

QUALITY OF LIFE AND MEASUREMENT METHODS

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Abstract: The publication presents the importance of methods of measuring quality of life. Particular attention was paid to objective and subjective assessments of individual spheres in relation to the values that the prosumer attributes in the healing process. Cancer, as a modern social phenomenon, significantly affects the perception and analysis of the quality of life. The article presents the evolution of research on the quality of life in terms of the fight against cancer disease. The importance of treatment, in particular rehabilitation, was emphasized.

Słowa kluczowe: jakość życia, prosument, EORTC QLQ-C30, FACT-G, AQLQ.

JAKOŚĆ ŻYCIA I METODY JEJ POMIARU

Streszczenie: W publikacji przedstawiono znaczenie metod pomiaru jakości życia. Szczególną uwagę poświęcono obiektywnym i subiektywnym ocenom poszczególnych sfer w relacji do wartości, jakie przypisuje prosument w procesie zdrowienia. Choroby nowotworowe, jako współczesne zjawisko społeczne, istotnie wpływają na postrzeganie i analizowanie jakości życia. W artykule przedstawiono ewolucję badań nad jakością życia w aspekcie walki z chorobą raka. Podkreślono znaczenie sposobu leczenia, a w szczególności rehabilitacji.

Keywords: quality of life, prosumer, EORTC QLQ-C30, FACT-G, AQLQ.

1. Introduction

The last twenty years have been a period of political and economic changes in Poland. The year 2004 brought another breakthrough: Poland's accession to the European Union. These changes caused that interest in the issues of living standards and quality of life in a changed reality came to life again.

Both during the system transformation and now, after accession to the European Union, numerous studies have been conducted (e.g. by the Public Opinion Research Center - CBOS or the Central Statistical Office) and research projects implemented (e.g. financed by the Scientific Research Committee). The presented studies draw attention (making comparisons with other countries) to the social and territorial diversity of living conditions in Poland.

Lifestyle and health-promoting behaviors, which together play an important role in the process of prosumer health modification, are also significant. These include physical, mental and educational activity, proper diet, rest and avoiding stimulants.

The occurring complications also impede normal functioning and significantly reduce the quality of life for prosumers. Due to the variety of factors conditioning the quality of life related to health, literature studies have been undertaken to present the subjective quality of life of prosumers.

Recently, the issue of quality of life has become the subject of interest for both theoreticians and creators of social life. Research often considers two dimensions of this quality: subjective and objective. Important requirements for these tests (implemented methods) are reliability, sensitivity and repeatability of results.

2. Identification of the concept of quality of life

The problem of quality is primarily that it is not a product, as he said (Varian 1992), but a feature of a specific product or service. It is difficult to capture or measure (Viscusi et al. 2000). There is also no "price for quality" but a price for goods of a certain quality.

It is believed that for the first time the concept of quality (Greek "poiotes") defined Plato as "a certain degree of perfection". Cicero creating the Latin term for the concept introduced the word *qualitas*, which came to some Romance and Germanic languages as English - quality.

Quality is a multi-dimensional term that is difficult to clearly define. There are many definitions of quality of life, they vary depending on the author and the context in which they arise. (Olkiewicz 2017) For a doctor, "a good quality of life means a condition without illness, for a philosopher it is a state of happiness, for a biologist it means self-fulfillment and maintenance of the species, and for a sick person it is a state in which he can achieve the goals of his life".

R. Kolman believes that the quality of life concerns everything that one encounters on a daily basis. He also believes that quality of life is the most important of the known varieties of quality (Kolman 2009).

However, according to Kowalik (Kowalik, Waligóra 1995), the concept of quality of life can be understood in two ways by accepting its cognitive or experience aspect. The first way assumes that a person can assess the quality of his own life based on information obtained through cognitive processes. According to Stolarska (Stolarska 2006), the cognitive sphere should include the personal definition of each patient's health. Well, he thinks that everyone has their own definition. It can take one of three forms of colloquial health concepts:

- "health means no disease symptoms",
- "health is a set of objective human traits (resources), such as resilience, constitutionally conditioned potentials",
- "health is a sense of biological well-being, psychological and social "(Sęk 1993).

Depending on the adopted personal definition of health, people may assess their quality of life differently, despite the seemingly similar situations in which they find themselves. The second way of understanding the quality of life assumes that a person can feel their own life through experiencing understood as the experience of various mental states in life.

Prosumer activity; social, professional is associated with meeting the needs and striving to achieve goals and make dreams come true with the hope of a better life, a sense of happiness or contentment. This satisfaction with life and its conditions is an individual matter, depending on many factors, including needs, aspirations and perceptions that are different for each person. The subjective sense of satisfaction with life is also conditioned by the system of values, comprehensiveness of quality of life, the so-called relative feelings of abuse (Borys 2002) and acquired experience, or awareness of fulfilling one's mission in social, professional and personal life (Skrzypek 2018; Alexandre et. al. 2009).

In the literature, satisfaction with life (its various spheres or areas of activity) is defined as the subjective quality of life (George et. al. 2016; Borys, Rogala 2008). It can be determined by the degree of satisfaction of needs or assessment of one's own life in relation to the idea of an ideal life (Borys, Knippschild 2014; Kłak 2015).

Other terms coexist with the quality of life category, including living conditions, standard of living, security (Olkiewicz et al. 2017), well-being. He ordered them T. Borys, proposing the classification of categories of quality of life according to six criteria (Borys, Rogala 2008).

In addition, quality of life is also the ability to perform everyday psychophysical functions and satisfaction with their provision. On the other hand, De Walden-Gałuszko gives definitions of the quality of life as an assessment of his own life situation, made in a given time, taking into account the adopted hierarchy of values or the difference between the real and the desired situation (Carr et. al. 2001; Walden-Gałuszko, Majkiewicz 1994; Kłak 2012).

Health according to the WHO definition is the fullness of physical, mental and social well-being, not just a lack of illness or disability. In 1994, the International Working Group set up by the WHO developed the following definition of QOL quality of life: "Quality of life

is the perception of individuals of their position in life, in the context of the culture and system of values in which they live and its relationship with individual goals, expectations, standards and interests" (WHO 1995; WHO 2002).

It was only in the 20th century that the quality of life caused huge interest in medicine. In 1948, Karnofsky (Karnofsky, Burchenal 1948) studied the degree of impairment of cancer patients. In 1960, Zubrod (Zubrod et al 1960) and co-workers developed a simple test assessing the degree of prosumer dysfunction with cancer based on determining the duration of bedtime. Initially, research on quality of life was limited to physical examination and impaired fitness associated with the disease. In 1966, a study on the quality of life of women after mastectomy for breast cancer was performed, and the results obtained for the first time, which were a subjective assessment of patients, were included in the assessment of treatment effects.

1986 was a breakthrough year in quality of life research. This year, the results of a randomized study on antihypertensive drugs including the prosumer quality of life were presented. The antihypertensive effects of the compared drugs were similar, but one drug proved to be particularly accepted by prosumers because it reduced the quality of life the least.

The concept of health-related quality of life - HRQOL (Health Related Quality of Life) was introduced by Schipper (Schipper 1980). The term defined as the 'functional effect of the disease and its treatment perceived by the patient' covers four areas: physical condition and mobility, mental state, social situation and economic conditions as well as somatic sensations.

For the purposes of the article, it was assumed that *the assessment of the state of health and the results of the treatment process should be comprehensive, because the assessment based on only one parameter (marker), most often physiological, contains many imperfections.*

In addition, the research also showed that the stage of the disease process in clinical terms does not translate proportionally into a decrease in the quality of life (Yokota et.al. 2018; Guyatt et al. 2008; Mowry et al. 2010). In a situation where two methods of therapy equivalent in terms of treatment are available, a method is chosen that improves the quality of life of a given prosumer. For the reasons mentioned above, prosumers should take an active part in making decisions about the type of therapy.

Since the jointly made decision mobilizes to follow the recommendations of the participants of the interdisciplinary team, it also allows to achieve satisfactory results in the treatment process. There is also an increase in the importance of the relationship between the prosumer and attending physician. It also allows you to effectively identify the symptoms of a particular disease, and then implement the adopted procedures. Therefore, quality of life

assessment should be the standard endpoint of clinical trials parallel to survival assessment. (Olkiewicz, Bober 2015)

The choice of the treatment process, taking into account its stages, is a complex task for both an interdisciplinary team and a prosumer. Extended survival may not necessarily be associated with improved quality of life. By definition, quality of life is a subjective concept and can only be assessed from a prosumer perspective (Olkiewicz, Bober 2016). It changes during the treatment process.

The procedures used to associate surgical procedures, e.g. with cytostatics, lead, among others, to side effects such as, for example, difficulties in food intake, pain, disfigurement. For these reasons, the effects of the disease itself and the treatment process significantly affect daily activity, reducing physical and functional fitness, also lead to moderate or severe discomfort, negative self-image, and impairment of interpersonal relationships.

Some of the works also emphasized the feeling of shame accompanying eating in the presence of other people, worse social acceptance, as well as reduced social and sexual activity. Therefore, the implemented procedures should be assessed according to standards taking into account important aspects of health and quality of life, because they determine the perceptible quality of life of prosumers (Moons et. al. 2006). Therefore, setting priorities from the prosumers' point of view is a determinant of choosing an effective (effective) treatment process.

It should also be borne in mind that the implementation of combined therapy allows to achieve local effectiveness and reduce the time of diagnostic processes, however, side effects characteristic of each of these methods of treatment are added together (Bober 2013). Taking into account the achievements of modern surgery and the so-called reconstructive surgery significantly shape the perceptible quality of prosumer life.

Contemporary medicine echoes the holistic approach to the prosumer (the process of providing medical services) taking into account important elements of his psyche. The aim of this approach is therefore not only to extend the prosumer's life, but also to improve his quality of life. In a situation where cure is impossible, the implemented processes of providing medical services should be primarily aimed at comprehensive control of significant disease symptoms and increase of satisfaction with his life.

3. Methods of assessment of quality of life prosumers

By definition, quality of life is a subjective concept and can only be assessed from the patient's perspective. Changes in the assessment of his quality of life can be a determinant of the treatment process, adaptation to specific situations or emotional factors.

Functional deficits or side effects do not necessarily correlate with the overall quality of the patient's quality of life. Multidimensional tools allow you to assess and prove the unique variety of factors associated with specific disease processes.

The most commonly used are the European Organization for Research of Life Questionnaire Core 30 Items (EORTC QLQ-C30 questionnaire) and Functional Assessment of Cancer Therapy (FACT-G) (Aaronson et al. 1993). These tools assess the overall quality of life as well as the importance of cancer and treatment effects on the patient. The collected answers are separated and summarized in relation to physical, functional, emotional and social features.

In addition to the general questionnaire, always use additional modules specific for specific disease entities, for example: the scale used to assess the impact of cancer and the treatment process on the prosumer state is Performance Status Scale for Head and Neck Cancer (PSS-HN) and the University of Washington Quality of Life Questionnaire (UW-QOL) (Letter et al. 2000). They allow assessing the patient's ability to eat, swallow, and communicate, and other sequelae that are much more severe in those treated for head and neck cancer compared to other locations. The most frequently used tool for assessing quality of life in cancer patients is the EORTC version 3.0 questionnaire, and in the case of patients with head and neck cancer the H & N-35 module is additionally used (Urdaniz et al. 2005). An additional advantage of this tool is the fact that it has been validated on the European population, including Polish, and translated into Polish.

The Asthma Quality of Live Questionnaire (AQLQ) is a questionnaire by E.F. Juniper (Juniper et al. 1992). It consists of 32 questions to be completed by the respondent or completed by a doctor during an interview. His idea is to assess the impact of the therapeutic process on the patient's daily activity. Using a scale of several degrees, you can assess: the level of physical activity, avoidance of factors affecting shortness of breath, the occurrence of night-time symptoms, anxiety, the impact of the disease on daily activity in society (Bowling 1995;). It is also recommended for use in clinical trials. In addition, E.F. Juniper has also developed the AQLQ version for children, used in numerous studies around the world.

4. Discussion

The quality of life is most often expressed in the context of the relationship between the prosumer and the environment, aspirations and possibilities and limitations of the environment. Therefore, it is a dynamic variable that undergoes transformations adequate to those existing in the area of a given prosumer and its environment and the relations between them.

Despite the fact that it is measured from the perspective of the subjective feelings of the subject, which is the modern prosumer, it covers both the subjective dimension (referring to his feelings) and the objective dimension (including the assessment of external conditions determining his development).

The subjective quality of life concerns satisfaction with certain areas of existence and life as a whole, it is associated with self-esteem, perception of control, perception of social support and optimism. In this approach, the norm is an individual evaluation system that accentuates life satisfaction, psychological well-being, the moral sphere, self-fulfillment and happiness.

Therefore, the objective quality of life includes meeting the social and cultural needs necessary to achieve physical, social and material well-being. In this sense, the prosumer's quality of life can be determined on the basis of objective indicators, such as, for example, income, cost of living, standard of living, educational options, access to medical services and others.

Both objective and subjective assessments of individual spheres of existence of an individual are relevant only in relation to the values which a given prosumer attributes to them in the healing process.

The effectiveness of treatment processes is measured by the objective response of the disease, the total survival time and / or the disease free survival time. As a result, many prosumers have access to various therapeutic options, differing in severity of side effects and individual differences in response to implemented procedures during the treatment process. Choosing the optimal treatment process is a difficult, complex task for both the interdisciplinary team (Olkiewicz 2018) and the prosumer himself.

The use of combined treatment and the possibility of alternative treatment processes resulted in the need to pay more attention to expectations and the subjective perception of their effects.

One of the factors presented in this paper are data obtained in the environmental intelligence process, which provide important information in terms of quality of life and decision-making process regarding the implemented treatment processes. They also allow you to understand the likely physical, psychological, social and functional consequences that occur in the healing process. In addition, they can also be a determinant of the decision-making process including the selection of an effective treatment process.

The adopted lists of symptoms and assessments of the prosumer's level of fitness may not include some of the essential quality of life features and insights. Therefore, it is very important to identify changes that take place over time, and thus collect relevant data in the environmental intelligence process (Bober 2013).

Analysis of the literature on the subject (Lubkin, Larsen 2013; Topór-Mądry 2011; Moons et. al. 2006; Saxena, Orley 1997;) showed that the predictive factors for assessing the quality of life are primarily the ability of prosumers to adapt to the current therapeutic regime, stable level of functioning social and accepted patterns of healthy behavior.

The quality of life is closely related to broadly understood rehabilitation (medical, occupational and psychosocial), and its satisfactory level depends on:

- type of disease and possibilities of conducting therapy,
- duration of the disease,
- prosumer age,
- individual psychophysical conditions and the patient's immunity,
- the patient's ability to undertake self-care, - resources and environmental support.

In accordance with the definition adopted by the American Commission for Chronic Illness chronic disorders are those disorders or deviations from the norm that have one or more of the following characteristics:

- have a long-lasting or permanent character,
- their etiology, course and treatment are not clearly defined,
- leave dysfunction or disability after passing it,
- require specialized rehabilitation, supervision, observation or care.

The consequences of chronic diseases are complex because they relate to different spheres of functioning and levels of organization of individual and collective life. Mostly they also create specific practical problems:

- generate rising costs of specialized medical care, which implies the development of the long-term health care sector,
- increase the level of social security benefits,
- they cause the patient's increasing physical and mental discomfort resulting from the pain, suffering, progressive limitation or loss of function.

An important measure of the effects of applied therapies and prosumer expectations in this regard, and indirectly also the effectiveness of the health care system, is the "quality of life" parameter. This parameter is increasingly subjected to subjective assessment of patients. His assessment introduces a humanistic element to health care, because this very often remains focused on the processes of providing medical services for the disease itself and reducing its ailments or symptoms.

5. Summary

Despite ongoing since the eighties increasing interest in the concept of quality of life researchers have not yet developed the social sciences, as well as the medical one, ingested by all "without reservations" the definition of quality of life. Moreover, does not have a definition that researchers could use both together in the social sciences and medicine.

The development of a common definition of the quality of life not only in medicine, but also in social sciences, and the unification and standardization of research methods would make it possible to compare obtained data in an interdisciplinary perspective. Including what is common to all research areas, would allow and facilitate the operationalization of a common definition and would provide a foundation on which researchers could construct research tools.

Therefore, despite the progress in the treatment process, due to the global, persistent increase in diagnosed disease entities in Poland and around the world, ensuring a satisfactory quality of life is a significant challenge for the health care systems of most countries.

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