OPEN QUESTIONS ABOUT THE USE AND DEFINITION OF THE STATUS OF A PALLIATIVE PATIENT

Zhogno Yu.[1]*, Riga O.*[2]

NGO "ELEOS", Odessa national Medical University, Ukraine[1]
Kharkiv National Medical University, Kharkiv, Ukraine[2]

The article discusses the issue of determining the status of a palliative patient in the context of institutionalization of the national system of palliative care in Ukraine and the statistical obscurity of palliative patients. The definition of "palliative status of a patient" is studied using the materials of scientific Ukrainian and foreign sources. Semantics of the concepts of "status", "patient" and "palliative" are featured. The criteria for determining the patient's palliative status and its differential diagnosis are discussed using modern approaches to its categorization. Recommendations for determining the patient's palliative status, including that of a child, were developed.

Conclusion. The question of the status of a palliative patient still remains unanswered in practice, especially when palliative care is not finally institutionalized as an integral part of both clinical practice and collective consciousness of Ukrainian society.

Key words: palliative care, status of a palliative patient, discrimination.

As it has been emphasized by the World Health Organization (WHO), the global need in palliative care (PC) will continue to increase as a result of the growing burden of non-communicable diseases and the continuing aging of the population [1]. The WHO also recognizes that of the 40 million people on the planet who require PC annually, only 14% receive it (data of 2011), which is the evidence of a low level of PD and pain relief accessibility and is a sign of the global humanitarian crisis [2]. Unfortunately, most patients requiring PC do not receive it [3, 4, 6]. This situation, in our opinion, has a predictor of a methodological, cultural and bioethical kind that requires some theoretical and practical elaboration. Moreover, the complexity and inconsistency of the definition and differential diagnosis of palliative patient status (PPS), the question of its diagnostic limits and classification complicates the introduction of PC, which is accompanied by a certain degree of misunderstanding among the medical community, patients and their families.

In the United Kingdom and the United States, where PC system is institutionalized, the project of the National Consensus on PC Quality Improvement emphasizes its "importance ... as a viable option for patients of any age with a life-threatening, debilitating chronic illness or injury" (cit. in [3; 7]). Such phenomenological descriptions, lack of specificity, normalized unambiguous determinants and practical recommendations in a language unified to specialists of a certain national health and social protection system that would enable the patient identification as a palliative and provide him with the necessary PC services. The necessity of terminological unification and standardization for the greater accessibility of PC, was emphasized by the WHO in 2009 [1; 278]. It should also be noted that such terminological interference, according to the WHO, is also observed with the methodology used for the global assessment of disability, which is still not up to date and is being improved [8].

The aim of this work was to raise the problem of determining the clinical and legal boundaries

---

Corresponding Author:
Zhogno Yu., PhD in psychology,
Head of NGO "ELEOS", Odessa, Ukraine,
e-mail: zhuyrii@gmail.com

of the concept "patient's palliative status" in Ukraine, which increases the PC accessibility and prevents statistical obscurity of palliative patients.

The object of the study was the definition and differential diagnosis of the status of a seriously ill (incurable) patient.

The method of research was content analysis of scientific literature on the semantics, legal and clinical content of the concept of "patient's palliative status".

Conflict of Interest. The authors state that there is no conflict of interest.

Results and discussion. In Ukraine, there is a clinical protocol that addresses the issue of PC, but at the same time there is insufficient implementation (about 25% were fulfilled fully) of Human Rights Watch's recommendations on PC standards in Ukraine. Human rights activists point out that, despite the changes in the normative framework, the legislation on PC (pain relief) is ignored by the doctors and not implemented [9]. Obviously, Ukraine "needs an immediate restructuring of the health system based on humanism, human rights, 'patient-centeredness' in the provision of medical services" [10; 1]. It is also clear that by introducing a palliative approach in Ukraine, professionals and decision makers in the health sector who are responsible for ensuring that PC is accessible to the population are faced with the problem of ***determining the palliative status*** per se, since it is extremely difficult to explain such situation using only economic reasons. We also assume that this is precisely the methodological "stumbling block", which nevertheless has the foundation of the collective consciousness of a nation that allows such a state of affairs.

Historically, PC programs focus primarily on the needs of cancer patients with a very heavy burden of aggravating symptoms [7]. Therefore, the status of a palliative patient has been discussed especially actively in cases that go beyond the traditional focus of oncology [1], or neglected because of the so-called phenomenon of "medicalization" [11; 4]. Specialists deciding on the initiation of PC, also discuss the moment at the time of the terminal stage of the disease, when PC should necessarily be proposed to the patient, because of the difficulties associated with the development of precise predictive criteria, in particular, for non-malignant diseases [4; 12]. The socio-psychological aspect of PPS is also actively debated by Ukrainian professionals and experts because of fears of a ***certain stigmatization on the basis of the presence of an incurable disease/condition***, even despite the legal possibility for the patient with a similar status to freely use pain relievers [12].

In Ukraine, since 2013, it has been legally determined that "a palliative patient is a patient of all age groups whose illness does not respond to the treatment aimed at recovery, and is accompanied by chronic pain syndrome and significant limitation of vital activity in its absence"; the legal status of "palliative" is determined by "a physician since the diagnosis of an incurable progressive disease with a predicted life expectancy "[13]. A similar definition, despite the criteria for exclusion from these medical indications: acute and chronic (infectious, mental) diseases in the stage of exacerbation, acute surgical states and conditions after surgical interventions, is obviously rather multiple and not sufficiently deterministic. The situation of statistical obscurity, obviously, originates from normative (legal) plurality and incorrectness.

In the first approximation, the meaning of PPS is disclosed clinically and can be systematized by ICD-10, DSM-IV and ICF headings [14]. The features of classification of the phenomenological diversity of the palliative human state have not received the appropriate nomenclature yet, which, as a consequence, has an unambiguous diagnostic conclusion of the doctor and is the legal basis for the further route of the patient in the medical and social plane of his life. It should also be noted that the differential diagnosis of a palliative condition/disease is still not defined, and even the experts of the countries leading in the field of PC (Great Britain, Australia) in spite of the high level of achievement of their national PC systems, still discuss the questions of the clinical aspects of PPS [7, 11].

The most relevant answer to the dilemma being discussed seems to have been found by the experts from Australia and Germany in the methodology for calculating the population's needs in the PC services.

Palliative status and its derived assessment of the needs for PC are complex and controversial issues, and the corresponding methodology is improved by the gradual specification of the inclusion-exclusion criteria adjusted by regional peculiarities of the population of palliative patients, resources of regional experts. The latter, in turn, are regulated by national professional (ethical) standards, which directly reflect the level of culture and humanity of society.

It should be noted that palliative child patients occupy a special place in solving the discussed dilemma. To determine PPS in a child patient, there is "List of Lifestyle Restrictions" containing about 400 ICD-10 codes associated with illnesses that can restrict the child's life. The classification of the state as one that "restricts life" means: its dynamics can be accurately described by at least one of the archetypes set forth in the standards of the Royal College of Pediatrics and Child Health in 1997, along with the Association for child PC [15]. This catalog was obtained in 2011 by grouping diagnostic data from children's hospices and specialized groups on PC provision from all over the UK and combining these data with death certificate data [16]. As the authors point out, the catalog is not exhaustive. There are certain conditions that also limit life, but they were not included in the catalog because of the fact that they were encountered extremely rarely.

The catalog is not decisive. This is a list of conditions that can restrict life, not a list of children, who should be sent to a specialist for PC. Not every child with a condition from this list will need a specialized PC at any time, and it will probably never be necessary for some, as some conditions may be of varying degrees of severity, such as cerebral palsy; even those children who will need PC at some stage may not yet need it; not all PC needs to be provided by specialists.

The catalog is not final. What is considered "life-restricting" requires a certain subjective judgment, which is influenced by modern concepts, the availability of technologies that can change over the time. The emergence of gene therapy can make the states of the directory list curable and they will not need to be included in the list. An acute trauma, such as a road accident, on the other hand, is not considered to be a "life-restricting" state at this stage, but there are reasons to consider it as such in the future.

Consequently, such multiplicity, polysemy and etiologic diversity constitute the obligatory context of the palliative status process, which must be taken into account by the clinician. The variety of nosologies, clinical forms and pathological health conditions that according to their transfinitum have a subjective significance of destruction of autonomy and self-service abilities of the patient and, above all, a limited life expectancy and an over-threshold risk of death for the patient, in our opinion, constitute the fundamental content of the palliative status per se.

From the standpoint of multidimensionality the above clinical manifestations consider that in an individual with a palliative status, it is possible to detect a wide variety of damage at almost all levels of life: chronic life-threatening and persistent dysfunction of organs and systems of the body, including due to pain syndrome, psychophysiological exhaustion, a sense of loss of dignity and the right quality of life. Multidimensionality, criterion uncertainty, correlation with regional peculiarities of the problem of PPS determination is confirmed, in particular, by the definition of the European Palliative Care Association (EPCA) in the White Book, "... PC is required by a much larger number of patients suffering from both cancer and non-cancer illnesses. The number of these patients also depends on the incidence of different nosological forms in different countries. The duration of PC can also be different - from several days to several years, because due to the possibilities of modern medicine, PC will be needed for some patients for a longer time, and not only during the last year of life "[4; 5].

A generally accepted European definition is crucial: "PC is indicated to all patients since the diagnosis of a life-threatening or debilitating disease is made", which emphasizes the life-threatening and debilitating illness of the palliative patients"... who are constantly or periodically in a state which negatively affects their everyday life" [4; 12].

Semantically, PPS is defined using the generic concepts of "status", "patient" and "palliative". The latter two, as opposed to the first one (legal), are purely clinical. Their intersection area is denoted by the legal fact that the doctor identifies a certain illness/condition as requiring PC, thus legitimizing all subsequent clinical and social routes of a particular palliative patient. Let us consider the notion of PPS both from the legal perspective, and from its clinical presentation.

The notion of "status" (Latin status - state, position) has a social and legal connotation, and denotes a stable position of an individual within the social system, associated with certain expectations, rights and obligations [17], which is determined by a number of features (economic, professional, ethnic, etc.) [18]. The term "status" relates to the state of a seriously ill patient within the social stratification system of society, reflecting the gradual destruction of his social roles and situation with the course of the disease. For our analysis, the semantic load, the explicit (declarations and legal norms of society concerning the seriously ill patients) and the latent (the real attitude of the society to the incurably sick person), which accumulates and reflects the social system of values and morals, is decisive. Given the specific lifestyle that unites the totality of individuals in a similar status situation (incurable illness), we can talk about the corresponding status group.

Due to a limited life expectancy, the human condition a priori has a downward trend in line with the level of actual social and psycho-physiological damage. It should be noted that the notion of status has one more facet, a legal one, which implies the direct effectiveness of the constitutional rights and freedoms of any citizen, including the rights of a seriously ill person, and is ensured by the protection by justice (the content of normative legal acts, direction of the activity of all branches of government, etc.). Consequently, the concept of "status" of a person determines the social and legal status situations between the person and society: rights, duties, normative communication, which stigmatize and/or discriminate the patients. For example, in Ukraine there is a special legal status of an individual for persons with disabilities and victims of Chornobyl accident, which are defined by the rules of a special legislation [19]. Actually, the existence of a legal status defines a person as a subject of law, thus legally establishing a range of possible and appropriate actions in his relations with the society. It should be noted that only the legal determination of the corresponding status (as a collective decision of the state medical and social expert commission, on the recommendation of the doctor, who establishes the preliminary diagnosis) allows a certain level of provision of this category of the population resources: financial, social, etc.

With regard to the concept of "patient", the national legal framework provides the following definition: "a patient is an individual who has applied for medical care and/or is provided with such care" [20, 21], which, according to some experts, is concise and incomplete, because it contains "one-sided characteristics of the patient as a consumer of medical services" (cited by [22]). In the context of palliative issues, this meaningful interference does not cause conceptual remarks of the specialists, but is an important component of the existing semantic field of the concept of PPS, which complicates the question of its definition.

In our opinion, the main complexity and contradictory of PPS definition are the practical problems of establishing its diagnostic boundaries through polynosology that is immanent. Based on the definition of the WHO, which focuses on the complexity of the physical, psychosocial and spiritual problems, "associated with life-threatening illnesses" and suffering [23], we tend to distinguish the main problem not only in its medical components, but, first of all, of the main psycho-physiological performance indicators.

In general, the status of a palliative patient makes debut a little later after setting the "patient status", namely with the onset of a palliative stage of the disease, when clinical manifestations of the disease already contain indications of incurability and/or the loss of self-care (autonomy) of the patient. PPS should legally confirm the already existing "patient status", emphasizing the deterioration of the clinical presentation and limitation of the patient's life expectancy. The clinical aspect of PPS is poorly explored due to phenomenological manifestations of the corresponding condition/disease, which, in turn, are indicated by the codes of the known international classifiers.

It is obvious that certain diagnostic collisions are concentrated in the dynamic peculiarities of the palliative status and its possible changes: the diagnosis, the start/stop of the palliative period of the disease/condition, possible exacerbation/ remission of the disease, the death of the palliative patient, which, according to pp 2.4 of the order of the Ministry of Health No. 41, "monitoring the state ... when changing the patient's status" [24]. Consequently, the notion of "palliative" obviously attributes the state of health of a person who is on the verge of abnormal functioning and/or life-death, when the basic psychophysiological indices indicate the presence of a threatening pathology, which makes impossible a decent quality of life. The impossibility of normative functioning to some extent can be offset by medical, psychosocial measures, but no means (technology) can provide dignity of a person's life/death, as they reflect the plane of the attitude towards the sick person, his/her needs and values from the environment (micro, meso- and macrosocium).

It seems that the very concept of "palliative" concentrates methodological dilemma, which leads to existing collisions of hypo- and hyperdiagnosis of PPS. In fact, the determinant definition of "palliative" in the order of the Ministry of Health No. 41 is semantically disclosed through the diagnostic procedure and clinical signs: "acute" "chronic" and "exacerbation", together with a negative particle "no". This method of determining PPS, as it seems to us, requires urgent correction to a level that will make statistical obscurity of palliative patients and their discriminator impossible [26; 56].

There is also a need to distinguish between the palliative status and the diagnosis, which was pointed out by the WHO and WPCA that call for caution when using ICD-10 diagnostic headings for such an assessment, since not all patients with a definite diagnosis require PC [25]. To clarify the PPS, they distinguish three groups of patients who definitely need PC: (1) those who have a palliative period of a progressive disease; (2) with a stable/unstable course of the disease, with a relatively small number of symptoms, whose condition may deteriorate even to sudden death; (3) and those suffering from chronic illnesses, when the disease does not progress, with periods of progression and remission, and who benefit from the use of PC. The WHO and WPCA emphasize the uncertainty of the proportions of these three groups of patients and indicate the specific symptoms of PPS: pain, end of life period. Relative diagnosis is also indicated by the European standard of PC, the White Paper: "PC is not limited to providing care to the patients with some definite diagnosis, it should be accessible to all patients with life threatening illnesses" [4; 21].

Conclusion. Our brief critical review of the state of PPS diagnosis can be summarized as follows: PPS definition is the result of interaction of conventional (legal, social), expert (professional) and ethical (traditional, social) markers. These include, in particular, mortality data of the region (country), the resources of the regional health system, and, above all, the ethical standards of society, which imply the meaning of the semantic field "palliative". It is this content that reproduces humanistic national standards that broadcast to the professional environment the relevant thresholds of sensitivity to the level of psychophysiological exhaustion, which enables the physician to include/exclude a patient who is seriously ill to a palliative status, and initiates PC.

Obviously, multiplicity of PPS etiology, which we reviewed, involves the appropriate fluctuation of the focus of gravity in the process of setting up and defining the diagnosis/condition, which involves the indispensable start of PC. In the legal field of the state, PPS determination is a guarantee of the normative functioning of social mechanisms for providing vital functions to vulnerable groups of the population. In the context of incurable, severe illness (state), it refers to the quality of life, survival of the patient and, in general, the conformity of the humanistic standards of Ukrainian society to civilization standards.

Palliative patient status definition remains without an adequate response, especially when PC is not finally institutionalized as an integral part of both clinical practice and the collective consciousness of Ukrainian society and requires further professional discussion.

References:

1. VOZ (2015). Palliativnaja medicinskaja pomoshh'. Informacionnyj bjulleten' ¹ 402. [Palliative care. Newsletter No. 402]. Available at: https://goo.gl/8VprDq

2. Gerasimenko N. (2017). Organizacija palliativnoj pomoshhi v stranah SNG. [Organization of palliative care in the CIS countries]. Available at: https://goo.gl/55Vraa

3. Cancer control: knowledge into action : WHO guide for effective programmes ; module 5. WHO Library Cataloguing-in-Publication Data. Available at: http://goo.gl/9DzSIJ

4. Radbruch L. & Payne S. (2009). White paper on standards and norms for hospice and palliative care in Europe part 1. In : European Journal of Palliative Care. 16, 6, p. 278–289.

5. Nakaz MOZ ¹ 368 (2007). Pro zatverdzhennja Kl³n³chnogo protokolu nadannja pal³ativno¿ dopomogi, simptomatichno¿ ta patogenetichno¿ terap³¿ hvorim na V²L-³nfekc³ju/SN²D. [On Approving the Clinical Protocol for the Provision of Palliative Care, Symptomatic and Pathogenetic Therapy for HIV / AIDS Patients]. Elektronnij dokument / Rezhim dostupu: https://goo.gl/Tqt5ik

6. Human Rights Watch (2011). Uncontrolled Pain Ukraine's Obligation to Ensure Evidence-Based Palliative Care. Available at: https://goo.gl/TmuRMA

7. Nakaz MOZ Ukra¿ni ¹ 420 (2011). Pro zatverdzhennja Metodichnih rekomendac³j shhodo rozrahunku potrebi naselennja u medichn³j dopomoz³. [On Approval of Methodological Recommendations on Calculation of the Population's Need for Medical Aid]. Elektronnij resurs / Rezhim dostupu: http://goo.gl/PI63yB

8. WHO (2017). Programmes. Disabilities and rehabilitation. Available at:http://www.wpro.who.int/rehabilitation/en/

9. Pres-sluzhba "Shhotizhnevika APTEKA" (2016). Nedostupn³st' adekvatnogo znebolennja: l³kar³ ³gnorujut' nov³ vimogi zakonodavstva. [Inaccessibility of adequate anesthesia: doctors ignore the new requirements of the law]. Elektronnij dokument / Rezhim dostupu: https://www.apteka.ua/article/396502

10. The Association for the Prevention of Torture (APT) (2016). Putting prevention into practice. 10 years on: the Optional Protocol to the UN Convention against Torture. Available at:https://goo.gl/9tcSQL

11. Scholten N. et al. (2016). The size of the population potentially in need of palliative care in Germany – an estimation based on death registration data. BMC Palliative Care, ð. 15–29. Available at:https://goo.gl/NRHtgf

12. Guz³j O.V. (2017). Pac³ºntor³ºntovana statistika ta pal³ativna dopomoga v Ukra¿n³. [Patient-oriented statistics and palliative care in Ukraine]. Redakc³ja zhurnalu "Ukra¿ns'kij medichnij chasopis", 4 (120), pp. 6–7.

13. Nakaz MOZ ¹ 41 (2013). Pro organ³zac³ju pal³ativno¿ dopomogi v Ukra¿n³. [About the organization of palliative care in Ukraine]. Elektronij resurs / Rezhim dostupu: http://zakon3.rada. gov.ua/laws/show/z0229–13

14. Stinson J, Nasser B. (2003). Pain management in children with sickle cell disease. Pediatric Drugs, 5, pp. 229–241.

15. Hofman M. et al. (2007). Posttraumatic stress disorder in children affected by sickle-cell disease and their parents. American Journal of Hematology, 82, pp. 171–172.

16. Hain et al. (2013). Paediatric palliative care: development and pilot study of a 'Directory' of life-limiting conditions. BMC Palliative Care, 12, p. 43.

17. Kelly Nicole Michelson and David M. Steinhorn (2007). Pediatric End-of-Life Issues and Palliative Care. Clin Pediatr Emerg Med, 8(3), pp. 212–219.

18. Il'ichjov L. F., Fedoseev P. N., Kovaljov S. M., Panov V. G. (1983). Filosofskij jenciklopedicheskij slovar'. [Philosophical Encyclopedic Dictionary]. M.: Sovetskaja jenciklopedija. Elektronnij dokument / Rezhim dostupu: https://goo.gl/YffG6n

19. Shemshuchenka Ju. S. (2007). Velikij enciklopedichnij juridichnij slovnik: slovar'. [Great encyclopedic legal dictionary: dictionary]. K.: Jurid. dumka, 992 s. Elektronnij dokument / Rezhim dostupu: https://goo.gl/NTbXKh

20. O'Malley P. (2006). American Academy of Pediatrics Committee on Pediatric Emergency Medicine. Patient- and family-centered care and the role of the emergency physician providing care to a child in the cmergency department. Pediatrics,118 (5), pp. 2242–2246.

21. Weaver M.S., Heinze K.E., Bell C.J., Wiener L. (2016). Establishing psychosocial palliative care standards for children and adolescents with cancer and their families: An integrative review. Palliat Med., 30(3), pp. 212–223.

22. On³shhenko O.V., Soroka G.M. (2012). Kol³z³¿ reguljuvannja okremih prav pac³ºnta pri nadann³ medichno¿ dopomogi. [The collisions of regulation of individual rights of the patient in the provision of medical care]. Juridichnij v³snik 2 (23), pp. 90–93.

23. WHO Definition of Palliative Care. Available at: http://www.who.int/cancer/palliative/definition/en/

24. Nakaz MOZ ¹ 41 (2013). Pro organ³zac³ju pal³ativno¿ dopomogi v Ukra¿n³. [About the organization of palliative care in Ukraine]. Elektronij resurs / Rezhim dostupu: http://zakon3.rada. gov.ua/laws/show/z0229–13

25. Connor S. and Bermedo M. (2014). Global Atlas of Palliative Care at the End of Life. Worldwide Palliative Care Alliance Edited. Available at: https://goo.gl/rxID0t

26. Zhogno Ju. P., B³rjukov V. S. (2017). Oc³nka potreb naselennja Odes'ko¿ oblast³ v pal³ativn³j dopomoz³. [Assessment of the needs of the population of the Odessa region in palliative care]. Anal³tichna dov³dka za rezul'tatami dosl³dzhennja. Odesa: TOV "²NVAC", 112 s. Elektronnij resurs / Rezhim dostupu: https://goo.gl/Q5A4au