

STATE OF PALLIATIVE AID IN NEONATOLOGY IN UKRAINE

Malyk Natalia

Candidate of Medical Sciences, Assistant professor

Makarenko Regina

Student

Kharkiv National Medical University

Kharkov, Ukraine

Annotation: The article considers the formation and current state of palliative care in neonatology in Ukraine, as well as analyzes possible ways of its further development.

Keywords: premature babies, incurable disease, palliative care, hospice

Introduction. In Ukraine, at this time there is an increase in the number of premature babies. This will inevitably be reflected in the future by the growing medical and social burden of chronic incurable diseases - malignant neoplasms, heart, and respiratory failure, cerebrovascular and neurodegenerative diseases, pathology of the musculoskeletal system, etc. In addition, a negative situation is emerging about the health status of newborn children, which is complicated in our country by the spread of HIV / AIDS and associated multidrug-resistant forms of tuberculosis, an increase in the level of child disability. [1] According to the World Health Organization, Ukraine ranks fifth in terms of the incidence of childhood cancers, thousands of children are diagnosed with cancer every year. The most common malignant disease is a blood cancer. Only 47% of children are cured, compared to 70% in the United States. Therefore, this indicates that one in two children with cancer dies of cancer. All these conditions and diseases at the terminal stages lead to various, extremely painful disorders and severe functional disorders in sick children, and psychological trauma in their families.[2] The growing need for solving a complex set of physical, psychosocial, and spiritual problems of terminally ill

children and their family members has become a new challenge for the health care system of Ukraine and an impetus for the development of palliative care institutions.

Main part. According to experts from the Association for Palliative and Hospice Care, at least 100 thousand children, as well as 1.5 million members of their families, need palliative care every year. This puts the importance of developing this area on a par with the most urgent and significant medical and social problems of our society

According to the World Health Organization, palliative care is an approach that helps to improve the quality of life of patients and their families facing a terminal illness by preventing and alleviating suffering through early detection, careful assessment, and treatment of pain and other physical symptoms, and psychosocial and spiritual support. [2]The task of palliative care is to alleviate the symptoms of a serious illness, first of all :

- adequate pain relief
- psychological support for the patient and his relatives who care for him
- to help treat death as a natural stage of a person's life
- to satisfy the spiritual needs of the patient and his relatives
- to solve social and legal, ethical issues that arise in connection with a serious illness and the approaching death of a person.

Serving incurable patients has its characteristics and requires medical personnel to have specialized knowledge in various fields of clinical medicine, psychology, pharmacology, as well as skills in communicating with the patient and his loved ones. It is also important to be able to counteract and overcome the consequences of professional burnout.

In Ukraine, palliative care as an approach began to develop in the late 90s of the XX century. In those days, the first Ukrainian hospices were opened - in 1996. In Lviv, in 1997. - in Ivano-Frankovsk and Kharkov. Until now, these hospices remain the leading institutions for the provision of inpatient and outpatient palliative care to the population in our country.[3]

According to the Ministry of Health, 17,000 children need palliative care

throughout Ukraine. At the same time, according to UNICEF calculations, their number is much higher and exceeds 50 thousand children.

Such a discrepancy in statistical data, according to many experts in this field, indicates insufficient attention on the part of the state to the problems of terminally ill children, who, like other citizens, have the right to provide qualified and affordable medical care. Despite such a significant number of incurable little patients, now in Ukraine, there is only $\epsilon\pi\pi$ children's hospices. The first hospice was opened in Ivano-Frankivsk. In 2017, a children's hospice was opened in Kharkov, where 20 children with their parents can stay. In addition, there is still no system for providing comprehensive psychological and social support for young patients who have been diagnosed with a fatal diagnosis, as well as their families. [4] Given the significant developments in recent years, most scientists and international experts agree that palliative care should be provided from the moment a diagnosis of an incurable disease is established.

It is clear that a complex set of problems arises when a child with a fatal the disease appears in the family. According to international experts, such a patient, as a rule, is surrounded by 10-12 conditionally healthy full-fledged members of society, who, as a result, have varying degrees of severity of psychological traumatization. This is manifested in the appearance of a feeling of guilt in front of the patient, sometimes aggression towards medical workers, depression, suicidal thoughts from a feeling of fear and doom to loneliness, and the threat of losing a family. At the same time, in most cases, the burden of day-to-day care of a sick child falls on the shoulders of the patient's relatives and relatives. Relatives should provide him with personal hygiene (washing, changing clothes, assistance in fulfilling physiological needs, and feeding). This is accompanied by sufficient physical activity (lifting, rotation, etc.) [5] According to WHO, caring for seriously ill children is work without pay and support, which can adversely affect health (after the death of sick children, the morbidity and mortality of their loved one's increases to 40%).

Taking into account the above facts, it becomes necessary to create a multidisciplinary team consisting of medical workers, social workers, psychologists,

clergymen, and volunteers. Thus, the organization of palliative care for children has its own characteristics. Effective palliative care requires a multidisciplinary approach that includes family members of the young patient, general practitioners, pediatricians, and specialized medical and non-medical care specialists to provide and coordinate high-quality services in solving medical and other problems.

Services should include:

- providing palliative care as early as possible during the progression of the disease, along with various forms of basic treatment such as radiation or chemotherapy that prolong the life

- medical care for pediatric palliative care specialists and general practitioners

- 24/7 nursing care

- social support

- education, play, and leisure activities;

- emotional support during illness for both the patient, and his relatives and during the period of mourning.

The professionals involved in the care must recognize and reduce the physical and psychosocial suffering of the child. [6]

Conclusions. In Ukraine, at present, the system of palliative care for children is far from perfect: care is provided in hospitals by staff who usually do not have enough qualifications and conditions to provide palliative care. The system of providing psychological and social support to young patients and their relatives has not been established. The issue of pharmacological pain relief for such children also needs to be resolved.

Therefore, it is necessary to raise the level of knowledge of doctors and other health workers about the peculiarities of working with terminally ill children and their family members, to create multidisciplinary teams of specialists to provide palliative care in medical institutions throughout the country.

LIST OF REFERENCES

1. Сисоєнко І. Паліативна допомога дітям в Україні [Електронний ресурс] / І. Сисоєнко // Обозреватель. – 09.10.2016. – Режим доступу : <http://my.obozrevatel.com/life/83174-paliativna-dopomoga-dityam-v-ukraini.htm>
2. WHO. Definition of Palliative. Geneva: World Health Organization, 2002 [Електронний ресурс]. – Режим доступу : <http://www.who.int/cancer/palliative/definition/en/>.
3. Вороненко Ю. В. Створення системи паліативної та хоспісної допомоги в умовах реформування охорони здоров'я в Україні: медичні та соціальні аспекти [Електронний ресурс] / Ю. В. Вороненко, Ю. І. Губський, А. В. Царенко // Охорона здоров'я і суспільство. – 2014. – No 1 (2). – С. 63–75. – Режим доступу : http://nbuv.gov.ua/j-pdf/nauipr_2014_1_11.pdf
4. Князевич В. М. Паліативна та хоспісна медицина: концепція, складові, розвиток в Україні (за даними наукової літератури) / В. М. Князевич, З. М. Митник, Ю. І. Губський // Україна. Здоров'я нації. – 2009. – No 3 (11). – С. 55–62.
5. Про організацію паліативної допомоги : наказ МОЗ України від 21.01.2013 р. No 41.
6. Рекомендації Європейської асоціації паліативної допомоги (Recommendations from the European Association for Palliative Care – White Paper on standards and norms for hospice and palliative care in Europe. Part I, 2009 [16]; White Paper on standards and norms for hospice and palliative care in Europe. Part II, 2010.