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Tanja Prođović¹, Biljana Prođović-Milojković², Miljan Krstović³, Šćepan Sinanović^{1,*}, Saša Bujanj⁴

**Palliative care – illness, dying, and death as biological-medical
and socio-cultural phenomena**

Палијативно збрињавање – болест, умирање и смрт као биолошко-
медицински и социјално-културолошки феномени

¹Milutin Milanković High Medical College of Professional Studies, Belgrade, Serbia;

²Metropolitan University, Futura Faculty of Applied Ecology, Belgrade, Serbia;

³University Clinical Center of Niš, Niš, Serbia;

⁴University of Niš, Faculty of Sport and Physical Education, Niš, Serbia

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***Correspondence to:**

Šćepan SINANOVIĆ

Milutin Milanković High Medical College of Professional Studies, 27 Cnotravska Street, Belgrade 11000, Serbia

E mail: scepan.sinanovic@gmail.com

Palliative care – illness, dying, and death as biological-medical and socio-cultural phenomena

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SUMMARY

Introduction In modern global times, the answer to the question of how to live well is palliative care. It is a type of care that is dedicated to creating circumstances in which the process of dying, and death itself, becomes a dignified and acceptable moment. The palliative approach is based on empathy, understanding, preserving the dignity of the patient, open two-way communication, but also caring for the patient's family.

Objective This article comprises three aims. First aim refers to introducing our professional milieu to the basic concepts and philosophy of palliative care. Second aim points out to the importance of multidisciplinary and comprehensive care (physical, psycho-social and spiritual) in palliative care in general and third aim was to critically consider various obstacles and resistance that exists in our environment regarding the organization of palliative care, through the prism of various models of palliative care around the world, particularly in Europe and in the regional countries. To search the literature, we used the following databases: Web of Science, PubMed, SCIndeks, Google Scholar; by keywords: palliative care; neonatal palliative care; nursing; palliative pain; national palliative care program. We presented the analyzed data using a descriptive method.

Conclusion If the right to palliative care is seen as a special human right, it can be concluded that our country lags significantly behind developed countries in this regard. Hence, the preoccupation of the author in this paper is the theoretical foundation of palliative care, with special emphasis on the multidisciplinary team. The purpose of this paper is to point out the connection between palliative care and the phenomenon of quality of life, as something that is extremely important not only for each individual but for society as a whole.

Keywords: palliative care; quality of life; social protection; multidisciplinary team

САЖЕТАК

Увод У савремено глобално време одговор на питање како квалитетно живети даје палијативно збрињавање. Реч је о таквој врсти неге која је посвећена стварању околности у којима процес умирања, а и сама смрт постаје достојанствен и прихватљив тренутак. Палијативни приступ је утемељен на емпатији, разумевању, очувању достојанства пацијента, отвореној двосмерној комуникацији, али и бризи о породици пацијента.

Циљ Овај рад обухвата три главна циља: Први циљ се односи на упознавање наше стручне јавности са основним концептима и филозофијом палијативног збрињавања. Други циљ подразумева указивање на важност мултидисциплинарне и свеобухватне бриге (физичке, психо-социјалне и духовне) у палијативном збрињавању уопште док је трећи циљ био да се кроз призму различитих модела палијативног збрињавања који постоје у земљама света, Европе и региона критички осврнемо на различите препреке и отпоре који постоје у нашој средини у вези са организовањем палијативног збрињавања. За претраживање литературе користили смо следеће базе: *Web of Science, PubMed, SCIndeks, Google Scholar*; према кључним речима: *palliative care; neonatal palliative care; nursing*; палијативно збрињавање; бол; национални програм за палијативно збрињавање. Анализиране податке приказали смо користећи дескриптивни метод.

Закључак Уколико се на право на палијативно збрињавање гледа као на посебно људско право, може се закључити да наша земља значајно заостаје за развијеним земљама по том питању. Отуда је преокупација аутора у овом раду теоријско утемељење палијативности, са посебним давањем значаја мултидисциплинарном тиму. Сврха овог рада је указати на повезаност палијативног збрињавања са феноменом квалитета живота, као нешто што има изузетан значај не само за сваког појединца већ за целокупно друштво.

Кључне речи: палијативно збрињавање; квалитет живота; социјална заштита; мултидисциплинарни тим

INTRODUCTORY CONSIDERATIONS

In addition to beautiful things, the constants in people's lives are dying, death, grief. The development of medicine in many aspects as well as technological advances have led to the

prolongation of human life [1]. However, death still finds its way to people, which is considered a frightening reality and a failure of medicine and doctors. Ever since the 4th century AD when the word hospice dates back, in ancient Greece (Latin word *hospitium* - home, hospitality) we have been trying to understand the psychosocial and spiritual aspect of the needs of sick and dying members of society [2].

The man of the modern age reacts to the challenge of death with greater fear than people from the past. Thus, for the sake of illustration, the famous philosopher Epicurus tries to bypass the mortal escape of life, defining death as "supposedly the most terrible evil". According to him, "death does not concern us, because as long as we exist, there is no death, and when death comes, then there is no more of us. Death therefore does not concern the living or the dead, because it does not apply to the former, "[3].

When curative medicine exhausts all possibilities in the treatment of a patient with active, progressive and advanced disease, palliative medicine continues with appropriate medical care. Palliative care of patients is a treatment, namely a series of specially adapted treatments that eliminate (as much as possible) the discomfort, symptoms and stress that severe illness itself brings to the patient, ie, pain, fatigue, nausea, loss of appetite, fatigue, depression, insomnia, anxiety, vomiting, stool problems, etc. The emphasis is on interdisciplinary treatment of patients and family members from the moment of learning about the diagnosis of an incurable disease to the period of mourning after the death of an individual. For these reasons, in addition to doctors and nurses, the team is joined by social workers, pharmacists, nutritionists, psychotherapists with special specializations in the field of palliative care, theologians, ie. specially trained spiritual advisors.

Quality of life (QOL) is increasingly considered the ideal of modern medicine from the aspect of bio-psycho-social point of view [4, 5, 6]. The question arises: "what is the quality of life?" [7, 8]. One of the most comprehensive definitions of quality of life is stated by Felce and Perry. They define the quality of life as overall general well-being, which includes objective factors and subjective evaluation of physical, material, social and emotional well-being, together with personal development and purposeful activity. Everything is valued through a personal set of moral norms of the environment» [8, 9]. Keith and Schalock say that quality of life can be used as a "sensitive term that provides recommendations and guidance", as a "social assembly", as an "organizational concept" or "all together" as: "a systemic framework which can be seen in the work aimed at improving the lives of individuals" [8, 10, 11]. There are

connections and differences between quality of life and similar concepts such as well-being, pleasure, satisfaction, functional status and health condition [8].

DEFINITIONS OF PALLIATIVE CARE

In Serbia, palliative care is still in its infancy [12, 13]. There are ambiguities about the terminology and the content of the hospice and palliative care [14]. "Hospice care is always palliative, but not every palliative care is hospice care." The terms palliative care or palliative treatment are most commonly used. It is often considered that palliative care is only for the elderly, only for cancer patients, only for the last few days of life.

The definition and meaning of the word "palliative" (from the Latin word: *palliatus*) heals only temporarily; solves an issue only seemingly, only for a while, which covers up, mitigates [15, 16, 17]. Palliative treatment is a treatment that seemingly removes only the external signs of the disease, and not the disease itself and its cause [16].

Although there are opinions that the term "palliative" comes from the Latin word "pallium" which means cloak, mantle or blanket [2]. This term is also translated as mask. It seems that this is the reason why the word palliative has a negative connotation in our environment, in the sense of concealing the real cause of a negative phenomenon. Such an opinion, which palliative care understands in terms of a procedure that eliminates only the symptoms, and not the disease itself and its cause, is logically correct, but it can overlook the essentially positive aspects and contributions that the palliative care program contains [18].

In medicine, the term palliative medicine is introduced by Balfour Mount of Montreal, who founded the first palliative care unit at the Royal Victoria Hospital in 1975 [19]. The etymology of the word palliative indicates that such care deals with symptoms that are "wrapped" or "alleviated" by treatment whose main goal is to improve the quality of life of patients under existing circumstances, and never to hide the effects of incurable diseases [20].

The evolution of palliative care can be roughly divided into three phases. In the first, earliest phase of development, the focus was on caring for terminally ill patients by establishing a place to die. The second, middle and key phase of development is related to the development of the modern hospice movement in Great Britain in the second half of the 20th century and Ms. Cicely Saunders. The third, modern phase refers to the present period, but it is still

developing [21]. The beginnings of modern hospice and palliative care are linked to Dame Cicely Saunders, who in 1967 founded the first modern hospice, St. Christopher's in London. The Hospice Movement, through the promotion of the principle of palliative care, has had a global impact and has led to improved standards of care for people facing a serious or incurable disease [14]. At that time, she opposed the dominance of the medical, conventional model by developing the so-called bio-psycho-social and spiritual holistic model for monitoring the needs, care and nursing of dying patients. From that period begins the development of the so-called hospice of medicine and philosophy of caring for dying people [22, 23].

In the foreign literature in the field of palliative care, the following terms are distinguished: life-limiting illness, life-threatening illness and terminal phase of the disease. In free translation, life-limiting illness refers to life-limiting diseases, ie all those diseases that lead to inevitable premature death (for example, Duchenne's muscular dystrophy). Life-threatening illness includes all those illnesses that lead to premature death but possible long-term survival (for example, children treated for certain malignant diseases in childhood). The terminal phase of the disease describes children or adults who are in the dying phase [2, 24].

The definition of palliative care has been developed over the years as the medicine has evolved [25, 26]. The World Health Organization (WHO) has most succinctly defined this term as active, overall care for patients whose disease is incurable. The WHO changed the definition on several occasions, so palliative care was a holistic and active approach, and comprehensive procedures applied in caring for the physical, psychological, social and spiritual needs of the seriously ill, as well as providing psychosocial support to the family [24] to achieving the best quality of life for terminally ill patients and their families through pain control and other patient symptoms.

The more recent 2002 definition: "Palliative care is an approach that improves the quality of life of patients and their families by tackling life-threatening problems through prevention and alleviation of suffering through early detection and unmistakable assessment and treatment of pain and other symptoms of illness: physical, psychosocial and spiritual" [24]. The patient suffers not only physically but also psychologically (fear of the unknown and unpredictable), spiritually (feelings of worthlessness, meaninglessness and hopelessness) and socially (abandonment). Thus, the notion of quality of life can only be determined by the patient himself [8]. In the field of hospice care, the quality of life is very often explained by the "Kalman gap". In 1984, Dr. Kalman graphically presented the quality of life and guidelines for improving the

quality of life (Figure 1). According to him, the quality of life is good if the expectations are in line with the current circumstances. The bigger the "gap" between expectations and possibilities, the worse the quality of life. Therefore, if we want to improve the quality of life, we must change our expectations in accordance with the possibilities of.

Palliative care can be seen as active, holistic care for the seriously ill by a multidisciplinary team [27, 28]. Palliative care is there to provide the best quality of life until the moment of death [29]; and that by [21, 30]:

- relieves pain and other symptoms of the disease,
- affirms life and all its values, but views death as a normal process,
- does not accelerate or delay death,
- integrates psychological and spiritual aspects of patient care,
- offers support to patients so that they can live as actively as possible until the moment of death,
- offers a system of support and assistance to the family,
- uses a team approach in identifying the needs of patients and their families.

MULTIDISCIPLINARY APPROACH IN PALLIATIVE CARE

Holistic palliative care is provided by a multidisciplinary team, with the patient and family members being key team members. The composition of the team varies, depending on the stage of program development or the specific needs of the patient at a given time [14]. Multidisciplinary approach implies elaborated team cooperation between experts of different education profiles (doctors of different subspecialties, nurses/pediatric nurses, dieticians, nutritionists, clinical pharmacologists, psychologists, psychotherapists and psychiatrists, social workers, theologians, i.e. specially trained spiritual counselors, educators, educator volunteers), who underwent training for palliative care [31]. The characteristics of a good team are considered to be trust, respect, honesty and support.

The author von Gunten [31] defined the basic skills that all members of a multidisciplinary palliative care team should possess, such as: adequate symptom management, empathetic communication with parents and inter-professional cooperation. Quality palliative care includes [14, 32, 33]:

- good communication,
- psychosocial and spiritual support,
- good control of disease symptoms,
- knowledge of ethical principles and ability to make decisions in accordance with those principles and existing circumstances.

PSYCHO-SOCIAL AND SPIRITUAL ASPECTS IN PALLIATIVE CARE

Psycho-social help and support in the field of palliative care refers to the effort to meet the psychological, social and spiritual needs of patients and their families [34].

The quality of psycho-social assistance provided depends on the way in which assistance is provided and created according to the individual and developmental needs of each child or adolescent separately [2, 35], on the personality traits of the support professional, and on teamwork cooperation and atmosphere that exists within the team dealing with palliative care [36, 37].

There is a growing trend that family members of seriously ill people, especially in the advanced stages of the disease, turn for help to institutions and providers of social protection services [5, 6]. Social work is focused on personal and social changes that have occurred as a result of the disease, and affect the patient, his family, social network and community. A social worker should help establish stability in the family. Social work is often cited as a profession that helps to guarantee guaranteed human rights, such as the right to care with choice and preservation of dignity, while respecting different cultures and traditions and insisting on the availability of social life. Social workers are often, among other things, the voice of the poor and marginalized in society [14]. Therefore, quality care of medical patients must be accompanied by social work and the main emphasis is on emphasizing the need for a significantly larger number of qualified social workers in health care institutions. As research

shows, the existing number of social workers does not meet even 10% of the needs. Therefore, there must be an initiative to create a Master's program of social work in health care institutions or to include subjects that would provide the necessary knowledge and skills of future social workers in this field through the existing curricula. The goals of social protection are to [14]:

1. achieve the minimum material security and independence of the individual and the family in meeting the needs of life,
2. ensure the availability of services and the exercise of rights in social protection,
3. create equal opportunities for independent living and encourage social inclusion,
4. preserve and improve family relations, as well as promote family, gender and intergenerational solidarity,
5. prevent abuse, neglect or exploitation, eliminate their consequences.

These goals are achieved through the provision of social protection services and other activities that prevent, reduce or eliminate the dependence of individuals and families on social services. This type of support also includes practical aspects of care such as finances, running a household and helping with daily life.

Spiritual support in palliative care means respecting the uniqueness of each individual and accepting the values [38], beliefs, doubts, dilemmas, concerns he has and provides through the personal relationship and contact between the spiritual counselor and the individual. Such support for the patient facilitates acceptance and preparation for death, assessment of life and completion of the life story, acceptance of one's own illness and inevitable death, facilitates parting and brings a sense of calm [39]. Useful questions that can help open various topics related to spirituality are contained in the acronym **BELIEF** (Belief, Ethics and values, Lifestyle, Involvement, Education, Future event [39]).

According to research conducted in the USA [40], a connection has been proven between higher levels of spirituality and improved symptoms in depression and addiction, heart disease, diabetes, immune system disorders and coping with chronic diseases [40]. Based on the established facts in numerous researches, spiritual support has become an important part of quality palliative care.

In that context, the joint palliative care commissions from various parts of the world and the World Health Organization called for recognizing the patient's needs of a spiritual nature, but also educating medical and other staff involved in recognizing the patient's spiritual needs. In their recommendations, they state that spiritual support should be at the heart of the health composition.

VALUES AND ETHICAL PRINCIPLES OF PALLIATIVE CARE

The ethical principles that guide and respect palliative care in practice are [41]:

- Autonomy, ie the right and ability of man to make independent decisions;
- Justice, ie. fair use of available resources, moral and social principles on which respect for justice is based without discrimination or prejudice;
- Benefit, ie doing good;
- Primum non nocere, ie not to harm.

Solving dilemmas and making the right medical and ethical decisions requires medical knowledge and skills, as well as understanding and accepting basic moral values and ethical principles. As professionals, we are obliged to ask ourselves whether our decisions are in accordance with the patient's will (autonomy) and in his best interest (welfare), and whether we will in any way harm the patient (primum non nocere) or society (justice) [41].

Considering that neither a successful cure nor recovery is expected in the seriously ill, the question arises, what can palliative care offer? Control of pain and other physical symptoms are basic interventions because it is important that the patient feels as comfortable as possible, which means no pain, no unpleasant symptoms, can sleep, can ingest fluids and food (depending on the stage of the disease) with maintaining hygiene. Pain as the dominant symptom in many conditions/diseases requires continuous monitoring. The assessment of pain and discomfort in patients has its own specifics, given that the self-assessment of the suffering they experience is often lacking. There are many and varied signs of the patient's suffering: painful grimacing observed on a furrowed and/or bulging forehead, wrinkling of the nasolabial fold, squeezing of the eyes, disturbance of physiological parameters (increase in heart rate, decrease or increase in respiration per minute, altered respiratory amplitude, apnea crises,

decrease in hemoglobin oxygen saturation, increase in arterial tension, increased intracranial pressure), altered body position and movement patterns in bed, altered sleep dynamics. Also, biochemical markers that appear in response to painful experience, suffering and stress can be measured: cortisol level, endorphin level, glycemic value, and other parameters [31, 42]. These inadequately manageable symptoms are called refractory symptoms and differ from other difficult-to-treat symptoms in that, contrary to the advice of many experts, they cannot be treated without compromising the patient's consciousness [43]. Palliative/terminal sedation can be defined as the use of sedatives (usually benzodiazepines) with or without complementary opioids given intravenously or subcutaneously to lower the level of consciousness deep enough to alleviate unbearable and persistent symptoms in patients whose life is coming to an end. These symptoms cannot be controlled in any other way. Sedation in this case is not a side effect of symptom control [41, 43].

The Ethical Working Group of the European Palliative Care Association considers palliative sedation to control symptoms justified if used temporarily [41, 44, 45], if the patient is monitored regularly and when clinically is indicated assisted hydration and feeding [46].

Knowledge and understanding of ethical principles and acting in accordance with them not only contributes to improving the quality of life of patients and their families, but also contributes to the satisfaction of professionals during their hard work, stress prevention and prevention of burn out syndrome [41].

INSTEAD OF CONCLUSION

The mutual philosophy of palliative care is based on an empathic approach, comprehensive consideration and assessment of needs and conditions with the aim of alleviating suffering and providing multidisciplinary assistance to people with life-threatening diseases, during all phases of illness and treatment. Palliative care seeks to ensure the quality of life of the patient until death, to preserve the dignity of every human being.

It should not be forgotten that one of the main obstacles to achieving quality palliative care is financial. Health systems in most countries face the problem of how to set priorities given the limited budget allocated to health. What gives hope is that in the future more and more individuals will receive good and quality care at the end of life, given the accelerated

growth in the aging population, especially noticeable in Western countries. The very philosophy of palliative care lies in the set of common values that are recognized throughout European countries. One of these values is the dignity of the patient, which in the first place means that palliative care should be performed in a decent, open and sensitive way, and special attention should be paid to personal, cultural and religious values of the individual.

No matter how palliative care takes place, within health systems that have developed national palliative care programs or are not yet the case, it should never be forgotten that the shared time that a family and their sick family member have at their disposal can be very short and limited - when missed, it disappears forever and the loss is irreparable; only painful memories remain.

NOTE

The authors declare that the article was written according to the ethical standards of the Serbian Archives of Medicine as well as ethical standards of medical facilities for each author involved.

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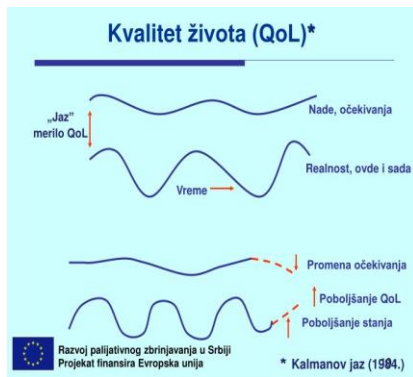


Figure 1. Kalman gap – graphically presented quality of life;

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