

## ЗДОРОВ'Я ЛЮДИНИ, ФІТНЕС І РЕКРЕАЦІЯ, ФІЗИЧНЕ ВИХОВАННЯ РІЗНИХ ГРУП НАСЕЛЕННЯ

### APPROACHES TO THE DEVELOPMENT OF PEDIATRIC PALLIATIVE CARE

### ПІДХОДИ ЩОДО РОЗВИТКУ ПЕДІАТРИЧНОЇ ПАЛІАТИВНОЇ ДОПОМОГИ

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#### Abstracts

Considering today's challenges to medicine and provision of social protection to vulnerable population groups, the issue of developing pediatric palliative care is relevant and crucial. **The aim of the study** is to analyze the development level of pediatric palliative care in Ukraine and European countries. **Material and methods:** analysis and generalization of data from scientific-methodological and specific literature, documentary materials, information resources on the Internet, and regulatory and legal frameworks of Ukraine, the Republic of Poland and the Republic of Italy. **Research results.** The goal of pediatric palliative care is to support the child and their family as soon as a life-threatening disease is diagnosed. Such care is provided throughout the entire trajectory of the child's disease. Pediatric palliative care is aimed at improving the level of physical, mental, and spiritual well-being of the child and their family within the limits of the diagnosed incurable, often progressive, disease. The solution of multidisciplinary tasks requires the work of an interdisciplinary team in a palliative inpatient department, a mobile crew, and assistance at home. The family-centered model of pediatric palliative care is one of the unique models of supporting the family to adhere to a series of socio-medical interventions and maintenance of intra-family communication, avoid social deprivation of the family, and promote and coordinate the care of a child with an incurable disease. **Conclusions.** Palliative pediatric care contributes to the improvement of the quality of life of the child and their family. Pediatric palliative care in Ukraine and the world needs solving a range of problems related to financing and specialized education of specialists and parents of the child. The functioning of the inpatient and mobile pediatric palliative care team should be coordinated and continuous. The family-centered model is an effective approach to pediatric palliative care for the child and family.

**Key words:** pediatric palliative care, interdisciplinary team, specialized care skills and abilities, family-centered model of care.

Ураховуючи виклики сьогодення, пов'язані з медициною й наданням соціального захисту уразливим групам населення, проблема розвитку педіатричної паліативної допомоги є актуальною та важливою. Мета дослідження – проаналізувати рівень розвитку педіатричної паліативної допомоги в Україні та країнах Європи. Методи дослідження: аналіз та узагальнення даних науково-методичної та спеціальної літератури, документальних матеріалів, інформаційних ресурсів мережі Інтернет, законодавчо-правової бази України, Республіки Польщі та Республіки Італії. Метою педіатричної паліативної допомоги є підтримка дитини та її родини відразу, коли діагностувалося захворювання, що є небезпечним для життя. Тривалість такої допомоги відбувається впродовж усієї траєкторії захворювання дитини. Педіатрична паліативна допомога скерована на покращення рівня фізичного, психічного, духовного благополуччя дитини та її сім'ї в межах діагностованого невиліковного, нерідко прогресуючого, захворювання. Для вирішення таких багатопрофільних завдань необхідна робота міждисциплінарної команди в паліативному стаціонарному відділенні, мобільній бригаді та допомозі в домашніх умовах. Сімейно-центрована модель педіатричної паліативної допомоги є однією з унікальних моделей супроводу родини для продовження низки соці-

ально-медичних втручань для дитини і підтримки внутрішньосімейного спілкування, уникнення соціальної депривації родини, сприяння та координування догляду за дитиною з невиліковним захворюванням. Паліативна педіатрична допомога сприяє підвищенню якості життя дитини та її сім'ї. В Україні та країнах Європи педіатрична паліативна допомога потребує вирішення низки проблем у сфері фінансування, спеціалізованої освіти фахівців та батьків дитини. Функціонування стаціонарної та мобільної педіатричної паліативної команди повинно бути скоординованим та безперервним. Сімейно-центрована модель є ефективним підходом педіатричної паліативної допомоги дитині й родині.

**Ключові слова:** педіатрична паліативна допомога, міждисциплінарна команда, спеціалізовані навички та вміння догляду, сімейно-центрована модель допомоги.

**Introduction.** In pediatric medicine, the number of children who need palliative care is steadily growing. Improving the quality of care has increased life expectancy in the case of incurable diseases. Thus, it is actualized the necessity for a new approach to pediatric palliative care [5; 7].

The World Health Organization recognizes pediatric palliative care as the active total care for the child's body, mind and spirit, and also involves giving support to the family [13]. According to the WHO recommendation, pediatric palliative care aims to improve the quality of life of children suffering from chronic progressive life-limiting diseases, and the form and scope of care should be individualized to the patient's needs. An essential principle of pediatric palliative care is the protection of terminally ill children and adolescents and their right to the highest attainable level of health and psychophysical well-being.

Pediatric palliative care is notionally different from adult palliative care in content, quality, and duration. Pediatric palliative is composed of various pathologies: 80% of cases are non-oncological pathology, which includes rare orphan or specific childhood diseases [4]. In view of highly developed medicine, the disease can last for years, or it can leave in a few days.

The debut of registering children for palliative care is also different, which is provided not at the last stages of life, not in the terminal stage, but when establishing the diagnosis of an incurable, in many cases progressive, disease. In a child, the disease course can be so personalized that it actualizes multifaceted needs at the clinical level. For the most part, they depend on the child's condition accompanied with a syndrome complex involving numerous problems and, given sensory communication, there may

be a sudden deterioration in clinical situations, which can lead to death [1; 7].

The purpose of the study is to analyze the development level of pediatric palliative care in Ukraine and European countries.

**Research methods** – analysis and generalization of data from scientific-methodological and specific literature, documentary materials, information resources on the Internet, and regulatory and legal frameworks of Ukraine, the Republic of Poland, and the Republic of Italy.

**Research results.** Pediatric palliative care aims not to prolong or shorten life expectancy but to provide the best quality of life and alleviate physical, psychological, emotional and spiritual suffering from the moment of diagnosis establishment for children suffering from untreated pathologies and their families [3; 5].

Determining the criteria for pediatric palliative care is more complicated than for adult one. The child's body is a dynamic system, and thus, there is a wide diversity in the need for assistance, depending on their age, communication skills, cognitive development, and response to treatment, as all these components change over time. At the same time, four different categories of clinical conditions of children who are in need of palliative care have been identified, each requiring specific and various therapeutic interventions [4]. These are children suffering from different groups of diseases: neuromuscular, metabolic, genetic, oncological, respiratory, cardiological diseases, and developmental pathologies involving frequent hospitalization and specific multidisciplinary care. Thus, it is crucial to guarantee such patients and their families the highest possible quality of life. The legislation of Ukraine [4] provides for the relevant approach and enshrines the right to receive pediatric pal-

liative care, and the legislation of the Republic of Italy [9] and Poland [15] guarantees packages of free services.

In Ukraine, as in Europe, there are different types of organization of pediatric palliative care: hospice, inpatient, at home [2]. In order to ensure continuity and effectiveness of care for the child, it is necessary to coordinate the actions of health workers within these levels.

The development of pediatric palliative care in Ukraine is improving from year to year. Therefore, inpatient pediatric palliative care in 2020 was provided in 276 inpatient departments, in 2021 – 532, and in 2022 – 1227. Mobile teams visited pediatric patients at home: in 2020 – 233 mobile teams, in 2021 – 1089 mobile teams, and in 2022 – 2052 mobile teams. Within the Medical Guarantees Program, Ukraine provides medical services and medicines related to palliative pediatric care at the expense of the state budget. The National Health Service of Ukraine pays for the medical component of palliative care both in the hospital and of mobile teams. The mobile palliative care team should visit or contact a patient remotely at least once a week. The inpatient facility should provide 24/7 patient counseling [3].

According to the Order of the Ministry of Health dated March 28, 2018, palliative and hospice care services in Poland are provided at home, in hospitals, inpatient palliative departments, and hospices. The analyzed publications emphasize the need to enhance a system of pediatric palliative care [13; 15]. The biggest obstacles in developing pediatric palliative care are a lack of specialists: doctors, nurses, social workers, psychologists, and physical therapists; limited capacity to train additional palliative teams; a lack of an appropriate system of funding and relevant international cooperation. At the same time, it is noted the necessity to unite the financing of pediatric palliative units via public funds, charitable organizations, and private donations. Coordination requires settling the issue of differentiating the system of pediatric palliative care, which would be independent of the corresponding system of adult care.

In Italy, citizens' right to access pediatric palliative care is enshrined in the Law of the Repub-

lic No. 38 as of 15.03.2010. The law defines pediatric palliative care as a set of therapeutic, diagnostic, and remedial measures intended for both the child and their family. The actions of medical personnel should be focused on adequate and comprehensive care for patients whose underlying disease is characterized by progressive development of a grim prognosis since the pathology no longer responds to specific treatment. Although Italy is one of the first countries to adopt the relevant law, a study of publications has shown that the enforcement of the mentioned law is poor. Specific tasks within palliative care are solved for a small number of patients. It is reported that it concerns 5% to 15% of those who need help. It is known that in Italy there are six inpatient hospices and seven palliative care units at home. These facilities are located in several densely populated areas of the republic, which is an obstacle to obtain palliative services by those who live remotely [9; 14]. There is range of reasons that caused that situation: the complexity of clinical management of a pediatric patient with irreversible pathologies; a lack of specific and adequate academic training of specialists; social and cultural factors, given that severe disease and death of a child are perceived very emotionally; organizational and economic difficulties that will require adequate redistribution of financial resources.

Interdisciplinary palliative care should be the standard of medical care for such patients [6; 11]. The work of an interdisciplinary team providing services to palliative children focuses on all aspects of the disease. In particular, it involves the control of disease symptoms, psychological support of the child and family, control of social life and deprivation level, and the distribution of spiritual and bioethical problems of children and their families. Medical care includes, first of all, the control of the underlying disease. At the same time, there is a need for the multidisciplinary approach aimed at promoting optimal physical, psychological and spiritual well-being of both the child and their family. An interdisciplinary team may comprise clinical practitioners, nurses, social workers, counselors, physical therapists, etc.

The model of family-centered help to children who are in need of palliative care is actualized within the approach of palliative care both in Ukraine and European countries [13–15]. The characteristic peculiar to all children or adolescents and their families relates to their desire to resist the disease, stay at home as long as possible, and live a full-quality life. The most appropriate environment to achieve the above is the home one, which includes care adjusted to the context and needs of the child and their families. The family-centered palliative care model marks the central place of the family in the child's life and guarantees professional support for the child and the family. Recent studies [8; 10] have confirmed a significant improvement in the stability of the child's functional state upon applying such a model since the family feels an active participant in caring for the child's health, understands its role in care and decision-making of the treatment strategy; guarantees symptom control in the child at home.

Pediatric palliative care, which is provided at home comprises a set of tasks: family support, adherence to some social and medical interventions necessary for the child, support within internal family relations, maintenance of a comfortable daily life, substantiation of forecasting and essence and quality of life.

The benefits of home pediatric care are multifaceted: the focus is on family needs, which reduce parents' feelings of guilt, isolation and powerlessness; the child continues to participate in family activities and everyone can use the opportunity for communication and relationships; family members share childcare responsibilities when possible. At the same time, home child care requires the involvement of a multidisciplinary team that interacts with the reference center, in which pediatric patients and their families are observed throughout the therapy term [12; 13].

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Thus, it follows that the family context must be adapted to the clinical needs of the child to ensure a good quality of life and care. It is important to take into account the high complexity and intensity of care characteristic of incurable pathology. In this case, the factor of information education of family members is crucial in order to receive adequate support through social learning, acquisition of skills and know-how to look after the child and, if necessary, provide pre-hospital care. This contributes to the optimal level of autonomy and education regarding the symptoms and course of the disease and guarantees coordination and integration between the family and providers of pediatric palliative services outside the hospice or hospital, starting with social and emotional support.

**Conclusions.** Pediatric palliative care is a unique phenomenon in pediatric medicine, as it focuses on improving the quality of life, care for the child's personality within the family, preventing or alleviating suffering, involving a specialized interdisciplinary team supervising the patient and their family in the form of inpatient, home and hospice care. The development of pediatric palliative care in the world is fragmented and needs solving a range of problems: uneven access to pediatric palliative care services, the quality of training of specialized medical workers, and the search for funding sources.

The functioning of an inpatient and mobile pediatric palliative team should be coordinated and continuous. The family-centered model is an efficient approach to pediatric palliative care of the child and the family, as it settles tasks related to patient support. At the same time, such a model requires implementing some measures: parent training to carry out simple pre-medical medical manipulations, monitoring child health, and providing daily high-quality care.

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