5) what they possess and what other people possess (mainly those who constitute a point of reference for them);

6) the extent to which their personal qualities match the requirements set by their environment.

According to J. Siegrist and A. Junge (1989), any evaluation of quality of life ought to take account of three interrelated factors:

- physical (e.g. disability, pain);
- psychological (e.g. mood, level of anxiety and depression);
- social (e.g. degree of isolation from the environment, opportunity to perform social roles).

The concepts of quality of life may differ depending on the objective or subjective approach. The former emphasizes the importance of health, living standards and personal qualities of the individual related to his/her social

status, as well as the objective features of their material, cultural and natural environment. The latter concentrates on the individual's subjective feeling of satisfaction with life resulting from the evaluation of various areas of their life and life in general. Thus, as H. Sęk notes (1993), it is the individual that is the most important source of data about the actual quality of his or her life. Quality of life, then, is a subjective, cognitive and emotional actuality reflected in the feeling of satisfaction or dissatisfaction with life, and, as such, it can have the character of either a passing or enduring attitude to life (Adamczak, Sęk, 1997).

In the English-language literature on the subject, the concept of quality of life is most often identified with subjective well-being, too. The evaluation of quality of life usually includes the following four elements:

1) satisfaction with life, i.e. the level of satisfaction from the achievement of a goal (cognitive component of subjective well-being);

2) happiness, i.e. a prolonged positive emotional state (affective component);

3) positive feelings – a predominating feeling of cheerfulness (positive affective component);

4) negative feelings – a predominating feeling of anxiety, depression, distress, etc.

The components mentioned above correlate with one another, constituting in the factor analysis the so-called factor of second order. In the meta-analysis, the first two components, i.e. satisfaction with life and happiness, are treated as traits while the other two as a state (DeNeve, Cooper, 1998).

The subjective evaluation of quality of life, expressed in the feeling of contentment with life, is a result, on the one hand, of a cognitive evaluation of an individual's life, and emotional satisfaction on the other. Accordingly, S. Kowalik (1995) talks of two aspects of quality of life, one of which concerns a reflective evaluation of one's life, and the other relates to the mood felt in a given period.

HEALTH-RELATED QUALITY OF LIFE

The concept of quality of life first appeared in medical science in the 70s of the previous century under the influence of, among other things, the changing paradigm of health and health-care (Sheridan, Radmacher, 1998). Although the 20th century saw extraordinary achievements in medicine, health-care system found itself in crisis. This was due not only to economic reasons but also the changing nature of illness, from acute to chronic, whose causes were increasingly linked to an individual's lifestyle.

New methods of treatment, spectacular advances in medicine and the huge costs of treatment did not seem to directly translate into effects noticeable to the patient. This called for a change of approach – giving priority to non-material values. Accordingly, medicine's interest in quality of life has been observed to relate in particular to the examination of medical and non-medical consequences of illness, as well as the assessment of medical and non-medical effects of health-care and treatment on the patient's well-being in such branches of medicine as oncology, cardiology, rheumatology, psychiatry or gerontology (Tobiasz-Adamczyk, 1996).

Attempts at delimiting the concept of quality of life led H. Schipper (1999) to the formulation of the concept of ''health-related quality of life'' (HRQOL), which defines quality of life as a functional effect of illness and its treatment as perceived by the patient. HRQOL is a multidimensional concept embracing physical, emotional and social components relating to illness and its treatment (Revicki, 1989).

According to the experts of WHO, the concept of quality of life ought to comprise an individual's mode of perception of their material and subjective resources, information about their functioning, its assessment and the level of satisfaction with it (*WHOQOL...*, 1995). Quality of life has been defined as the perception by an individual of their position in life in the context of value and culture systems they live in, and in relation to the culture's expectations, standards and interests. It includes the following elements:

- physical condition,
- mental condition,
- self-reliance,
- social relationships,
- environment,
- religion, beliefs, convictions and views.

The above definition views quality of life from the perspective of the individual. Previously, research on quality of life focused on the objective aspect, tending to ignore the subjective one. The former includes, among other things, the state of health and socio-economic status of an individual (occupation, family income, spare time); the latter stresses the level of contentment with life, satisfaction of one's needs and participation in social structures.

The assessment of health-related quality of life commonly takes into consideration the following three elements:

1) The functional capability of an individual, i.e. the ability to satisfy their everyday needs, to take up or continue in social roles; intellectual and emotional efficiency.

2) The way an individual perceives his/her situation in life; the level of satisfaction and contentment with life.

3) Symptoms of an illness, and the general level of fitness following on the illness and age (Tobiasz-Adamczyk, 1996).

QUALITY OF LIFE IN THE HOLISTIC APPROACH TO HEALTH

The evaluation of quality of life must address both particular aspects of the individual's life as well as their life as a whole (Sęk, 1993; de Walden-Gałuszko, 1994). It is significant that the concept of quality itself carries positive connotations, as does the notion of health. Health has an absolute value, but it also has an instrumental value, i.e. it enables the individual to achieve his/her goals, most importantly, a better quality of life. To quote A. Schopenhauer, *Health, surely, isn't everything, but without health everything is nothing.*

Health, on the one hand, is treated as a general predisposition to and capability for all-round development, the ability to perform social roles and to adapt to the ever-changing environment. On the other hand, it is a process of seeking and maintaining an equilibrium continually disturbed by the pressures of the internal and external environment. Health thus conceived is the most valuable resource of the individual; therefore, its role in the shaping of quality of life cannot be overestimated (Juczyński, Ogińska-Bulik, 2003).

The holistic approach to health is based on five dimensions:

1) physical,
2) psychological (mental and emotional),
3) social,
4) public,
5) spiritual.

In comparison with the most frequently cited definition of health included in the WHO charter defining health as a physical, mental and social well-being, and not merely a lack of disease or ailment, the newer definition supplements the concept of health with public and spiritual dimensions (*WHOQOL...*, 1994).

The holistic approach differs from most other approaches in that it places a greater emphasis on the spiritual aspect. A healthy person can find meaning in their life and thus derive satisfaction with it. But achieving a better quality of life cannot be directly equated with ensuring oneself satisfactory living conditions. As P. Oleś notes (2002), quality of life measured by affluence and variety of the environment can have an influence

on the sense of meaning of one's life but does not decide it. One may have excellent living conditions, enjoy good health and yet be dissatisfied with life.

MAIN AREAS OF RESEARCH ON HEALTH-RELATED QUALITY OF LIFE

As it turns out, patients diagnosed with the same disease, having a similar medical history and prognosis can differ in respect of the sense of quality of life. A very sick person can display a greater contentment with and enjoyment of life than a person suffering from a minor ailment. The quality of life in illness, then, is not determined solely by the objective state of health. This compels one to adopt a biopsychosocial model of quality of life based on the general theory of systems, which basically differs from the mechanistic and reductionist biomedical model still predominating in medicine. Including psychosocial factors allows creating an approach that incorporates human qualities of both the physician and the patient (S h e r i d a n, R a d m a c h e r, 1998).

Psychosocial aspects of health-related quality of life include, among others, the fear of treatment and losing physical and mental efficiency, as well as the fear of losing the ability to work and provide for one's family. This is accompanied by the fear of losing one's self-sufficiency and self-reliance, the fear of social isolation and withdrawal from social activity. In this perspective, the assessment of quality of life cannot confine itself to an assessment of the symptoms or discomforts of treatment, but must consider every aspect of an individual's activity on which their illness may have an impact.

Increasing research into quality of life indicates a growth of interest in this field. A survey of research published in the years 1956–1976 in six major journals showed that issues concerning quality of life were dealt with in a few dozen studies. A similar survey carried out in 1988 contained a few thousand such studies (J u c z y ń s k i, 1998). Besides life expectancy and costs of treatment, quality of life has become a basic criterion of the quality of health-care.

Most research into health-related quality of life concentrates on the following groups of people:

1) suffering from chronic diseases (cancer, AIDS, diabetes, epilepsy etc.);
2) disabled or terminally ill requiring constant medical and nursing care;
3) living in stressful conditions (staying in hospices or refugee camps, old people);
4) suffering from personality disorders;
5) children (*WHOQOL...*, 1995).

Measurement of health-related quality of life was first used in oncology. The measurement took the following three dimensions into account:

1) functional state of the patient together with general and specific symptoms;

2) psychological dimension;

3) social aspects, such as family, social support, economic status etc.

Later on, measurements came to include the spiritual dimension (Schwarz, 1996). Measurements of health-related quality of life carried out by patients with terminal diseases comprise four areas:

1) physical efficiency as affecting the ability to function unaided;

2) somatic state reflecting the efficiency of basic physiological functions, and the somatic sensations that a patient experiences;

3) psychological condition, especially the assessment of fear and depression, and possible disorders of psychical functions;

4) social sphere reflected in the kind and quality of human interactions (de Walden-Gałuszko, Majkowicz, 2000).

With regard to elderly people, it is assumed that quality of life is related to satisfaction with life in this period (Bowling, 1995). In chronic diseases, quality of life depends on comprehensive rehabilitation (medical, occupational, psychosocial) (Tobiasz-Adamczyk, 1996). In dermatological diseases, particular attention is directed to the negative impact of physical appearance on social and interpersonal relationships (Papadopoulos, Bor, 1999).

MEASUREMENT OF HEALTH-RELATED QUALITY OF LIFE

Initially, researchers studying quality of life addressed the objective factors mainly. Economists and statisticians determined quality of life in terms of material prosperity measured by the number of goods and services that an individual could afford. Sociologists and politicians viewed quality of life as the manner and extent of the satisfaction of the individual's needs. Since people respond differently to change in their environment, and, what follows, there are virtually no objective determinants of quality of life, it was accepted that the consideration of subjective perceptions should constitute the basis for the assessment of quality of life (Farquhar, 1995). This is a consequence of people belonging to different cultures or social classes, and, most importantly, a result of the differentiation of values, attitudes and past experiences (Chamberlain, 1985).

The transference of the concept of quality of life from social sciences to medicine resulted from the inadequacy of the traditional methods of asses-

sment of the state of health (Tobiasz-Adamczyk, 1996). The focus of attention was shifted from diagnosing and treating infectious diseases to preventing and monitoring chronic diseases, during whose course the functional condition and quality of life of the patient grow in importance. The concept of health-related quality of life allowed justifying the health benefits accruing from innovative and costly treatment programmes, and alternative treatment methods. There is no doubt that research into quality of life enables a more comprehensive assessment of the efficacy of health-care, as well as a comparison of different treatment programmes. Needless to say, such an approach brings with it humanistic values to health-care.

Different approaches are used in the assessment of HRQOL, such as general vs. specific, considering one-dimension, or a broader context, or using complex scales. In the beginning, when mainly objective indicators were taken into account, such an indicator was, for example, the number of hospital beds per 100,000 inhabitants. Later on, assessments of quality of life were increasingly based on subjective indicators, which gave the assessments a more psychological character.

R. M. Kaplan and others (1989) criticize the specific approach to HRQOL, thinking that every illness or disability has an impact on the quality of life of a patient, and the purpose of the measurement is not a confirmation of clinical data but determining the impact of an illness on the patient's life in general. Therefore, the general approach is more conclusive as it does not depend on random variables such as tiredness, depression or sleeping disorders.

The more complex indicators of quality of life take into consideration various forms of everyday activity (walking, eating, getting dressed) as well as a wide influence of symptoms, emotions and cognitive processes on satisfaction with life. Besides health, these include employment opportunities, personal security, education, relaxation etc (Peterman, Cella, 2000). In some measurements, much importance is attached to the situational context, which comprises personality characteristics, the sociodemographic profile as well as personal and social resources including social support, which reduces stress and facilitates adaptation to illness and its consequences.

Within the European Organization for Research and Treatment of Cancer, a special study group was set up to study quality of life. In 1986 it started work on the preparation of special questionnaires, the basic version of which QLQ-C30 (*EORTC...*, 1995) consisted of 30 questions and also contained a few modules suited to different groups of patients. The questionnaire enables assessment of quality of life according to the type of cancer or method of treatment. Apart from the general index of quality of life, it provides indexes of the patient's functioning on the following levels:

physical, cognitive, emotional, social, performance in roles, as well as indexes of worsening of the symptoms of the following: fatigue, nausea, pain, short breath, sleeping disorders, eating disorders, constipation and diarrhoea.

SOME PROBLEMS CONNECTED WITH THE MEASUREMENT OF QUALITY OF LIFE

If quality of life is identified with subjective well-being, why not simply ask the patient him/herself? It turns out, however, that such a way of investigation can be misleading, particularly when other methods of assessment are lacking. A reliable rating of subjective well-being requires such a measurement that will minimize the role of the measurement itself during the assessment process. A measuring construct requires an operational definition i.e. specifying the rules of correspondence between the construct and the subject's behaviors. The test of a measuring construct is a procedure of obtaining a sample of such a behavior or behaviors that enable an evaluation of the construct (Anastasi, 1990).

Various factors reduce the reliability of self-assessment, which is strongly influenced by the patient's own evaluations of his/her past life events and experiences (at home, work, in marriage, medical history etc.) (Headey, Wearing, 1989). Assessment of these is made against various standards, both one's own and normative. Job satisfaction, for example, may be a result of general satisfaction with life, but at the same time itself has an impact on general satisfaction with life. Similarly, the objective state of health is related to satisfaction with life, but, according to E. Diener (1984), this relationship is not as close as that between the subjective state of health and contentment with life.

The general feeling of satisfaction with life is strongly influenced by personality and the strategies of coping with stress. Stable dimensions of extraversion and neurotism allow predicting subjective well-being for the following 20 years (P. Costa and R. McCrae cited Headey, Wearing, 1989), while the strategies of fight and denial used within 3 months after an oncological operation (as opposed to helplessness and hopelessness strategies) prognosticate 5 and 10-year survival periods (Greer et al., 1979; Pettingale, 1984).

Various adaptation mechanisms influence the feeling of contentment regardless of the direct impact of the state of health. Studies based on self-assessment often show a slight difference in satisfaction with life between very sick and healthy people, as well as between oncological patients with malignant and benign tumors. It turns out that the differences between the sick and healthy are smaller than might be expected. This also applies to

the differences between cancer patients and other groups of patients (Kalembrik, Juczyński, 2001). Even the thesis that the quality of life of cancer patients is worse than that of healthy people is not always confirmed (Haes, 1988). Cancer patients do not come out as more anxious or unhappy than healthy population, which contradicts the everyday experiences of physicians and others having contact with sick people. In a number of studies, assessment by family members and other caregivers of chronically ill patients concerning their emotional health and satisfaction with life was worse than that of the patients themselves (Epstein et al., 1989).

The construction of tools for the measurement of quality of life requires paying special attention to all those elements that relate to their reliability, validity and standardization. It is generally assumed that no single measurement is absolutely reliable; each is error-prone, each construct must be defined in operational terms i.e. in relation to the subject's observable behaviours, events in his/her surroundings and other constructs. The concept of quality of life may be defined succinctly as the assessment of the individual's life situation made by him/her at any given moment of time (de Walden-Gałuszko, 1997). The sense of a particular quality of life, then, is a result of reflection on one's life, which does not rule out the possibility that, at least with some people, the feeling of contentment with life is its good measure (Czapiński, 2002).

Psychologists studying quality of life emphasize the role of mental and emotional processes and, at the same time, increasingly concentrate on the desirable aspects of the individual's performance. This new approach called positive psychology (Seligman, Csikszentmihalyi, 2000) no doubt agrees with the ideas and objectives of modern health psychology and promotion.

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JAKOŚĆ ŻYCIA ZWIĄZANA ZE ZDROWIEM: TEORIA I POMIAR

W medycynie pojęcie jakości życia związanej ze zdrowiem (HRQOL) odnosi się do zdrowia somatycznego i psychicznego jednostki. Lekarze używają często pojęcia HRQOL do pomiaru skutków chorób przewlekłych u pacjentów w celu lepszego zrozumienia powiązania choroby z codziennym życiem chorego. Podobnie profesjonaliści z zakresu zdrowia publicznego używają pojęcia HRQOL do pomiaru skutków różnych zaburzeń, krótkotrwałych niesprawności i chorób w różnych populacjach. Celem przeglądu jest podanie podstawowych informacji na temat pojęcia jakości z perspektywy holistycznej w przekonaniu, że zaprezentowane informacje, analizy i przemyślenia mogą być użyteczne w badaniach interdyscyplinarnych.

Słowa kluczowe: jakość życia związana ze zdrowiem, koncepcje teoretyczne, pomiar.