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В КОНТЕКСТІ ЄВРОІНТЕГРАЦІЙНИХ ПРОЦЕСІВ**

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**PALLIATIVE CARE AS QUARANTEE OF CHILDREN’S RIGHT TO HEALTH
CARE: INTERNATIONAL REGULATION, HISTORY AND PERSPECTIVES FOR
UKRAINE**

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Article 49 of the Constitution of Ukraine especially dedicated to health and medical care, which enshrines that “everyone shall have the right to health protection, medical care and medical insurance. Health protection shall be ensured through state funding of the relevant socio-economic, medical and sanitary, health improvement and prevention programs. The State shall create conditions for effective medical service accessible to all citizens. State and communal health protection institutions shall render medical care free of charge; the existing network of such institutions shall not be reduced. The State shall promote the development of medical institutions under all forms of ownership. The State shall provide for the development of physical culture and sports, and ensure sanitary-epidemic welfare”[1, p.11].

Due to Article 7 of the International Covenant on Civil and Political Rights [2] and Article 3 of the European Convention on Human Rights no one shall be subjected to torture, cruel, inhuman or degrading treatment or punishment [3]. Article 27 of the Convention of the Rights of the Child outlines that “states Parties recognize the right of every child to a standard of living adequate for the child's physical, mental, spiritual, moral and social development”, in the Article 24 is prescribed that “states Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services”[4].

Recommendations of the Committee on Economic, Social and Cultural Rights stress the importance of “attention and care of chronically or incurable ill people, alleviation of their suffering as far as possible and providing them with the opportunity to end their life with dignity”[5, p.3].

Palliative care is one of the types of care that state should supply and guarantee to the citizens. According to the definition mentioned in the World Health Organization (hereinafter –

WHO) “palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual”. Palliative care: provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patients illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications [6].

WHO developed a definition of palliative care which is directly concerned on children – “palliative care for children represents a special, albeit closely related field to adult palliative care”. WHO’s definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a): palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family; it begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease; health providers must evaluate and alleviate a child's physical, psychological, and social distress; effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited; it can be provided in tertiary care facilities, in community health centres and even in children's homes [6].

In Europe, the problem of palliative care was started to solve in the 80's, and in 1988 the European Association for Palliative Care (EAPC) was created. Today, the organization brings together volunteers whose efforts are aimed at developing approaches to palliative care, social work, cultural and anthropological issues of the ill-fated patients. Now the organization has got more than 6,000 regular members who represent different countries and all medicine areas relating to the care of patients with advanced and terminal cancers and other diseases. In 2014 the World Health Assembly of the WHO adopted a separate resolution on the need for palliative care as a part of health care [7].

According to Joan Marston, Chief Executive of International Children's Palliative Care Network, the main thing in children's palliative care development is a confident voice of

communities and parents to be heard by the authorities. There are many models of palliative care in the world. Even in countries where resources are very limited, we can successfully provide palliative care. As a striking example let's take Romania, which has built a system of palliative care from scratch over the last 15 years. In any state aid should follow the child, not the child to seek help. This is an indicator of a healthy society [7].

Hospice Casa Sperantei is a Romanian charity founded in 1992 in Brasov, in partnership with a British hospice based in Dartford, Kent. Its mission is to introduce and support the development of hospice and palliative care for patients with incurable diseases in advanced and terminal stages in Romania. Services started in 1992 in the city of Brasov as home-based palliative care for adults and extended in 1996 with pediatric palliative care in the children's homes. In 2002 the first Romanian purpose-built teaching hospice was opened in Brasov, hosting a 13-bedded adults inpatient unit and a six-bedded unit for children, as well as day centres and outpatient clinics for adults and children with cancer and other life-limiting conditions. The organization has been actively involved since 1997 in the education of professionals interested in setting up new palliative care services (over 12,000 doctors, nurses, social workers, psychologists, therapists, clerics and carers), as well as over 500 volunteers. Hospice Casa Sperantei is actively involved in introducing palliative care in the undergraduate training of medical and nursing students (University of Brasov) and since 2010 a two-year masters degree in palliative care is available at the same university. Hospice Casa Sperantei has made a major contribution towards raising awareness about the need for palliative care in Romania, in improving the legal framework to allow better access of patients to pain control medication, in the recognition of palliative care as a medical competence, and developing minimum standards for palliative care services. It has also contributed to setting up some of the funding mechanisms for hospices and palliative care services. Hospice Casa Sperantei is a resource centre for palliative care development in eastern Europe, providing theoretical and clinical palliative care courses for countries in the Balkan region and Commonwealth of Independent States (CIS) countries. It provides a complex of free-of-charge palliative care services in the Brasov county (Brasov, Fagaras and Zarnesti areas) and in Bucharest, in various settings, for adult patients with cancer and children with various life-threatening diseases covering over 1,700 patients every year. The model developed over the past 19 years in Brasov provides an integrated approach, where patients admitted in the program can choose and receive care either at home, or in the hospice (inpatient admissions, outpatient consultations, day centre attendances), adapted to the stage of the disease. The model has been replicated by several other hospices and palliative care services throughout Romania [8, p.52].

On October 28, 2016 an open discussion “Palliative Care for Ukrainian Children” devoted to this crucial topic was held in Kyiv. According to the statistics mentioned here – there are no clear statistics on children in need of palliative care in Ukraine. According to the Ministry of Health, about 17 500 children, according to UNICEF, this number may be from 30 to 70 000 young patients are in need. Juliana Suprun, acting Minister of Health of Ukraine, commenting on the issue, said that the way the state treats ill children shows the level of civilized society. Currently, the Ministry is interested in a process to address this problem. In particular, within the National Program "Oncology" the first batch of the morphine for children (syrup) will be purchased next year. So, this set is planned for children diagnosed with cancer, whose fraction among palliative pediatric patients is only 20%. However, it can be considered the first significant step in the recognition of palliative care needs of children in Ukraine [7].

Mykola Kuleba, Commissioner of the President of Ukraine for Children's Rights, says that a reform is not far-off, “90% of these children deal with educational state institutions, which provide medical services at a very low level. The mortality rate in such institutions is extremely high. This system is a relic of the Soviet past. It does not work and will change in the near future”. Another enormous problem is limited access to pain relief. Victoria Tymoshevskya, director of the Public Health Initiatives of the International Renaissance Foundation, explains: “Doctors put off the complete radical treatment that does not bring results until the last moment, and transfer the patient to palliative support. Often it is a difficult step for the doctor. By providing palliative status, a physician undergoes a professional defeat, although it is not true!”. However, there is no such thing as morphine for children in Ukraine, so they can't get an adequate pain relief, no matter they are in agony. Pervova Anna, the mother of a palliative patient, sharing her experience, said, “Unfortunately, some doctors still do not know how to prescribe painkillers to palliative patients, which blanks to use ... Often the needed drugs are simply not available. Two weeks in a row my sick child was anesthetized by usual Solpadeine, the effect of which lasts 20-30 minutes, and then ... pain, pain, pain”[7].

Mykola Kyleba commented the situation with the level of palliative care in Ukraine “Palliative care is a step to the civilized society. To develop the system of supplying of palliative care we should conduct a set of nosologic, social, psychologycal and other peculiarities of their palliative conditions, adopt amendments in special standards and protocols, within the position of patents, charity and public organizations establish a single way of adoption of the new models of palliative care for children” [9].

I totally agree with the position of Mykola Kyleba – the system of providing palliative care for children should be improved. To my opinion, experience of Romania good be used as a good model:

- based on the stage of disease parents together with children should choose and receive care either at home, or in the hospice;
- education of professionals interested in setting up new palliative care services should be increased;
- courses of palliative care should be available in the medical universities;
- awareness about the need for palliative care should become the fundamental goal of the state;
- minimum practical standards for palliative care services for children should be established;
- palliative care for children should be free of charge.

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