

State of Hospice Care in Ukraine, in the Period Before the Russian-Ukrainian War 2022-2024

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Abstract:

This article presents materials from a study concerning the formation and development of palliative medicine and hospices in Ukraine for the period before the start of the Russian-Ukrainian war, February 24, 2022. Historical moments that contributed to the creation in Ukraine are given, and people and organizations are indicated. Which contributed to this process.

Keywords: palliative medicine, hospice, patients, care for seriously ill patients

Introduction

One of the most urgent problems today remains the aging of the population in most countries of the world and the relentless, poorly controlled growth of a number of serious and incurable diseases [1-5]. For Ukraine, the aging process of the population, the growth of such diseases as cancer, tuberculosis, HIV/AIDS, diabetes, hepatitis C, hematological problems, especially in children, a consistently high level of strokes, heart attacks and their serious complications, industrial and domestic traumatism, etc. [4,6-9]. According to the data of various studies of national and international experts, in Ukraine every year about 500 thousand people need palliative and hospice care and, in addition, psychological and social help is needed by their families and relatives [10-14,23]. In general, it can be from 1 to 2 million people, who will be involved in overcoming the difficulties of fighting an incurable disease, physical and spiritual pain [15-18]. According to the data of various studies of national and international experts, in Ukraine every year about 500 thousand people need palliative and hospice care and, in addition, their families and loved ones need psychological and social assistance. In general, it can be from 1 to 2 million people, who will be involved in overcoming the difficulties of fighting an incurable disease, physical and spiritual pain [10-14,19-23]. The treatment and care of these patients, huge sums for treatment and social compensatory costs are an unbearable burden both on the shoulders of the family, relatives, and the Ukrainian state [10-14,19-23]. In this situation, the issue of organization and development of palliative and hospice care is urgent and painful, and it is not easy to solve the issue of the fastest and large-scale introduction into the social and medical present of the country [10-14,19-23]. According to modern international approaches and concepts, and according to WHO's calls, palliative medicine should be an integral, integrated component of medical care and social care, and should be part of the structure of national health care systems [24-30].

The word "hospice" comes from the Latin word "hospitum", which means affection, hospitable reception, hospitable home [24-30]. This medical and social direction, new for our society, is aimed at making life easier for hundreds of thousands of Ukrainians and their relatives, with the aim of providing seriously and terminally ill people with decent conditions in the last days of their earthly existence, in severe and sometimes incurable illness, in pain and suffering [24-30]. The appropriate form of care for a seriously ill person is palliative and/or hospice care. A hospice is a place where an elderly person or a seriously ill patient should receive comprehensive help and care [24-30]. Patients with incurable, progressive diseases are surrounded by this help. The main goal of treatment in this case is, first of all, to relieve physical and psychological pain, as well as to provide the sick person with spiritual support and all other types of activities that are designed to provide the patient, in this situation, with a better quality of life. In hospice, the focus is not on death and suffering, but on the value of life, regardless of its condition [24-30]. Unfortunately, there are more and more such people all over the world, including in Ukraine. The provision of hospice care involves receiving medical assistance and care for patients around the clock and full provision of means for pain treatment, in accordance with WHO recommendations, care for the treatment of other symptoms, nursing care and rehabilitation services, according to the appointments of the hospice doctor [24-30]. In addition, the duty of hospice care includes the provision of specialized medical consultations, both in the inpatient department of the hospice and at home, ensuring the implementation of all prescribed examinations and research, providing the necessary transportation [24-30].

Aim of study

The purpose of writing this article is an attempt to highlight the retrospective and current state of palliative and hospice care in Ukraine.

Material and methods

Analysis and generalization of available literary data and sources of information on the studied issue; analysis and generalization of the available scientific and methodological base of the main international organizations, the EU, and Ukrainian national institutions for the provision of palliative and hospice care; analysis of statistical reporting in Ukraine on issues of palliative and hospice care over the past 20 years, before the war started.

Results and discussion

The degree of scientific development of theoretical and practical problems in the implementation of international standards in the field of palliative care in our country cannot be called sufficient [10-14,19-23]. In Ukraine, during the period of its existence as an independent state, scientists covered only certain aspects of this issue in their works [19-23,31-33]. Among the Ukrainian scientists who dealt with the problems of palliative and hospice medicine, the following scientists should be noted: L.I. Andriishyn, V.V. Bezrukova O.E. Bobrova, N.V. Verzhikovska, Yu.I. Gubskiy, N.B. Datsun, I.I. Kulikov, N.N. Sachuk, V.V. Tchaikovsky, Y.I. Gubskiy, A.V. Tsarenko, O.O. Wolfa N.G. Goydu, V.M. Knyazevicha, V.G. Serdyuka, I.V. Yakovenko, O.P. Bratsyun and others [10-14,19-23]. In Ukraine, palliative care, as an approach that allows improving the quality of life of patients with incurable diseases, began to develop from the end of the 90s of the 20th century. At that time, the first Ukrainian hospices were opened - in 1996 in Lviv, in 1997 - in Ivano-Frankivsk and Kharkiv [22,36,39,40]. The first modern hospices appeared in 1996 in Lviv, under the patronage of the Ukrainian Greek-Catholic Church, and in Ivano-Frankivsk on the initiative of the Department of Health Protection of the regional state administration, in Korosten with the support of the Red Cross Society [10-14,19-23]. The first free Ukrainian hospice for cancer patients was opened in 2001, at the Kyiv City Oncology Hospital, by the VALE Hospice International charitable foundation. In 2001, the hospice "Hospice of Archangel Michael" was established in the city of Zaporizhzhia.

The creation of hospices in Ukraine was first proposed in the Program "Health of the Elderly", approved by the Decree of the President of Ukraine "On the Program "Health of the Elderly" No. 1347/97 dated 10.12.1997 [19-23,31-33]. This document provided for the creation of hospitals for patients in the terminal stage (hospices) in the regional centers and cities of Kyiv and Sevastopol. A joint order of the Ministry of Health of Ukraine and the National Academy of Medical Sciences of Ukraine was issued for the implementation of the Program, which defined the terms of hospice creation - 1998-2002 [19-23,31-33]. In 1999, the Association of Minimally Invasive and Palliative Therapy was established. It was this Association that joined the Working Group on Palliative Care in Eastern and Central Europe and spread the recommendations of the Council of Europe regarding the inclusion of the palliative care system in the system of national policy, developed the Manifesto of the hospice movement in Ukraine [19-23,31-33]. In 2002, the All-Ukrainian charitable organization "Council for the Protection of Patients' Rights and Safety" was established (Y.I. Gubskiy, V.G. Serdyuk), which, with the support of the "Renaissance" International Foundation, for the first time raised the socially important issue of ensuring rights before the Ukrainian public patients at the end of life [19-23,31-33]. In 2007, the All-Ukrainian Association of Palliative Care (S.D. Martynuk-Gres) was established, which, together with the Council for the Protection of Patients' Rights and Safety and with the support of the International Renaissance Foundation, initiated the celebration of the World Day of Palliative and Hospice Care in Ukraine (in 2007–2010), the involvement of a number of churches and religious associations in helping the terminally ill, the development of palliative care at home [10-14,19-

23]. In September 2012, with the assistance of the International Renaissance Foundation, Interchem and other sponsors, the League held the First National Congress on Palliative Care in Kyiv, which was attended by more than 350 participants from different countries and continents [15-18]. Fundamentally important steps in the development of palliative care in Ukraine at the national level were the creation of the Institute of Palliative and Hospice Medicine as the main research and organizational and methodological institution of the Ministry of Health of Ukraine for the provision of palliative care (2008) and the Department of Palliative and Hospice Medicine of medicine at the National Medical Academy of Postgraduate Education named after P.L. Shupyka in 2010, which for the first time started professional training of doctors and nurses in this medical and social field [10-14,19-23]. For Ukraine, which is only at the beginning of the path of creating hospices and palliative care, Poland's long-term experience on this path, both positive and, unfortunately, negative, is invaluable. It needs to be studied and understood. Therefore, practical contacts with our nearest neighbor in this matter are relevant and require understanding as a state, government and society that "death is what awaits each of us". Ukraine has been faced with important and difficult issues of introducing palliative and hospice care into medical and social work for a long time, practically from the first days of its independence. The country operated an outdated post-Soviet model of caring for the elderly and senile and terminally ill [10-14,19-23]. For older people, who with age already had a whole "bouquet" of chronic diseases, special boarding schools and so-called "nursing homes" functioned, in which they lived out their lives and died under the supervision of a team of social and medical workers [15-18]. Tuberculosis patients were cared for by anti-tuberculosis dispensaries at the local, regional, and republican levels. There was also its own specificity of treatment and supervision of chronically and seriously ill patients in oncological, endocrinological, psycho-neurological and other dispensaries of different levels of subordination. The most severe patients died either in specially designated wards of specialized departments, or most often, at home, in the arms of relatives and friends, in suffering and pain [10-14,19-23]. In the country, unlike most countries in Europe and the world, there were practically no institutions for providing palliative and hospice care, the first of them began to be created in the 90s of the 20th century on the initiative of foreign charitable organizations and some churches [10-14,19-23]. There has been talk of creating palliative care in Ukraine for a long time, but it has not progressed beyond impassioned speeches, speeches at authoritative gatherings and materials of congresses, congresses, and magazine articles. In Ukraine, the project "Concept of the State Program for the Development of Palliative and Hospice Care in Ukraine for 2010-2014" was created. According to the authorship of V.M. Knyazevicha, A.V. Tsarenko, I.V. Yakovenko, O.P. Bratsyun, at the First National Congress on palliative care held in Irpin on September [26-27]. 2012, the project "National Strategy for the Creation and Development of the Palliative Care System in Ukraine" was presented [24-37]. And already in 2013, the same authors submitted a document entitled "The state, problems and prospects of the implementation of the National strategy for the development of the palliative care system in Ukraine until 2022" for consideration by the state leadership and the public in general [24-37]. In 2009, the first (and so far the only) department of palliative and hospice medicine in Ukraine was created at the P.L. Shupyk National Medical Academy of Postgraduate Education, and in 2013, the State Educational-Scientific-Methodological Center of Palliative and Hospice Medicine of medicine, as a structural division of the academy (as the successor of the SE "Institute of Palliative and Hospice Medicine of the Ministry of Health of Ukraine"). In addition to inpatient care, the direction "Hospice at home" is actively developing [33-45]. Multidisciplinary teams providing palliative care at home were created in Kharkiv (Helping Hand BF), in Vynogradovo of Zakarpattia Oblast (Joint Association of Society), in Mykolaiv (Vita Light BF), Ivano-Frankivsk (Mother Teresa BF " and "Caritas Ukraine"), in Donetsk ("Angel of Mercy" Foundation), in Chortkov, Ternopil region ("Caritas Ukraine" Foundation) and others [31-42].

In Ukraine, as in most developed countries of the world, the problem of medical and social care and palliative care is becoming more and more

relevant every year, as more and more people in the final period of life suffer from serious diseases accompanied by pain, psychological problems, and stress [42-46]. The increase in the number of elderly people in society, patients with oncological diseases, the consequences of strokes and myocardial infarction, and other chronic incurable diseases causes a significant need of the population for specialized palliative and hospice care [42-46]. Over the past three decades, an unfavorable demographic situation has been observed in Ukraine, which is characterized by a relentless aging of the population and an increase in the specific weight of people suffering from severe chronic incurable diseases, primarily malignant neoplasms [21-35]. According to statistics, the number of people aged 60 and older in Ukraine today is 10 million, and the number of people aged 75 and older is about 3 million [21-35]. This leads to an increase in the total mortality of the population of Ukraine. According to WHO recommendations, about 5% of people over 60 years of age need palliative care, and after the age of 75, the proportion of such people increases to 60% [42-46].

In Ukraine, palliative and hospice care develops much more slowly than in the leading countries of Europe and the USA. Over the past 5-10 years, a big step forward has been made, but the number of specialized institutions that provide such medical care in Ukraine, including children's hospices, is limited, and the entire field of palliative care in Ukraine is still far from world standards [19-44]. Despite such a significant number of incurable young patients, there is currently only one children's hospice in Ukraine in the Ivano-Frankivsk region [21-37]. Today, there are about 3 million people over 75 living in Ukraine, most of whom need medical and social care, palliative and hospice care [21-37]. In addition, about 160,000 cancer patients are registered annually in Ukraine, and more than 90,000 patients die from this disease, most of whom develop an extremely severe pain syndrome. Effective pain control in such patients can be achieved only with the use of opioid analgesics [19-44]. Already by 2022, the incidence of oncological diseases is predicted to increase to 200 thousand [3-15]. All over the world, there is a tendency to increase the number of patients with common forms of malignant neoplasms [16-32]. According to the World Health Organization, 3.5 million cancer patients suffer from pain every day in the world [34-41]. Every year, about 500,000 patients of all age groups suffering from serious oncological, cardiovascular, neuropsychiatric diseases, tuberculosis, HIV/AIDS and other incurable diseases in the terminal stages need palliative and hospice care [42-46]. In addition, family members of palliative patients also need professional help. A terminally ill person causes a decrease in the quality of life of the entire family, becomes the cause of severe psychological, social and economic disorders of functioning, impoverishment and destruction of the family. If to the number of palliative patients we add 1-2 relatives who take care of them, then it turns out that about 1.5 million people need palliative and hospice care every year, suffering from physical and moral pain, from the powerlessness to help their loved ones [21-37].

Every year in Ukraine, more than 600,000 terminally ill patients need palliative care - these are cancer patients, elderly people, patients with HIV/AIDS, diabetes, tuberculosis and other terminal diseases [10-22]. About 700,000 people die annually in Ukraine, including more than 100,000 from cancer [23-27]. Also, in Ukraine, there is practically no extensive system of care for terminally ill patients at home, although, according to the statistics of the Ministry of Health, the majority of palliative patients die at home [10-22]. In Ukraine, there is an urgent need to develop a system of palliative care and access to pain relief, since the percentage of provision of this care is extremely low, and about 85% of seriously ill patients do not have access [31-39]. In Ukraine, the development of palliative and hospice medicine is ensured, in particular, by the State Enterprise "Institute of Palliative and Hospice Medicine of the Ministry of Health of Ukraine", which was established according to the submission of the All-Ukrainian Public Organization "All-Ukrainian Council for the Protection of Patients' Rights and Safety" dated June 9, 2009 by order of the Ministry of Health of Ukraine No. 159-0 dated July 24, 2008, as a basic scientific-methodological and clinical institution for palliative and hospice care for people with incurable diseases and a limited life expectancy (prognosis of life) [31-39]. Palliative care for

children is a step towards a civilized society [41-46]. In order to develop the system of providing palliative care to children in Ukraine, today it is extremely important to conduct in-depth scientific research on the nosological, social, psychological and other features of the palliative state of children, to introduce appropriate changes in medical standards and protocols without fail, to develop a unified approach, taking into account opinions of parents, charities and public organizations regarding the development and approval of typical models of palliative care institutions for children [10-21]. According to the summarized statistical data of the Ministry of Health of Ukraine, during 2015, more than 30 thousand children needed palliative care, long-term care and received medical care in health care institutions [10-21]. Unfortunately, today there is no integrated system of specialized institutions for providing palliative care to children [19-32]. There are not enough hospices, appropriate departments in children's hospitals, the practice of using mobile teams to provide palliative care at the child's place of residence is not widely implemented today [19-32]. According to the Chairman of the Board of the Association for the Promotion of Palliative and Hospice Care, former Minister of Health of Ukraine Vasyl Knyazevich, there are no clear statistical data on adults and children in need of palliative care in Ukraine [21-37]. Thus, according to the Ministry of Health, there are about 17,500 children, according to UNICEF, this number can range from 30 to 70,000 young patients []. Ukraine is among the top ten countries in terms of cancer incidence rates, every year 200,000 new patients appear, 100,000 die, and each of these patients at a certain stage needs palliative care [21-37]. According to data from the World Health Organization, 85% of seriously ill Ukrainians do not have access to pain relief [49], and the provision of adequate palliative care to patients in our country is extremely low [28-43]. Data from experts of the All-Ukrainian public organization "Ukrainian League for Promotion of Development of Palliative and Hospice Care" indicate that over the past 5 years, about 1.5-2 million patients and members of their families annually need palliative care, the purpose of which is to alleviate the physical pain of patients and provide them with psychological and spiritual support for their families [38-43]. However, Ukrainian medicine is unable to fully meet these needs. The first is due to the lack of special institutions, qualified workers, as well as the unavailability of high-quality methods of pain relief [25-35]. The number of palliative care units and hospices in Ukraine does not meet civilized requirements, because according to expert data, there are about 20 institutions in Ukraine that can be identified as hospices and palliative care units, which have about 850 hospice beds deployed, with a minimum need of 4.5 thousand beds [24-30].

But the main problem of hospices is not only their number, but also their underfunding. After all, now only 13 hryvnias are allocated daily for the food of one patient of the Kyiv hospice [24-30]. According to Vasyl Knyazevich, head of the League of Palliative and Hospice Care, "the issue of palliative care is not a problem of one day, one industry or one solution. This is a long road, a change in the culture and philosophy of the Ukrainian people regarding helping each other" [24-31]. In recent years, significant changes have taken place in the organization and functioning of palliative hospice care in Ukraine. About 40 institutions that provide palliative care and operate on various bases - state, communal, charity [32-40] have been created and operate. According to preliminary expert assessments, Ukraine should have at least 4,500 inpatient beds for palliative and hospice care. According to estimates by WHO experts, the need for palliative care is an average of 7 beds in hospitals and 10 patients who need palliative care at home per 100,000 population [32-40]. Based on this, there should be at least 3.7 thousand palliative beds in Ukraine. In addition, about 85 thousand patients daily need palliative care at home [41-46]. Currently, Ukraine has an extremely imperfect system of palliative care for children: care is provided in medical institutions according to the child's disease profile by medical personnel who usually do not have sufficient skills and conditions to provide this kind of care [24-31]. In Ukraine, the need for inpatient and outpatient palliative care is met for only a small percentage of patients. As a result, hundreds of thousands of patients in the terminal stage of cancer and many chronic incurable diseases who require palliative and hospice care die at home alone, suffering from pain, depression, other symptoms of diseases, in the

absence of the necessary anesthesia, professional care, social and psychological support [32-46]. In addition, today in Ukraine palliative and hospice departments of treatment and prevention institutions are extremely limited in resources and do not have the ability to provide patients with even the most necessary: medical equipment, effective pain relievers, anti-bedsores mattresses and other medical devices. Unfortunately, due to a lack of funds, the material and technical base of many operating hospices and palliative care departments does not yet meet international standards, and the conditions of patients' stay in these institutions are unsatisfactory, which can be considered as a violation of patients' rights [32-46].

Conclusions:

1. As of May 1, 2022, in many regions of Ukraine, neither the bed fund nor the material and technical base of operating hospices and departments of palliative and hospice medicine meet international standards, and the conditions of stay of patients in these institutions are not always satisfactory.
2. The provision of palliative and hospice care in Ukraine needs further development, both at the level of creating new and modernizing already established departments, and in the matter of training a sufficient number of highly qualified and specially trained medical and nursing staff, nurses, auxiliary staff and attracting volunteers from voluntary and charitable organizations.
3. To date, in Ukraine, methodological principles for the study of the rights of incurable patients have not been developed, there are no special laws, relevant standards, protocols regulating legal relations in the provision of palliative care; the system of appropriate training of specialists who provide palliative care is not regulated.
4. One of the urgent issues in the development of the palliative care system is the urgent development of national palliative care standards, protocols of medical recommendations and instructions for specialists who provide palliative care in health care and social welfare institutions and at home.
5. Regarding the educational training of future and existing specialists in the provision of Palliative Hospice Care, the following should be noted:
 - a) it is necessary to continue the scientific and methodical work in the direction of creating and improving the system of training, retraining and upgrading the qualifications of medical workers - specialists in palliative and hospice medicine, with an emphasis on the features of providing Palliative Hospice Care to both adult patients and children;
 - b) when training nurses in Ukraine, it is necessary to introduce the study of the course of providing palliative and hospice care both at the undergraduate and postgraduate stages of training. For this, it is necessary to separate the study of providing Palliative Hospice Care into a separate discipline and significantly increase the number of both theoretical and practical hours, taking into account, for example, the experience of studying this discipline by nurses in neighboring Poland at all levels of training of nurses.
 - c) If possible, practical classes on palliative and hospice care should be held both in specialized departments of Palliative Hospice Care, where there are terminally ill patients (oncological, hematological, neurological, etc.), and in hospices.

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