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PAEDIATRIC PALLIATIVE CARE AS VECTOR OF PUBLIC HEALTH POLICY IN UKRAINE

Анотація. Purpose. The purpose of the article is to reveal paediatric palliative care as a direction of public health policy in Ukraine based on a systematic analysis of the integration of administrative and medical law. **Results.** The article reveals that paediatric palliative care is an integrated system of medical and psychological care and social support for children with serious or incurable diseases aimed at improving the quality of their lives and the lives of their families, provided from the moment of diagnosis and covering all aspects of the child's development, education, socialisation and emotional support. It has been established that the specific features of the provision and management of paediatric palliative care in Ukraine are as follows: 1) integration into the medical and social spheres. Paediatric palliative care in Ukraine requires the active involvement of various medical specialties, as well as integration with educational, social and psychological services to provide comprehensive support to children and their families; 2) accessibility, individuality and child-centredness. Palliative care should be available wherever the child is. The age-related peculiarities of children, their physical, emotional and cognitive development require special approaches to palliative care. **Conclusions.** Palliative care is provided from the moment of diagnosis until the end of the child's life, taking into account individual needs and characteristics; 3) planning and coordination of services. An important component of palliative care is the development and regular review of a follow-up plan for each child, which ensures ongoing monitoring of the child's condition and appropriate adaptation of medical and social interventions; 4) the special role of the family. Parents or legal representatives are actively involved in decision-making regarding the treatment and care of the child; in addition, training parents in home care skills is an important aspect of providing quality palliative care; 5) social effects. A child's long-term illness affects the social life of the whole family, so palliative care should help to preserve and support the social roles and functions of the child and his or her family in the context of illness.

Key words: administrative law, public policy, accessibility, health, medical care, medical services, healthcare, patient, principles, actors.

1. Introduction

One of the priorities of the healthcare and public health system of Ukraine is to develop and improve the quality of palliative care in accordance with international standards, as palliative care is a set of medical, social and psychological measures aimed at improving the quality of life of patients with incurable diseases and a limited life expectancy. To create a highly effective palliative care system in Ukraine, a number of barriers need to be overcome (Saturska, 2021, pp. 33–39).

Palliative care is undoubtedly important, as for a large proportion of incurably ill patients, this support is the only source of medical treatment. That is why it is necessary to ensure that palliative care services are available to every patient. However, Ukraine cannot yet be proud of such achievements in the field of palliative care. Volunteer organisations play an important role in providing palliative care, organising mass events, campaigns, and cooperating with

the media, thus helping patients to receive palliative care (Development problems of palliative and hospice care services, 2016; Kolenichenko, Kuzmenko, 2016).

Ukraine has not yet developed a national policy for the development of the palliative care system. Although certain progress and successes have been achieved in the palliative care system over the last period, initiatives, policy priorities for the development of this system, and their lobbying in political circles are usually formed and implemented from the "bottom up". Often, the efforts of initiative groups consisting of progressive doctors, scientists, and NGOs to resolve urgent issues in this system at the state level are met with indifference from politicians and political parties and are levelled by them (Danyliuk, 2017, pp. 218–229).

Modern research emphasises the need to develop and implement public policy that would meet the needs of society and take into account current challenges. Issues that focus on

an integrated approach to reforming the healthcare system in the context of administrative law are covered in the works by such scholars as: V. Averianov, I. Buriak, Z. Hladun, D. Homon, H. Muliar, A. Kuchur, A. Manzhula, A. Markina, S. Sabluk, O. Sidelkovskiy, E. Sobol, S. Stetsenko, O. Yunin, and others.

Moreover, given the difficult political, social and environmental conditions of the Ukrainian population, new administrative and legal approaches and mechanisms are required to ensure quality healthcare and the readiness of the healthcare system to respond to global threats.

The purpose of the article is to reveal paediatric palliative care as a direction of public health policy in Ukraine based on a systematic analysis of the integration of administrative and medical law.

2. Public health policy in Ukraine

According to the Fundamentals of Healthcare Legislation of Ukraine, palliative care is a set of measures aimed at improving the quality of life of patients of all ages and their families who face problems related to life-threatening diseases. This complex includes measures to prevent and alleviate patient suffering through early identification and assessment of symptoms, pain relief and overcoming other physical, psychosocial and spiritual problems. Palliative care is provided free of charge upon referral by the attending physician in accordance with the procedure determined by the central executive body responsible for the formation and implementation of public health policy. Palliative care is divided into general and specialised palliative care by type. The procedure, content and scope of palliative care, calculation of the need for the number of palliative care services to provide it, and the list of relevant medical indications are determined by the central executive body responsible for the formation and implementation of public health policy (Law of Ukraine Fundamentals of Ukrainian legislation on health care, 1992).

The Procedure for Palliative Care, approved by Order of the Ministry of Health of Ukraine No. 1308 of 04 June 2020, states that the basis for the provision of palliative care is a multidisciplinary approach, which provides for the engagement of a multidisciplinary team, which may be different and is determined depending on the patient's condition, the amount of care, and the size of the service area. The activities of the multidisciplinary team are regulated by the procedure for interaction between palliative care providers and social service providers approved by the Ministry of Health of Ukraine and the Ministry of Social Policy of Ukraine. The main components of palliative care are

medical (symptomatic therapy, prevention and treatment of chronic pain syndrome, drug therapy, provision of effective pain relief), social (including provision of social palliative care services), spiritual and psychological support for the Patient and his/her family, and other persons caring for the Patient. The provision of palliative care is based on the principles of accessibility, planning, continuity and succession, in accordance with the wishes of the Patient regarding the choice of the place of treatment and place of death, ensuring the possibility of receiving curative treatment in parallel with palliative care, considering the ethical and humane treatment of the Patient and his/her family members, other persons caring for the Patient, 7 days a week (Order of the Ministry of Health of Ukraine On improving the organization of palliative care in Ukraine, 2020).

Paediatric palliative care, on the one hand, is a separate area of medical and psychological care, and on the other hand, it requires such a broad service that it should be integrated not only into various medical specialties but also into other areas of human life. Palliative care should be provided to children with incurable diseases from the moment of diagnosis; be available in any city, regardless of the institution (providing an adequate service in an adequate place at the right time for the child, for as long as necessary); be child and family-centred; all measures should take into account age-specific features and be aimed at improving the quality of life of the child and his/her family, but not at giving up the fight. The age-related peculiarities of childhood cause certain difficulties in providing medical support to palliative care patients and require numerous additional interventions to ensure the development, education, socialisation and other needs of the child and his/her family (Kurilina, 2019, pp. 40-48).

In Ukraine, palliative care as a separate type of care has begun to develop only in the last few years, first as care for children with onco-haematological diseases, and later, with the emergence of models based on children's homes, as care for children with congenital and hereditary pathology and other conditions (Cherny, Radbruch, 2009; Moiseienko, 2015, p. 36).

According to the Procedure for Palliative Care, approved by Order of the Ministry of Health of Ukraine No. 1308 of 04 June 2020, palliative care for patients aged from birth to 18 years (hereinafter referred to as paediatric patients) is provided in accordance with the provisions of general legislation, taking into account certain specifics. Planning of palliative care for a paediatric patient provides for the development and review of the Plan of care for a paediatric patient in need of palliative care.

Palliative care services for children are created in accordance with the needs of the child population, morbidity, demographic, geographical, infrastructural and other features of the region, as well as the needs of local governments (amalgamated territorial communities). When organising palliative care for paediatric patients, preference shall be given to organisational forms that allow for the provision of palliative care at home with the involvement of family members or legal representatives of the child, subject to the informed consent of the paediatric patient or his/her legal representative and taking into account changes in the condition and needs of the paediatric patient. During the stay of a Paediatric Patient in a healthcare facility providing palliative care, the child's right to stay with his/her family members, regardless of the Paediatric Patient's condition, until the end of his/her life is ensured. In case of changes in the condition of the Paediatric Patient and the need for examinations, treatment of acute conditions and surgical interventions, the Paediatric Patient shall be referred to specialised healthcare facilities with his/her consent and/or consent of his/her legal representative. A healthcare facility, regardless of its form of ownership and individual entrepreneur, providing palliative care to a Paediatric Patient may provide his/her family members/legal representatives with medicines and medical devices for use by the child at home, organise training for parents or legal representatives of the child to work with equipment used at home and skills of caring for the Paediatric Patient (if the Paediatric Patient and/or family members/legal representatives wish to continue treatment at home). After the Patient reaches the age of 18, for the purpose of continuity of palliative care, the Patient is referred to a health care facility that provides palliative care to the adult population. Palliative care for the Patient after reaching the age of 18 may be provided in children's health care facilities, taking into account the Patient's condition, mobility, availability of palliative care services for the adult population in the administrative-territorial unit (hospital district) and by the decision of the head of the health care facility (Order of the Ministry of Health of Ukraine On improving the organization of palliative care in Ukraine, 2020).

3. Paediatric palliative care in Ukraine

Palliative care for children is a new area of medical and psychosocial care. In order to properly develop approaches to palliative care for children in Ukraine, it is necessary to study the differences in its provision to this category of patients. Distinctive features of paediatric palliative care: 1. Few patients (compared to palliative care for the adult population). 2.

A variety of pathologies (neurological, metabolic, chromosomal, cardiac, respiratory, infectious, oncological, traumatic, neonatal, etc.) with unpredictable duration of illness; many diseases are familial, some remain unverified. 3. Official age restrictions on the use of medicines for children, resulting in many medicines being prescribed by paediatricians in the "off label" mode (i.e., without mentioning them in the instructions for use). 4. Developmental factors: children are in the process of constant physical, emotional and cognitive development, which affects all aspects of palliative care - from medication dosage to communication, education and support. 5. Significant role of the family: the patient's parents are deeply involved in the process of making decisions related to palliative care - clinical, ethical, social. 6. Paediatric palliative care is a relatively new field of medicine, which at this stage of its development results in an insufficient number of experts and specialists who have undergone special training in palliative care. 7. High level of emotional involvement: when a child dies, it can be extremely difficult for family members and staff to accept the failure of therapy, the incurability of the disease and death. 8. Loss and grieving: after the death of a child, these processes are often difficult, prolonged and complicated for parents and relatives, which determines the nature of long-term professional support for parents after the loss of a child. 9. Legal and ethical aspects of palliative care for children: as a rule, these aspects are addressed to parents or official representatives of the child's interests. The child's wishes and participation in the decision-making process are often not considered, which can lead to great moral and legal difficulties in providing care. 10. Social consequences: it is difficult for the child and his/her family members to maintain their social roles in the context of the disease (school, work, family support, etc.) (Cherny, Radbruch, 2009; Moiseenko, 2015).

The diversity of conditions in children in palliative care requires the creation of integrative links in general paediatric care, both at the outpatient and inpatient levels. The model of optimal paediatric palliative care is based on three interconnected levels of service provision in the healthcare system for synergistic functioning and for the earliest possible start of care. This determines the rapid development of a wide network of palliative care in the world, with primary care providing educational and policy initiatives to ensure the basic elements of paediatric palliative care from the moment of diagnosis of a life-limiting illness. At the secondary level, specific groups of children at the end of life are identified in order to obtain standardised

approaches to the management of individual conditions and to determine the location of services. This frees up specialised palliative care as a tertiary level to address the most complex issues: complex symptom management, complex issues and complex decision-making (Friedrichsdorf, Bruera, 2018; Kurilina, 2019). Specialised care is provided by a team of trained professionals, including doctors, nurses, psychologists, social workers, priests and other specialists who can be called upon to provide specific medical interventions, treatment and counselling. In addition to providing the right amount of care in the right place, such integration ensures adequate parental and healthcare provider relationships, family adaptation to the child's illness, communication and decision-making (Mack, Wolfe, 2016; Kurilina, 2019).

4. Conclusions

Therefore, paediatric palliative care is an integrated system of medical and psychological care and social support for children with serious or incurable diseases aimed at improving the quality of their lives and the lives of their families, provided from the moment of diagnosis and covering all aspects of the child's development, education, socialisation and emotional support.

The specific features of the provision and management of paediatric palliative care in Ukraine are as follows:

1) Integration into the medical and social spheres. Paediatric palliative care in Ukraine requires the active involvement of various medical specialties, as well as integration with educational, social and psychological services to provide comprehensive support to children and their families;

2) Accessibility, individuality and child-centredness. Palliative care should be available wherever the child is. The age-related peculiarities of children, their physical, emotional and cognitive development require special approaches to palliative care. Palliative care is provided from the moment of diagnosis until the end of the child's life, taking into account individual needs and characteristics;

3) Planning and coordination of services. An important component of palliative care is the development and regular review of a follow-up plan for each child, which ensures ongoing monitoring of the child's condition and appropriate adaptation of medical and social interventions;

4) Special role of the family. Parents or legal representatives are actively involved in decision-making regarding the treatment and care of the child; in addition, training parents in home care skills is an important aspect of providing quality palliative care;

5) Social effects. A child's long-term illness affects the social life of the whole family, so palliative care should help to preserve and support the social roles and functions of the child and his or her family in the context of illness.

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ПЕДІАТРИЧНА ПАЛІАТИВНА ДОПОМОГА ЯК НАПРЯМ ДЕРЖАВНОЇ ПОЛІТИКИ У СФЕРІ ОХОРОНИ ЗДОРОВ'Я В УКРАЇНІ

Анотація. Мета. Мета статті полягає в тому, щоб на основі системного аналізу інтеграції адміністративного та медичного права, розкрити педіатричну паліативну допомогу як напрям державної політики у сфері охорони здоров'я в Україні. **Результати.** У статті розкрито, що педіатрична паліативна допомога – це інтегрована система медико-психологічної допомоги та соціальної підтримки дітей з важкими або невиліковними захворюваннями, спрямована на покращення якості їхнього життя та життя їхніх сімей, що надається з моменту встановлення діагнозу та охоплює всі аспекти розвитку, навчання, соціалізації та емоційної підтримки дитини. Сформовано, що особливості надання та управління педіатричної паліативної допомоги в Україні полягають у наступних аспектах: 1) інтеграція в медичну та соціальну сфери. Педіатрична паліативна допомога в Україні передбачає широке залучення різних медичних спеціальностей, а також інтеграцію з освітніми, соціальними та психологічними службами для забезпечення комплексної підтримки дітей та їхніх сімей; 2) доступність, індивідуальність та орієнтованість на дитину. Паліативна допомога повинна бути доступною у будь-якому місці перебування дитини. Особливості розвитку дітей, їх фізичний, емоційний та когнітивний розвиток потребують спеціальних підходів у наданні паліативної допомоги. **Висновки.** Паліативна допомога надається з моменту встановлення діагнозу і до кінця життя дитини, з урахуванням індивідуальних потреб та особливостей; 3) планування та координація послуг. Важливою складовою паліативної допомоги є розробка та регулярний перегляд плану спостереження для кожної дитини, що забезпечує постійний моніторинг стану дитини та відповідну адаптацію медичних та соціальних втручань; 4) особлива роль сім'ї. Батьки або законні представники активно залучені у прийняття рішень, що стосуються лікування та догляду за дитиною; окрім того, навчання батьків навичкам догляду за пацієнтом вдома є важливим аспектом надання якісної паліативної допомоги; 5) соціальні наслідки. Довготривала хвороба дитини впливає на соціальне життя всієї сім'ї, тому паліативна допомога повинна сприяти збереженню та підтримці соціальних ролей та функцій дитини і її сім'ї в умовах хвороби.

Ключові слова: адміністративне законодавство, державна політика, доступність, здоров'я, медична допомога, медичні послуги, охорона здоров'я, пацієнт, принципи, суб'єкти.