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Quality of life and its measurement between subjective perception and objective assessment

جودة الحياة وقياسها بين الإدراك الذاتي والتقييم الموضوعي

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Abstract:

This article aims to illustrate the complexity of the concept of quality of life and the different theoretical approaches that explain it, while presenting the most important tools designed to measure it. The concept of quality of life is a good example of the complexity, multidimensionality, connotations and uses of the term. Quality of life is a multidimensional assessment of an individual's current living conditions in the context of the culture in which they live and the values adopted. Above all, it is a personal sense of well-being and satisfaction, in the various physical, psychological, social and spiritual dimensions. The study of the concept of quality of life from a psychological point of view has gained great importance, as a result of the realization by economists, sociologists and policymakers that life is not measured by figures and statistics, but in fact by responses and feelings. Therefore, the quality of life is evaluated under two aspects, one objective (symptoms, autonomy, etc.) and the other is subjective (psychological, social life, etc.); it is also evaluated by the patient himself.

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- *Quality of life*
- *QoL measurement*
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- *Objective assessment*

ملخص:

يهدف هذا المقال إلى توضيح مدى تشعب مفهوم جودة الحياة واختلاف المقاربات النظرية المفسرة له، مع عرض اهم الأدوات التي صممت لقياسه، ذلك أن مفهوم جودة الحياة أحد الأمثلة الجيدة على إشكالية تعقيد المصطلح وتعدد أبعاده ودلالاته واستخداماته. فجودة الحياة هي تقييم متعدد الأبعاد للظروف المعيشية الحالية للفرد في سياق الثقافة التي يعيش فيها والقيم المتبناة، إنه قبل كل شيء شعور شخصي بالرفاهية والارتياح، في مختلف الأبعاد الجسدية والنفسية والاجتماعية والروحية. وقد اكتسبت دراسة مفهوم جودة الحياة من وجهة نظر نفسية أهمية كبيرة، نتيجة لإدراك الاقتصاديين وعلماء الاجتماع وصانعي السياسات أن الحياة لا تقاس بالأرقام والإحصاءات، بل هي في الواقع ردود ومشاعر، ومنه أصبح يتم تقييم جودة الحياة من جانبين أحداهما موضوعي(الأعراض، والاستقلالية، وما إلى ذلك) والآخر ذاتي (البعد النفسي، والحياة الاجتماعية، وما إلى ذلك)، علاوة على أن تقييمها يتم من قبل المريض نفسه.

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➢ **Introduction:** According to the World Health Organization, quality of life is a combination of psychological, physical, social, and material factors, in order to assess an individual well-being.

This organization defines it; «as an 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»

Such a definition, as mentioned above, includes physical aspects, physical independence, psychological state, psychological functioning, well-being, social interactions, professional activities, and economic resources.

However, what concerns us is the health field, and then the quality of life can be considered as: « the sum of perceptions about the health status, the physiological state, satisfaction and life satisfaction» (Mac Keigan et Pathak, 1992), therefore we have excluded the professional and spiritual fields and get closer to the concept of health defined by the World Health Organization in 1947, and gave it a perceptual, situational, subjective, intimate and individual value. It reflects the point of view of the patient or the person who has to face a health issue. This point of view takes into consideration the physical, psychological and relational aspects.

This concept becomes close to another concept, which is well-being, and it is also close to the concept of happiness, as well as the concept of wholeness, which is, in short, a mixture of satisfaction, general life satisfaction, and personal well-being.

Health-related quality of life is also related to an assessment of overall health, disease progression, number of symptoms, pain, independence loss and self-esteem.

Quality of life can also be defined according to the perceived needs of patients, what are their needs and desires that should be questioned in order to assess the quality of their life. For Sonja Hunt and Stephen McKenna, each pathological situation interferes in a certain way with the ability of individuals to satisfy their needs. If the perceived needs are satisfied, the quality of life rises, and vice versa. The focal point here, is to understand the importance of patients perceived needs, not just the needs revealed by doctors.

The following is a list of important needs, necessary to satisfy them in order to reach a good quality of life;

- Eating, sleeping, activity, sexual life, absence of pain, housing, security, stability.
- Kindness, love, connection, collective sense, sense of belonging.
- Curiosity, games, creativity, the feeling that life has a meaning.
- Identity, collective recognition, respect, self-esteem, Self-fulfillment capacity.

The interest in the health field, does not dispense with taking even a brief look at other approaches, but before that, we will refer to the concept of quality of life, then we present the most important approaches that have interpreted this concept, each from their perspectives.

➢ **Definition of quality of life:** It is from the definition of health given by the World Health Organization (WHO) in 1948, as: «a complete state of physical, mental and social well-being, and not merely the absence of disease or infirmity», that interest in assessing patients' quality of life has increased.

Indeed, WHO places health in a more general context. Until then, health had only been studied under objective, clinical or biological aspects (symptoms, adverse events, biological results, etc.). It will now explore more subjective aspects (feelings about the treatment, self-vision, etc.). Thus, health is no longer only related to illness or disability but also to physical, mental and social well-being. Clinicians must no longer work in the uniqueness of the disease,but in the multidimensionality of the patient.

From this new approach of health, quality of life assessment takes on its full meaning, many teams of researchers will work on the subject and present their own definition of quality of life. There is therefore no clear universal definition of the quality of life.

According to the research's teams, quality of life is defined as:

- "A global individual satisfaction with life and the overall sense of personal well-being".
- "The Subjective perception of satisfaction or happiness with life in areas important to the individual"
- "Patients' assessment of satisfaction with their current level of function relative to what they perceive to be possible or ideal".
- "A wide range of human experiences related to each other's well-being. … Quality of life is defined by subjective experiences, states and perceptions…
- The term "quality of life" goes beyond health itself, but is influenced by the individual's perception of his or her physical, psychological, social, economic and political environment."

These definitions, however, all have in common the integration of objective and subjective considerations. From these variants emerges a consensual framework in accordance with the overall framework defined in 1948 by the WHO. It is hardly surprising, then, that the definition most often mentioned is the one proposed by the WHO in 1993: « the perception that an individual has of his place in life, in the context of the culture and value system in which he lives, in relation to his objectives, expectations, standards and concerns. It is a very broad concept which can be influenced in a complex way by the physical health of the subject, his psychological state and level of independence, his social relations and his relation to the essential elements of his environment». (Septans, 2014, pp.8-9)

Finally, regardless of the definition of quality of life, the subjectivity of its appreciation is searched, as long asit's the patient himself who is the first interpreter of his feeling, according to his emotions and his environment.

➢ Theoretical Approaches of Quality of Life:

1. **The philosophic Approach of Quality of Life:** For some philosophers, happiness is the supreme goal of existence, a goal that any human being, wherever he is, seeks. However, this goal is not always achievable. For the Epicureans from Epicure; the Greek philosopher, and even modern empirical approach leaders, such as John Stuart Mill, every person seeks pleasure and avoids pain, and this understanding is not far from happiness, while other philosophers see that seeking for happiness is

frustrating, for them most people in search of happiness are the least to found it, so this quest needs to be avoided

2. **The social scientistic approach of quality of life:** Sociologists were the first to research the concept of quality of life, they distinguished between; happiness, the subjective feeling of well-being, the physical comfort feeling and life satisfaction.

   The feeling of well-being depends on two factors, the first one is external, it represents the socio-demographic and socio-economic variables, as well as life events and integration into society, and the second one is internal, such as; self-esteem, different needs and desires, perceived effectiveness, and emotional balance.

3. **The economic and political approach of quality of life:**Quality of life in its economic and political sense, refers to the good material conditions that an individual seeks to reach, for example, the American presidential candidate promised in 1932 to guarantee for all Americans «a car in the house and a chicken on every table».

   As for Flanagan (1982), who was charged with assessing the quality of life of Americans, he suggested taking into account indicators of living conditions, such as education and socio-economic level, but also aspects of subjective well-being such as perceived health, ambitions and a sense of freedom, since democratic countries with high economic development,theirs Politicians became from a while aspire to satisfy the material needs of their citizens, but are looking for how to make them psychologically happy, for the President of the United States Thomas Jefferson in the period (1809-1801), he proposed to include in the American Constitution;«The pursuit of happiness» for every American citizen,so it's confirmed again that the concept of quality of life and psychological satisfaction cannot be reduced to quantitative objective aspects or only to qualitative subjective assessments.

4. **The medical approach of quality of life:**The recent developments in the field of medicine, prevention and various social sciences, have shown the difficulty of giving a comprehensive definition of the concept of health. The appropriate definition can only be relative, based on observations and assessments that take into consideration, the individual in his or her concrete social interactions with his or her physical, psychological, cultural and social environment.

   Perhaps the Arabic proverb that says; «Health is a crown over the heads of the healthy, only the sick can see», is the best expression of the ambiguity and mythology surrounding this word, which some sees it as «the most valuable properties» and «it is a well-being feeling, clear thought, easy and subconscious digestion, and normal sleep», In this regard, Leriche says: «Health is life under the silence of organs».(Lazorthes, 1998, pp.351-352).

The lack of concern for body care, goes with some one's perception of the health situation, but sometimes this silence may be referred to symptoms. The disease may exist even in the absence of pain and functional disorders, which leaded"Knock" to «consider health as an intermediate state between two diseases, and every healthy individual, is a sick ignorant one, for me, health is just a word that might be appropriate to be deleted from our vocabulary, and I only know sick people who vary in the degree of their illness. Modern functional biological tests often reveal people who appear to be in good health, but are in fact carrying diseases in their subclinical stage, in the other hand, other individuals complain of various subjective symptoms such; as pain, psychosomatic disorders and visceral imbalances, when biological investigations show that they do not suffer from any injury.

Some note that since the development of pathology, we no longer use the term "disease" except in the plural, but we still use the word health in the singular, and it may be better to

use it in the plural, since a half century ago, specialists in diabetes began to talk about what they called the "insulin health" of diabetic patients, who are having a good diet and treatment.

The above case is not unique. Many people carry diseases, but they control them to the point where they can be considered to be in a state of therapeutic health, (It may be surgery, for example), but they soon return back to their first state, so they move like all of us from the state of health to the state of illness and then they return again to the state of health. These individuals are in a state of health despite their illness because they are treated, and like them they form the absolute majority of the adult population, because when people reach a certain age, it becomes extraordinary that there is no vision disorder or dental decay, as it is the regular examinations of the population indicate the prevalence of heart disorders, blood pressure and other diseases among them.

The results of many social, anthropological and medical research indicated cases, that were considered pathological in some societies and at some technological levels, and were considered not pathological cases in other societies, for example; There's a common infectious disease in some tropical areas, and because it's popular and prevalent, people don't consider it as a disease at all.

Also, a spreading illness was found in one of the American Latin tribes, with symptoms showing spots of different colors on the patient's skin, and as a result of its widespread, the Indians from this tribe looked at those who did not have colored spots on their skin as unusual or abnormal, those were the same persons considered by the doctors as normal, healthy, free from the deployed diseaseamong the members of the tribe.

This was probably the same reason that weakens doctors and health care workers resistance impact, in a disease such the schistosomiasis. The high prevalence of the disease in the Egyptian countryside, makes many rural people indifferent with the health instructions that guide them, and simply take its symptoms without caring about the disease and the treatment, unless if that disease evolves in to a serious condition, difficult to treat by then (Ramdane, 1985).

For Ayoub (1985) cited by Boumediene (2004), People's health condition assessment, is not easy and direct. Rather, it seems that in order to decide that, they must make comparisons in their minds before reaching the required answer, that is, they compare their present health situation with what it was in the past, and they compare between their condition and other people condition with the same age, linking their health condition with their lifestyle, and between their hopes and aspirations for the future, for that , they are trying to identify the possibility of achieving these ambitions through their health condition ,so, they do not measure objectively their condition as measured by a doctor, for example, but rather they measure it subjectively, which is broader than objective measurement.

A number of studies results, indicated that, what concern an individual to determinate himself, is his health condition and its assessment, and that his behavior and attitudes depend's on it, which means that, a person's vision of his own health condition, has more influence on his health-related behavior, than his (objective) health condition as estimated by the medical examination (Boumediene, 2004).

It is clear now, that every individual has an idea, even intuitively, of his state of health. He knows or thinks that he knows that his health is good or bad.

Other studies, also indicate that social groups within a single society, vary in their speeches on the topic of health, the study of Bouziani and others in Algeria show, that health

represents for women from modest social environment, a reference value, it is “everything”, it is “richness nothing like it", "something that is essential in life".

Such a perception of health has a meaning, it expresses the problems of daily life that women in general must face, since women are at the bottom of the socialhierarchy, facing poverty, high cost-of -living, bureaucracy and lack of transparency in social institutions, they have nothing left but to hang on to this precious capital, which is health.

In the same study, a sample of employees in Oran indicated, that health represents for them an "ideal", "body and mental well-being", "it’s happiness", "it’s life", here the perception of health appears more abstract.

Perhaps the most important definition of health is the one given by the World Health Organization, which includes full integrity of the following aspects:

- The physical aspect: it is concerned with all physical, bio-chemical and anatomical aspects.
- The psychological aspect: it is determined by the criteria of coexistence, behavior, and psychological functions.
- The social aspect: it is related to the integration of the individual and his adaptation to social standards and requirements.
- Absence of any disease or infirmity.

In addition to the previous "objective" definition of health as defined by; medical diagnoses, expert reports, external judgments, biological and social criteria, the individual subjective feeling of himself that he is not ill, or what we might consider as "subjective-health", is also important in this procedural definition, which includes physical, psychological and social aspects.

In light of the above concept of health and its relativity, came the concept of quality of life, to complete it at times and compensate for it at some others times. Accordingly, doctors and researchers in the field of public health and epidemiology have contributed to the remarkable success of the concept of quality of life, the development in the treatment of infectious diseases, leaded to an increase in people’s age, but in return, chronic diseases with physical, psychological and social effects have increased, affecting the psychological comfort of patients more than threatening their lives, for that, it is necessary to protect the quality of life of these patients and build tools (scales and tests), to assess the psychological, physical and social effects, as well as the impact of treatments and medicines associated with these diseases.

Therefore, a scientific and social debate arose about the different qualitative types of treatment for chronic diseases, in terms of patient's comfort, not only by the number of additional years their lives. Cancer, for example, an evolutive disease, requires heavy and painful treatments such; chemotherapy, surgery, immunotherapy and radiotherapy, which are often effective treatments, but in turn, they negatively affect the patient's normal life because of their side effects.

The palliative care given to patients at the end of their lives, have become better than heavy and painful treatments, and the most important thing is the patient's benefit, not the modern technologies or the type of treatment.

In the recent years some have gone so far, as to talking about the right to administer death (the euthanasia right), for some developmental illnesses that make the patient completely dependent on machines,however, some also talk about the extraordinary experience or adventure of the disease. A new awareness has emerged among patients in developed countries of the need to involve them in decisions related to their treatment, also grow's on theme suspicious about the modern medicine capabilities. In France, for example, there is a social debate about the cost of services provided to patients in exchange for their quality of life, in what has become called «utility analysis», which means the necessity of using high-cost techniques in exchange for a bad patient quality of life.

For several years, it has been a conviction among researchers in the field of public health, that the quality of life, that depends on the objective functional state of patients, also depends on subjective satisfaction, which are two different measures , and the correlation between them is so tiny, for the patients as for the general public, and then came the definition of the World Health Organization as the inherent state of physical, psychological and social well-being, and not just the absence of disability or disease.

The Perception of symptoms and the decision to consult the doctor, and commit to his instructions, all depends on the patients' perceptions mor than on their real functional condition. (Bruchon-Schweitzer, 2002, p.36)

4. **Quality of life measurement (assessment):**The quality of life is essentially subjective, and its measurement cannot be deduced exclusively from objective measurements of the conditions of life. It is generally recognized, that subjective and objective measures of quality of life are not strongly correlated with each other, so a valid study of the conceptualization and measurement of quality of life, requires careful investigation of both objective and subjective factors. This aspect underlines the importance of a subjective assessment of the life experiences of people themselves, because personal beliefs influence what is considered important about how to view the world (Schalock, 1990).

So, there is a clear difficulty in how to measure the concept of quality of life for many reasons, most important of them is; the presence of many definitions about it, which have evolved over time. Only some researchers formulated the idea of quality of life; around the concepts of physical and social functioning, and the individual limitation in playing his role, as a consequence of the physical and the emotional problems, or because of his mental health, or a lack of energy and vitality, or even more for the individual's general awareness of his own health condition.

For this purpose and in order to better understand the concept, Flare field (1990)determined four basic dimensions of health:

- The psychological dimension (mood, emotional stress, adaptation to illness).
- The social dimension (relationships, recreational social activities).
- Work dimension (paid or unpaid work).
- The physical dimension (movement, pain, sleep, appetite). (Leplège& coste, 2001, p.21)

Although, some researchers believe, that the quality of life in its current form , has being conceptualized since 1975, with the exacerbation of chronic diseases (cardiovascular diseases; pulmonologist, neurological diseases, AIDS and psychological diseases), also the aging of the society, the increase in the number of people with disabilities due to accidents among young people and the emergence of plastic surgery, have all helped the concept of quality of life to take up a wide range in the scientific literature.

However, the first signs begun before that; in the 1940s, with the emergence of the KATZ scaleabout daily activities, and the Carnovsky scale (1948) about the physical condition of the patient.

Hence, the concept of quality of life is at the core of the concerns of those working in the health field (doctors, nurses, educators, clinical specialists), because health care at the present time in civilized countries is no longer satisfied with treating the patient medically, but rather goes beyond that to enable the patient to have a better life, so this concept has always been associated with subjective and cognitive elements. Only the individual can assess the quality of his life, what is important to him, his values and beliefs, as well as his condition over the years.

In conclusion, the concept of quality of life is an abstract, complex and multi-dimensional concept, linked to several other concepts such as well-being, financial ease, achievement ofobjectives and satisfaction. So, there is nota global definition, but researchers on the domains that affect individual's quality of life of, which are:

1. Health status and disability severity
2. Psychological and spiritual aspects
3. Family and the environment
4. Socioeconomic level. (Formarier, 2007, p.03)

Given the complex nature of the concept, the assessment of quality of life is a complex undertaking requiring multiple measures to capture subjectivity and multidimensionality. Various instruments have been developed to measure the above domains, adding the subjective parameters considered necessary for a comprehensive assessment of quality of life.

The most widely used instruments are either generic (general standards), which provide an overall assessment of the impacts of health status, or specific (qualitative standards), designed to measure particular aspects of QoL, such as QoL related to oral health, visual function, cancer, HIV, etc. (Pequeno, et al, 2020, p.02)

This classification of instrument that measure the quality of life, resulted in two concepts which are: the concept of Global QoL, and the concept of health-related quality of life (HRQoL).

However, it is noticeable in these instruments, whether general or qualitative, that they do not always reflect a match between their designation and the dimensions they measure. It may appear from the name of the scale that it is a general measure of the quality of life, and is classified as such, while its content measures the quality of life in disease state, as in the case of the scale developed by (Leplège, 1999).

In the following, we will briefly present some of the most used instruments.

- ✓ **Sickness Impact Profile:** This profile was developed by (Bergner et al, 1981) to measure the effect of the disease, on physical and psychological functions. This scale consists of (12) dimensions in (136) questions, he focused on measuring the limits that the disease exercises on those functions through, certain indicators suchas; movement easily and the ability to do usual activities, and also through other indicators measuring the influence on the psychological functions level such as; emotional state and relationships with others.

This scale is concentrating on describing the degree of harm and impairment, practiced on aspects of an individual's life, through behavioral changes actually observed and not the description of the disease itself or its clinical symptoms.

The total score on this scale is estimated, based on the total answers recorded in the physical and psychological dimension, to reflect the impact of the disease. The individual subject to this scale, is classified according to the score obtained compared to the general average observed (clinically), among the members of the same group of people affected the same disease. This profile has an acceptable validity and reliability, which they were confirmed by the study of (Chwalaw, 1993).

In addition to its length and the time it takes in the application process, this scale is more concerned with assessing the health status after the disease affection, more than with measuring the quality of life.

Also, the estimation process takes a normative character, when it does not depend primarily on the individual's impressions about their own health status appraisal, and instead, it made a clinical comparison with those in the same ill category of patients.

- ✓ **Nottingham Health Profile (NHP):**It was suggested by (Hunt et al, 1981), in the form of (38) questions to inquire about physical mobility, sleep, activity, pain, emotional reactions to social exclusion resulting from illness, relationships with others in general.

There searchers designed this questionnaire, by following the same steps adopted on the construction of the (SIP) scale, and it has a French version called: the Perceived Health Index of Nottingham (ISPN) by (Baquet et al, 1990).

We note that both version shave reliable and valid character, as well as shortness and easily applicable, where the questions are answered by a yes or a no.

- ✓ **Subjective Quality of Life Profile (SQLP**): It is a questionnaire consisting of (29) items to measure the subjective quality of life, through specific indicators from life lick; physical, psychological, emotional and relational domains. In measuring these dimensions, the measurement of these dimensions focuses on the quality of the individual's behavior in dealing with them, and the value he gives to each of these domains.So, this profiledoesn't care about the classification as much as, about focusing on people's lifestyle according to their impressions and their self-description of that pattern.

Therefore, the QOLmeasurement tools, differ in their designs by the individuals for whom they are designed,and according to the targets set for them**. (Azarouk,2015)**

- ✓ **WHOQOL or World Health Organization Quality of Life:**This scale, as its name suggests, was developed by WHO and, is available in two versions, one with 100 items called WHOQOL-100 and the second, the WHOQOLBREF with 26 items.

The major interest of this scale is its development in the framework of an international collaboration between 15 centers located around the world, and its development in the optics of a universality allowing to limit cultural biases.

In its full version it explores 6 areas: physical health (behavior, energy and fatigue, pain and discomfort, rest and sleep), mental health (body image and appearance, negative and positive feelings, self-esteem, thinking, learning, memory and concentration), level of independence (mobility, activities of daily life , dependence on drugs or medical aid, work capacity) social relationships (personal relationships, social mutual assistance, sexual activity), environment (financial resources, freedom and security, accessibility and quality of the health care system, domestic environment, propensity to obtain information and training, leisure activities, physical environment (pollution, noise, traffic, climate, transport) and finally the spiritual dimension and personal beliefs.

There are currently around 20 versions in different languages. This scale has the advantage of modularity, since WHO is developing additional modules thus making it possible to address specific pathologies (cancer, infectious diseases, etc.)(Moizan,2005, p.49)

- ➢ **Conclusion:** We conclude through this article that quality of life is a multidimensional self-perceived concept, which is clearly difficult to define it, not only that, but researchers and clinicians find difficulties in measuring it despite the scales and questionnaires (NHP, SIP) designed for it. It is a concept that is greatly influenced by the individual's perceptions of both health and disease, as well as the impact of the environment and culture in which they live.

Therefore, the quality of life remains relative, affected by the individual and his perceptions (the cognitive aspect), and his psychological, emotional, physical and social aspects, which has made it as a term or concept with a rich and wide field of research.

The desire to improve the health-related quality of life also has become in many contexts just as important as that, once global and exclusive, of increasing the quantity of life. This has led to a closer interest in relevant methods of measure of the concept in the health field.

Before embarking on QoL measurements, it is important to think deeply about this concept, placing it in its historical context, and observing its evolution as a multidimensional aspect of the way of life. Research in this field is increasing and arousing in both medical and social sciences.

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