

## **Ethical aspect of quality of life of palliative care patients**

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### **ABSTRACT**

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In the paper, we attempt a semantic analysis of patient quality of life, which plays an important role in evaluating the patient's condition and health. The issue seems to be the most important in palliative-hospice care, where doctors work with seriously or terminally ill patients. One of the aims of this branch of medicine is to improve quality of life. This may be achieved, among others, by recognizing the current problems the patient is facing pertaining to family and social relations, beliefs, views or religion. Moreover, by monitoring the behavior of patients and symptoms of their illnesses, the best therapy methods may be selected. Patient quality of life assessment may also enable comparing health care units of the same specialization and be used for the selection of the best standards of care.

When discussing the broader meaning of "quality of life", we caution against equating quality of life with the value of life. The main arguments are as follows: subjective character of evaluation of quality of life and, in the future, the possibility of postulates for shortening life of poor quality of life patients when funds for their treatment are insufficient. When accepting quality of life as equal to the value of life, it may result in eliminating unprotected and helpless patients and allowing only the strong to live. Later, this may result in the discrimination of seriously and terminally ill people, even those who do not wish to shorten their lives despite experiencing burdensome symptoms and being aware of the incurable nature of their illness.

**Key words:** quality of life, value of life, sanctity of life

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In addition to the fundamental paradigms of Hippocratic medicine, such as the sanctity of life and intrinsic value of life, the concept of quality of life has been used more and more frequently. The range of meanings of these terms may cause semantic confusion, often encountered in daily clinical practice. The aim of this paper was to analyze these concepts according to the theory and practice of palliative medicine.

The term “value of life” appeared in the literature during the second half of the 20<sup>th</sup> century. Initially, it was connected with the economic dimension of life and was identified as the quantity of manufactured goods. Over time, its meaning has been extended to variables related to the human environment, the sphere of mental and spiritual needs of people, their life goals, and satisfaction with health status [1].

The World Health Organization defines quality of life as “Individuals' 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 and expectations” [2, 3].

Quality of life includes the following elements:

- Physical functioning
- Mental state
- Social relationships
- Environment
- Religions, beliefs, convictions, and opinions [2].

In medicine, the concept Health-related quality of life (HRQL) is used. Introduced by Schipper in 1990, the term is multi-dimensional and comprises the relationships between patients, their disease, and the natural and social environments in which they live. HRQL is determined by health, occurring diseases, and the natural aging process. It analyzes subjective and objective determinants pertaining to the degree of fulfilling patients' needs [1-4]. Standardized questionnaires (for example: WHO, EORTC, SF-36 and others) are used to assess patient quality of life.

A clear definition of “quality of life” has yet to be determined and accepted. This term is used in both its narrow and broader sense. An example of its broader sense is the “quality of life doctrine,” associated with ethical issues of the patient's life, suffering, and death.

Currently, investigating and monitoring quality of life plays an important role in evaluating the health and life status of seriously ill people, particularly those facing impending death. Thus, it is of great importance and usefulness in palliative medicine, whose aim is to increase patient quality of life. As an essential element of describing and assessing quality of life, in clinical practice, it allows to:

- “Catalogue” a patient's particular states and conditions during treatment

- Select the best and most effective therapeutic methods in particular situations
- Compare the effects of work of different palliative centers
- Create guidelines and standards of palliative care [1, 4].

In the 21<sup>st</sup> century, along with great achievements in prolonging survival of people with serious diseases and rapid development of bioethics, a link has been made between burdensome symptoms and patient quality of life analysis. Some have argued that the life of suffering patients may be a wrongdoing. Such opinions can be found in English-language publications where the expressions “wrongful life” and “wrongful birth” - if serious developmental anomalies are found - have appeared. It seems these new terms are in line with an earlier one: “life not worth living” (*Lebensunwertes Leben*) used by K. Binding (1920), which was later improperly utilized by totalitarian systems, particularly by the Nazis, to legalize euthanasia [5]. Both concepts, **quality of life** and **value of life**, have created serious ethical dilemmas related to the beginning and the end of human life - various dilemmas if we consider the assumptions of different ethical models, of which the personalistic and - much different - utilitarian ethic views are worth mentioning [1].

Contrary to **personalistic** ethics where human life - also a poor-quality one - is of the highest value, utilitarian ethics tries to connect the value of human life with its quality, arguing that a poor-quality life may be wrongful for a patient, so he or she should have the right to euthanasia or supported suicide. It seems these postulates are included in the “life quality doctrine,” a rather new auto-construction of relative values connected with the arduous life circumstances of an ill person. It is easy to see that this attitude may serve as a strategy aimed at eliminating weak, seriously ill people allowing only the strong to survive, particularly when there are insufficient funds for the treatment and care of seriously ill people [3,5-7].

However, there is a general belief that the value of life cannot be quantified, so it should not be determined by quality of life. Life itself is an absolute value.

Consideration of quality of life is connected with sanctity of life, which may be understood in different ways and is not necessarily associated with any religion. It seems sanctity of life is primarily a result of “natural law” (*lex naturalis*) - a phenomenon closely related to human nature. The above statement is supported by our age-long search for transcendence. Examples of this are: various religions that exist from the very beginning of humankind, objects found in graves of our ancient ancestors, or the opinions of ancient

philosophers (Socrates, Plato, Sophocles, and others).

*Lex naturalis*, neither a Christian nor other religion's idea, is mainly based on **synderese**, which is the innate ability of the human brain to learn the first principles of ethics: "do good, avoid evil."

The following are main attributes of *lex naturalis*:

- Eternal
- Constant
- Cognizable
- Applicable to all people
- Superior to statutory laws
- Superior to religious laws [1,3,5,7]

At the end of this discussion on the value and sanctity of life, it is worth remembering that all actions against human nature and natural law may lead to **d e g e n e r a t i o n** and dangerous consequences, as those we witnessed in the 20<sup>th</sup> century (Nazism, Communism, new Left Wing, etc.).

It is extremely important to save each human life, because it is an indispensable condition of existence of good and other values experienced by an individual. Also, it allows the individual to fulfill his/her duties – even a person burdened with major health problems.

Death or non-existence – as a remedy to suffering and poor quality of life – must not be compared with life, including the life of a person with disability or serious illness, since these phenomena are the opposites [3, 7].

## CONCLUSIONS

Quality of life assessment plays an important role in all branches of medicine. It is of particular importance in the case of diseases we cannot cure and can only ameliorate suffering and other somatic complaints. Palliative medicine is a specialization in which quality of life is of particular importance; its main aim is not to cure the disease but to improve patient quality of life. The terminally ill patients are most at risk of death, therefore their doctors should be well acquainted with the ethical dilemmas of the end of life. We believe that understanding the difference between the meanings of basic and key terms, such as: quality of life, value of life, sanctity of life, is of great importance [4, 8-13].

We wish to emphasize that **quality of life is not a synonym for the value of life**. The value of life cannot be dependent on its quality since it is unquantifiable, an absolute value in itself [3, 7]. Value of life is anchored in sanctity of life, which is an eternal, beyond religion, natural right of a human being. History of mankind teaches us that attempts to change human nature are not effective and actions contrary to human nature degenerate people

and bring them confusion, tragedies and calamities, as was experienced by people under totalitarian systems of the 20<sup>th</sup> century [1, 12].

Evaluation of the quality of life, which is a subjective assessment, can be differently determined in the same person at the same time. Furthermore, the patient cannot always be a judge in his/her own matters; sometimes he/she may be incompetent to do so. That is why we believe the "quality of life doctrine" is a new auto-construction of relative values contrary to human nature, it is a philosophy derived from utilitarian ethics which attempts to decrease the value of life and opens the door to the legalization of abortion and euthanasia. This philosophy is detached from the medical practice and simplifies problems of life, suffering, treatment, and death. It may also be a function of substitute activities when there is insufficient funding of health care institutions treating terminally ill patients. Additionally, it may serve as a means of agitation for euthanasia or supported suicide of patients with poor quality of life, and as such, it may be a source of discrimination in the future – also those patients who want to live as long as possible notwithstanding their suffering and consciousness of approaching death [3, 12].

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