

CENTER OF PALLIATIVE MEDICINE AT KHARKIV NATIONAL MEDICAL UNIVERSITY: PRESENT-DAY CHALLENGES AND DEVELOPMENT STRATEGIES

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Abstract

In the majority of the countries, palliative care is an integral part of quality medical care, which includes comprehensive medical, social, psychological, and spiritual support for critically ill patients and their relatives. According to the WHO, every year about 20 mln people worldwide need palliative care at the end of their lives. There are many more who need palliative care until the last year of their lives. Thus, the total number of people who need palliative care annually is about 40 mln. It is estimated that of the 20 mln people in need of end-of-life palliative care, 78% live in low- and middle-income countries; about 67% are elderly and about 6% are children. However, only 14% of people who need end-of-life palliative care receive it. Palliative care considers the principle of respect for patients' decisions and aims to provide practical support to their family members during illness and in the event of a patient's death to overcome grief over the loss of a loved one. The WHO's global strategy for health care, based on human approach and integration, is to strengthen palliative care programs for patients with various diseases. Despite the fact that some steps have already been taken in Ukraine towards the development of palliative care, there are still some problems, such as lack of qualified medical staff; lack of relationships between primary and secondary, tertiary care and coordination; imperfect system of informing medical workers about ensuring the right to anesthesia for seriously ill patients; lack of a sufficient number of pharmacies licensed to operate controlled medicines; lack of interagency programs in the field of palliative care.

Keywords: *medical care, palliative care, patients, quality of life.*

In the majority of countries, palliative care is an integral part of quality medical care, which includes comprehensive medical, social, psychological and spiritual support for critically ill patients and their relatives. In 2014, the first-ever global resolution on palliative care, WHA67.19, called on the WHO and Member States to improve access to palliative care as a core component of health systems, focusing on primary health care and community-based or home-based care [1].

Palliative care was first introduced in 1990 by the WHO and is defined as "an approach to care that improves the quality of life of patients and their families with life-threatening illnesses through the implementation of preventive measures, the assessment and treatment of pain, and the prevention of physical,

psychological and spiritual problems." In 2004, the WHO described palliative care for children in detail as active full care of the child, his/her physical condition, his/her state of mind and spirit, as well as measures to support the family. Recently, in 2013, the 18th edition of the WHO Model List of Essential Medicines and the 4th edition of the WHO Model List of Essential Medicines for Children were published. These papers included sections on the use of pain medications in the context of palliative care. The use of these medicines and the need to ensure the availability and accessibility of all medicines needed for optimal palliative care are described. In addition to opioid and non-opioid drugs intended for the treatment of pain syndrome, these lists also included drugs for the treatment of various general symptoms, such as anorexia, nausea, constipation, diarrhea, etc. [2-5].

WHO estimates that around 20 mln people worldwide need palliative care at the end of their lives every year. There are many more who need palliative care until the last year of

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their lives. Thus, the total number of people who require palliative care every year is about 40 mln. Of the 20 mln people who need palliative care at the end of their lives, an estimated 78% live in low- and middle-income countries; about 67% are elderly people (over 60 years old) and about 6% are children [6, 7]. However, only 14% of people who need palliative care at the end of life actually receive it [1].

According to the WHO, palliative care aims to improve the quality of life of patients and their families who experience all the clinical, psychological, ethical and spiritual problems associated with incurable diseases. Palliative care takes into account the principle of respect for patient decisions and aims to provide practical support to their family members during illness and in the event of a patient's death to overcome grief over the loss of the relative. Palliative care should be based on the principles of patient's autonomy, accessibility and continuity, with the obligatory consideration of all the rights of the patient and his/her family members. Within national health systems, palliative care should be involved in the ongoing care of children with life-threatening illnesses. There is a need to develop a strategic link between palliative care and prevention, early detection and treatment programs for these diseases.

With regard to palliative care and the right to health, the Committee on Economic, Social and Cultural Rights, in General Comment 14, noted that "...States have a duty to respect the right to health by refraining from taking measures that close or restrict equal access for all to preventive, curative and palliative health services" [8].

The main document regulating children's rights is the UN Convention on the Rights of the Child (1989) [9]. But the authors focus on another important document, which was published in 2013. This is the "Charter of the Rights of the Dying Child (Trieste Charter)" [10]. The death of a child is a devastating tragic moment for everyone involved in it. The Charter of the Rights of the Dying Child was created to highlight the rights of young patients, which should not be forgotten because of the age or condition of the child, nor because of cultural traditions, nor because of the place and time when it occurs. Each right has a number of responsibilities. The charter describes and defines them, seeking to combine all professional,

moral, legal and scientific aspects. However, this knowledge often remains divorced from the real hospital, family and social conditions in which the child lives and dies and often does not correspond to the personal situation of the young patient [10].

To meet the needs of children with life-limiting or life-threatening illnesses, the International Children's Palliative Care Network (ICPCN) was established to bring together leaders and organizations from around the world, to improve childcare, to create global policy, research, education and technical assistance health care systems and governments. Also, the success of the ICPCN is the introduction of palliative care for children into the global health program [11].

Thus, the WHO global strategy for health care, based on a people-centered approach and integration, is to strengthen palliative care programs for patients with different diseases.

Despite the fact that some steps have already been taken in Ukraine towards the development of palliative care - mobile palliative care services have been created locally for both adults and children, inpatient beds are functioning, hospices have been opened, the state finances inpatient and mobile palliative care, a number of regulatory documents and so on, but the palliative care system is still in its infancy [12]. According to the authors, the problems are a critical shortage of qualified medical personnel; lack of effective methods of providing assistance; lack of opportunities to learn good practice in this area; lack of state policy and a common understanding of the philosophy of this type of medical care; lack of relationships between primary and secondary, tertiary health care and coordination; an imperfect system of informing medical workers on ensuring the right to pain relief for critically ill patients; lack of a sufficient number of pharmacies that have received a license to circulate controlled medicines; lack of interagency cooperation in the provision of palliative care (by the education sector, social services, confessors, lawyers, economists); lack of interdepartmental palliative care programs; lack of assessment of financing of palliative care measures.

Training palliative care professionals is an important component, while all health care professionals must have a basic knowledge of the principles of palliative care and proper pain management [13].

Despite this, most health care professionals do not receive training in palliative care at the start of their work, or take short courses that are insufficient. As stated in the WHO Planning and implementing palliative care services - a guide for program managers (2016), palliative care training should be provided primarily to physicians, clinical staff or physician assistants, who should receive at least 35 hours of theoretical and practical components. Nurses, community health workers or volunteers with 35 hours of training in basic palliative care are also not an exception. Volunteers and parents or relatives must be trained to provide some home care services, and must complete at least 6-16 hours of training. This will allow learning to recognize uncontrolled physical or psychological disorders or significant social problems and communicate this information to community health centers [6].

Kharkiv region is a favorable platform for development of palliative care because of its powerful educational component and scientific base, as well as opening and working of hospices for adults and children in recent years, a developed pharmaceutical base ("Health" factory and National Pharmaceutical University), creation of the Regional Clinical Center for Medical Rehabilitation and Palliative Care for Children, active media. As shown by a survey of the opinion of 378 pharmaceutical specialists conducted by the scientists from the National University of Pharmacy, only 67% of them demonstrated an average level of knowledge on the tasks of palliative care. The insufficient level of theoretical knowledge and practical skills on certain issues of palliative care was determined, namely, the basic definitions, principles and objectives, nosological forms of diseases in which palliative services are provided; the main provisions of the current regulatory framework for the organization of this type of medical care. The researchers came to the conclusion about the feasibility of introducing educational and scientific activities in order to increase the efficiency of palliative care in Ukraine, taking into account global trends in healthcare development, the implementation of scientific research in the system of providing palliative care with the definition of a socio-pharmaceutical component; development and improvement of educational and methodological cases at pre- and postgraduate

levels of education for pharmaceutical specialists [14].

In the recent years, some basic aspects of palliative care have been included in the educational programs for preparation of bachelors, specialists and masters at Kharkiv National Medical University. Highly qualified personnel of the third level of higher education are trained thanks to the inclusion of the search for palliative care in the educational and scientific component of the educational and scientific program in the specialty "Pediatrics". Three theses for grade of candidates of medical sciences have been defended and 2 PhD theses on aspects of palliative care in pediatrics are being carried out [15].

Establishing palliative care services in a community involves either integrating care into the day-to-day work of existing health facilities or, where not existing, creating a new service.

The Center of Palliative Medicine was established at Kharkiv National Medical University in November 2021 to solve some of the pressing problems of palliative care, both at the regional and national levels.

The aim of the Center of Palliative Medicine is to improve the quality of palliative care for adults and children at the regional and national levels through the organization and conduct of educational activities; organizing, coordinating and conducting research in palliative medicine, popularizing research results; development of draft regulatory documents on palliative care; international cooperation in the branch of palliative medicine.

The main tasks of the Center of Palliative Medicine are:

- teaching students, graduate students, doctors, nurses, social workers, volunteers and the general public in the basic principles of palliative care;
- introduction of the philosophy and principles of palliative care in the process of professional development of medical workers, acquisition of new competencies and practical skills in the provision of palliative care to adults and pediatric patients;
- training of scientific and pedagogical workers of KhNMU in the basic principles of palliative care;
- conducting research in the branch of palliative medicine, including international projects;

- promotion and dissemination of knowledge on palliative medicine and care;
- cooperation with public authorities and local government, institutions and organizations of various sphere of activity, communal non-profit enterprises, volunteers, non-governmental public organizations, charitable foundations, domestic and international partners, church and religious organizations; participation in development of draft regulatory documents on palliative care.

Solution of the main tasks of the Center of Palliative Medicine will be realized by means of:

- creation of on-line educational platforms on pediatric and adult palliative medicine for students, graduate students, nurses, doctors, social workers, volunteers, and the public;
- cooperation with international experts in the branch of palliative medicine;
- collection of materials for research on palliative care, their generalization, publication of the results;
- creation of information resources on the problems of palliative care and dissemination of knowledge among the medical, academic community and the population;
- informing about the activities of the Center through the media; conducting information campaigns to advocate for development of palliative care;
- participation in scientific conferences and other forums on palliative care;
- preparation and holding of annual international events.

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Conclusions.

Some results of the activities of the Center of Palliative Medicine will go beyond our vision and the established task. These are the so-called indirect consequences of the activity, because the Center will play a leading role in fostering a culture in which academic research thrives; children and their families will participate in the research and contribute their voice to increase the evidence base; leading role in supporting parenting organizations; a leading role in external work with the wider academic world; a leading role in the cost-effectiveness of palliative care provision and adaptation to demographic changes. That is, the main results of the activities of the Center of Palliative Medicine can be used by palliative care services, the media for the information space and the academic community for the cultivation of national experts.

Declarations

Statement of Ethics

The author has no ethical conflicts to disclose.

Consent for publication

The author gives her consent to publication.

Disclosure Statement

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