PROBLEMS OF PALLIATIVE AND HOSPICE CARE IN TERRITORIAL COMMUNITIES AS A PART OF PLACE BRANDING

Abstract. In the EU, palliative care is a comprehensive system of patient support: social, psychological, spiritual and, of course, medical care. How it works in other countries and what the experience should be applied so that children in Ukraine can not only adequately anesthetize, but also not violate their rights. These and a number of other issues and challenges today are highlighted in this study. The object of research is palliative and hospice care. The research was preceded by the following questions: to analyze current problems of palliative and hospice care in Ukraine and the world; to analyze the regulatory and legal support for palliative care in Ukraine; to study statistical data on the need for palliative and hospice care in Ukraine and local communities; to conduct a survey of residents of the united territorial communities on their awareness of palliative and hospice care and its needs in communities; to develop recommendations for the implementation of modern methods of palliative care for residents of united territorial communities. The analysis examined the experience of European countries in this issue and the challenges facing Ukraine. The legal framework governing the provision of palliative care to terminally ill patients in Ukraine was analyzed. A representative survey was conducted on public awareness of the provision of palliative and hospice care to patients among the population of Sumy region. 150 respondents took part in the survey: 33% of women and 67% of men. According to the results of the research, hypotheses about the problems and needs of hospice and palliative care were confirmed. It has been found that the elderly and people with incurable diseases need it the most, and most agree that such people should be cared for in special institutions that need to be formed at the level of territorial communities. Which in turn has a significant impact on the place brand formation due to the stakeholders involvement. As a result of the study, proposals were presented to address current issues of palliative and hospice care in Ukraine, using the experience of EU countries and the implementation of it through the efforts of local communities, which in turn forms the brand of the place.

Keywords: palliative care, palliative care, hospice care, medical system, hospice, territorial communities, territorial marketing, place branding.
Introduction. The urgency of the problem of palliative care and hospital care (PHC) among the population increased significantly in the second half, and especially - in the late twentieth century due to a significant increase in the number of people dying from chronic, serious, incurable diseases. About fifty-two million people die each year in the world. It is estimated that tens of millions sick people die each year from serious physical and mental disorders. In particular, about five million people die each year from cancer, suffering from severe pain and mental depression. In Ukraine, this number is about 90 thousand people.

In addition, since the end of the twentieth century, the world has undergone profound demographic and social changes, typical of most post-industrial countries, in particular (in recent decades) for Ukraine. These changes are the population ageing with a significant accumulation in the elderly population and corresponding significant changes in the structure of morbidity and mortality, especially among the elderly people (Knyazevych, 2013, Tsarenko, 2016, Tsarenko, 2018).

The organization of patients palliative care has always been a pressing issue in the healthcare industry. After being diagnosed with clinical group IV, these patients are alone with their problem and receive neither specialized medical care nor social and psychological support. Very often the main frustrating syndrome of the patient's life is a chronic pain, which requires constant anesthesia. Adequate psychological specialists assistance, social support, communication with relatives - these are the main factors of palliative care, without which it is impossible to imagine a reduce the patient's suffering (Shekera, 2018, Tsarenko, et al., 2019). That is, there is a significant difference between what patients could receive and what they actually receive. All these factors significantly complicate the situation in the patients families.

Literature Review. The problem of palliative and hospice care is very carefully considered in the world and in Ukraine.

The area of research on palliative care in Ukraine has been studied, in particular, by such scientists as K. Aymedov, L. Bilyk, G. Bondar, Y. Voronenko, Y. Gubsky, K. Danyliuk, D. Dyachuk, K. Danyliuk, Zh. Zolotareva, S. Kryukov, I. Kuzhel, E. Moskvyak, S. Prokip, V. Shatilo.

In the article by Shevchenko (2017) was analyzed the main problems of hospice and palliative medicine both in Ukraine in general and in the Kherson region in particular. The author believes that under these conditions, proper professional training of nurses is an extremely important task.

K.V. Danyliuk studied the essential characteristics of palliative and hospice care. The etymological meaning of the terms is defined in the article. The essence of the category "palliative" is revealed through the connection with the field of health and social protection, namely with: the process of allocation and provision by the state to certain categories of sick drugs, chemicals drugs and medicines, the use and application of which reduces their pain, the suffering from which they suffer (Danyliuk, 2018).

Savka (2019), in his article, notes that the provision of palliative and hospice care in Ukraine needs further development both at the level of creating new and modernizing existing departments, and in training a sufficient number of specialists - nurses and doctors, social workers.

In the article, H. M. Kurnytska (2018) proposes a strategy for the development of palliative care in Ukraine until 2027. The strategy proposes to systematically regulate the organizational framework for palliative care, including the development of legal and organizational mechanisms that promote effective health care and ensure the development of a network of palliative care facilities.

Political and legal issues of palliative and hospice care for incurable patients in Ukraine are also considered. Palliative care is a human right to dignity at the end of life. Dignity, including the absence of fear, pain and loneliness, the right to a dignified end to one's life. The main task of palliative care is to maintain and improve the general patients well-being in the terminal stage of the disease.
Methodology and research methods. To achieve the goals used these research methods: comparative, analytical, statistical, questionnaire method. The information base of sociological and medical-demographic researches.

Comparative method was used to compare the development of palliative medicine in different countries. The United Kingdom, Poland, Iceland and Germany were elected.

An analytical method was used to analyze the comparison of countries and statistics collected after the survey. The statistical method was used to collect, process and analyze information.

A questionnaire was created for the study, which consists of 3 parts: general questions, detailed and passport part. The main questions were about public awareness of palliative care.

The survey involved 150 respondents, including 33% female and 67% male, 91% are city residents and 9% live in a village. The age of the surveyed respondents ranged from 25 to 46 years and more, namely: 25-30 years - 15.2%, 36-45 - 39.4% and 46 and more - 39.4%.

Results. Palliative care is a comprehensive approach aimed at ensuring the highest possible quality of life for palliative patients and their families by preventing and alleviating suffering through early detection and accurate diagnosis of pain and disorders symptoms, adequate treatment, symptomatic (adjuvant) therapy and care, psychological, social, spiritual and moral support, regardless of illness, age, social status, nationality, religious and political beliefs, place of residence of the patient, etc. Palliative care is based on a comprehensive interdisciplinary assessment of the patient's physical condition, the degree of pain and dysfunction, psycho-emotional, cognitive and cultural characteristics, the maximum possible and comprehensive consideration of the needs and wishes of the patient and his family, prognosis and life expectancy. Palliative care begins from the moment of diagnosis of incurable progressive disease and limited life expectancy and continues until the end of the family grief period (MOH, 2017, Goyda, 2015).

Today, more than 25.5 million people in the world die each year from serious incurable diseases, and another 35 million people are living in the final stages of the disease. Unfortunately, a significant percentage of such patients suffer from excruciating pain, severe dysfunction of organs and systems of the body, depression, etc., which causes a significant reduction in their life quality. Experts estimate that approximately 26.8 million to 40 million patients in the world need palliative care (PC) each year (Brennan, 2007).

In the EU, palliative care is not just about painkillers and hospitals. This is a whole system of support: social, psychological, spiritual and, of course, medical care. How this works in other countries and what experiences should be applied so that Ukrainian children can not only adequately provide pain relief, but also not violate their rights, we will consider the example of three countries.

United Kingdom. The palliative care system for children in the UK is only 30 years old. Here they work at the beginning of a «decent life to the end». There are a total of 220 dormitories in the country, most of which are funded by charities. These institutions are also supported by local communities and philanthropists. State aid, depending on the hostel, is from 10 to 30%. In the UK, it is recognized that it is more profitable to keep teams on the ground and help only at home, but at the same time, a dormitory in the UK is an indicator of quality. In the UK, as in other European countries, the home care system is well developed. Children are cared for by doctors, nurses, social workers and volunteers. Therefore, children usually go to the hospital several times a year when needed or when parents need rest. This is 16 free days for the family each year (Lapotnikov, 2003, Chaikovska et al.,2018).

Poland. A feature of palliative care in Poland is the interaction, equality of patient and doctor. The same hospital is not a medical institution, it is a social center where not only medical services are provided, but also many others. Such institutions also participate in information activities. There are rooms where doctors, social workers, and public figures share their experiences in a free circle. There is also education for relatives of patients, so the dormitory seems to delegate powers, unlike Ukrainian parenthood. Another feature of palliative care in Poland is the lack of access to adequate pain relief. As a result, doctors
generally give patients and their relatives knowledge and a note about everything they can do at home without a doctor's supervision. Parents are taught to care for their children at home (WHO, 2019).

Iceland. In terms of hospitality and palliative care, this island nation is interesting in terms of legislation that has a fairly broad guarantee of children rights in need of palliative care. Article 27 of the Icelandic Patients Law №74 / 1997 «On Patients' Rights» provides: «Every effort shall be made to enable a sick child to develop and enjoy life, regardless of illness or medical care, as permitted by the child's condition». The law also stipulates that children should be excluded from unnecessary examinations and procedures. As in the UK, the right to stay in a medical facility with parents is enshrined in law. Brothers, sisters and friends also have the right to visit the patient. Depending on the state of health, Icelandic children, regardless of their location, have the opportunity to continue their education. In Iceland, it is considered necessary to fully comply with the child's wishes regarding the distribution of time, and they believe that it is necessary to be specific and competent in the process of explaining to the child the meaning of death. Icelanders believe that children must ensure the fullness of life, even if they do not live long, that it is necessary for a child to leave the world with a sense of duty and goal in life (WHO, 2019, Voronenko, 2014).

Germany. Today, there is a fairly dense network in Germany, which includes more than 300 palliative care clinics, 236 inpatients and about one and a half thousand outpatients. In addition, more than 300 mobile groups are assisting dying patients. Each group consists of doctors, nurses or siblings, physiotherapists, clergy and social workers. In 2015, under the influence of new large-scale discussions on euthanasia, Germany passed a law that effectively equates palliative medicine with traditional medicine. All the costs of creating decent living conditions are borne by the health insurance system. In 2016, this value exceeded 600 million euros. People in need of palliative care include not only patients with end-stage cancer, but also, for example, people with incurable heart disease, Parkinson's disease, acquired immunodeficiency syndrome, severe kidney, lung or liver disease. In most cases, it is about relieving a persons unbearable pain with strong painkillers containing care (WHO, 2019).

As the examples of four European countries show, we do not have access to pain relief. In civilized European countries, the emphasis is very different in the context of hospitality and palliative care.

More than 600,000 people in Ukraine need palliative care. More than 200,000 of them are children. Only 15% of the total number of patients can receive quality palliative care (Knyazeyvych, 2013b, Kolenichenko, 2014, Kolenichenko, 2016).

There is no clear legislation in Ukraine that would define the procedure for providing services to children in need of palliative care. Thousands of young patients with serious illnesses and their parents cannot be sure what pain they have received. Despite the permission to prescribe the so-called gold standard of anesthesia for children - morphine in syrup, doctors are still hesitant, and some of them do not even recognize the fact that children suffer from pain because it is «invisible». There is no procedure for providing palliative care by medical institutions and palliative care by social institutions. There is no definition of who is a child in need of palliative care. The issue of hospitals is also relevant, as is the need to create and establish interdisciplinary palliative care groups. Parents need help and clarification. And although this is not the case, palliative care in Ukraine is a constant overcoming of obstacles, walking in agony in a circle (Bezrukov, 2000, Tsarenko, 2013).

Patients in need of palliative care are seriously patients with a diagnosis that limits their life expectancy. As of 2019, there are 5.3 million children in the world in need of palliative care, and only 1% of them have access to it. According to experts, there are more than 200,000 young patients in Ukraine who need palliative care, but can receive only 15% of the total (Voronrenko, 2014, Tsarenko, 2019).

In Ukraine, a European model of palliative care should be introduced, which includes three links: family doctor - mobile service - hospital care (hospital) (Kniazevych, 2015a, Kniazevych, 2015b).
Currently in Ukraine it is proposed to create 2 packages of palliative care: «Palliative care for adults and children» and «Mobile palliative care for adults and children».

The tariff for palliative care was increased in 2021: for mobile palliative care for one patient, the institution will receive UAH 14,066 from the National Health Insurance Fund and UAH 13,129 for inpatient care.

The calculation of adult needs is based on mortality and quality, and accuracy will depend on the accuracy of the proven cause of death. According to the State Statistics Service, the need for palliative care is 343.5 thousand adults (985 people per 100 thousand adults) (Figure 1).

The first place in the prevalence of death and the need for palliative care among the adult population of Ukraine is occupied by diseases of the circulatory system (753.1 per 100 thousand population aged 18+), followed by malignant neoplasms (180.4/100 thousand), chronic obstructive pulmonary disease (12.9 / 100 thousand), cirrhosis (11/100 thousand), tuberculosis (10.5/100 thousand), HIV/AIDS (9.2/100 thousand), diabetes (3, 6/100 thousand), kidney disease (2.6/100 thousand), Parkinson’s disease (0.4/100 thousand), Alzheimer’s disease (0.3/100 thousand) and rheumatoid arthritis (0.3/100 thousand) (SSSU, 2020a).

According to the simulation, every thirtieth child needed palliative care - i.e. 3348 children per 100 thousand children (Figure 2).
The first place in terms of prevalence and need is occupied by diseases of the circulatory system (1592.4 per 100 thousand children), the second place - congenital malformations (128.6/100 thousand), the third - cerebral palsy (130.3/100 thousand). Then the prevalence - perinatal conditions (102.2/100 thousand), diabetes (70.6/100 thousand), malignant tumors (62.1/100 thousand), mental retardation (47.6/100 thousand), inflammatory diseases of the CNS (39.9/100 thousand), tuberculosis (6.5/100 thousand) and chronic hepatitis (6.0/100 thousand) (SSSU, 2020b).

The total need for palliative care among children was 255 thousand people. It is currently unknown how many children actually received palliative care, as there are no relevant statistical tools, forms of medical statistical reporting, etc.

Figure 3. The need for palliative care for each territory (total in Ukraine, people)
Sources: developed by the authors.

Among the regions of Ukraine are Kharkiv and Dnipropetrovsk regions - the general need for palliative care in Kharkiv region 25.4 thousand for adults and 28.4 thousand for children. In the Dnipropetrovsk region - 31.5 thousand (Figure 3) (Etkind et al., 2017).

With the help of the questionnaire we can analyze the public awareness of the hospital and palliative care, as well as suggest ways to improve, provide nursing care in the field of palliative care.

Thus, 150 respondents took part in the survey. When asked about the importance of palliative care, 85% of respondents said that it is a type of medical care for people with serious illnesses (Figure 4).

Figure 4. The results of the study on the question «What is palliative care?»
Sources: developed by the authors.
About raising public awareness about current issues of modern health care, 100% of respondents said they were informed about it. About the need for hospital gowns 150 respondents, 97% of respondents answered «yes» (Figure 5).

![Figure 5. The results of the study «Is there need for hospice gowns?»](image)

Sources: developed by the authors.

Who needs hospice chambers, 62.5% of respondents believe that they need patients who are not cared for, 46.9% - people who have no relatives, and 50% of incurable patients (Figure 6).

![Figure 6. The results of the research on the question «Who do you think hospice chambers need?»](image)

Sources: developed by the authors.

According to the respondents, the state should pay for the maintenance of hospices - 91% (Figure 7).

![Figure 7. The results of the study on «Who do you think should pay for hospices?»](image)

Sources: developed by the authors.

We see that 76% of respondents believe that palliative care for patients should be provided in special institutions, 22% believe that in medical institutions (Figure 8).
According to the respondents, oncology patients (26, 81.3%) and patients with severe physical pathology (20, 62.5%) need more palliative care (Figure 9).

Figure 9. The results of the study on «Who do you think needs palliative care?»
Sources: developed by the authors.

According to the respondents, palliative care should be provided (Figure 10):
- Along with the treatment of the underlying disease - 43.8% (14);
- Since the diagnosis - 40.6% (13);
- The last weeks of life - 40.6% (13);
- After radical treatment - 21.9% (7).

Figure 10. The results of the study on «When do you think palliative care should be provided?»
Sources: developed by the authors.
The problem of caring for desperately ill and elderly people 9.4% - who now care for such people, 25% - relatives of people in need of palliative care and 65.6% have not dealt with and do not need palliative care (Figure 11).

![Figure 11](image1.png)  
*Figure 11. The results of the study on the question «Have you or your loved ones faced the problem of caring for the terminally ill or the elderly?»
Sources: developed by the authors.*

Almost 54% of people have an elderly family member who needs medical care. 46.9% do not have (Figure 12). Of these, 21.9% suffer from incurable diseases, 78.1% do not get sick (Figure 13).

![Figure 12](image2.png)  
*Figure 12. The results of the study on «Are there elderly people in your family who need medical care?»
Sources: developed by the authors.*

![Figure 13](image3.png)  
*Figure 13. The results of the study on the question «Are they suffering from an incurable disease?»
Sources: developed by the authors.*
Of the total number of respondents, 68.8% are willing to pay for palliative care (Figure 14).

![Figure 14. The results of the study on «Are you ready to pay for palliative care?»](..)
Sources: developed by the authors.

According to respondents, more money should be spent on medicines - 20 people, 100 votes - for medical staff, 20 votes - for equipment and 10 - for food. Most respondents believe that most of the money paid should be used for medical staff. Food, equipment and medicine received almost the same number of votes. (Figure 15).

![Figure 15. The results of the study on the question «What do you think should be used most of the money you pay for palliative care?»](..)
Sources: developed by the authors.

**Conclusions.** So, in conclusion, we can see that the elderly and people with incurable diseases need a lot of hospice care, most agree that such people should be cared for in special institutions. Patients who have no one to take care of also need hospice care.

The problem of palliative care is relevant for all countries of the world, including Ukraine. Therefore, we propose a program that will improve the situation in Ukraine:
- the European model of palliative care should be introduced, which includes three links: family doctor - mobile service - inpatient care (hospice);
- create a constantly updated register of children and adults in need of (mobile and inpatient) palliative care;
- Introduce the Leadership of Territorial Communities, involve public organizations and volunteer movements to solve existing problems in hospice and palliative care, including social and psychological support.

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Проблеми паліативної та хоспісної допомоги в територіальних громадах в складі брендингу місця

У країнах ЄС паліативна допомога є комплексною системою підтримки хворих: соціальна, психологічна, духовна і, звичайно, медична допомога. Як це працює в інших країнах та які досвід слід застосовувати, щоб діти України могли не лише адекватно знеболити, але й не порушувати їхні права – це та низка інших питань і виклики сьогодення, виствлені у дослідженні. Об’єктом дослідження є паліативна та хоспісна допомога. Постановлені такі завдання дослідження: проаналізувати сучасні проблеми паліативної та хоспісної допомоги в Україні та світі; провести аналіз нормативно-правового забезпечення надання паліативної допомоги в Україні; вивчити статистичні дані щодо потреби паліативної та хоспісної допомоги в Україні та територіальних громадах; провести опитування жителів об’єднаних територіальних громад щодо їх освідомленості з питань паліативної та хоспісної допомоги та її потреби в громадах; розробити рекомендації щодо впровадження сучасних методів надання паліативної допомоги мешканцям об’єднаних територіальних громад. У ході аналізу було досліджено досвід європейських країн у даному питанні та виявилося, що стоять перед Українкою. Були проаналізовані нормативно-правові засади, які регламентують надання паліативної допомоги невиліковно хворим пацієнтам в Україні. У ході аналізу було виявлено недопустимі наступні. Було проведено власне дослідження цільової аудиторії паліативної медицини методом анкетування. Було проведено представницьке опитування щодо обсягів надання паліативної та хоспісної допомоги хворим серед населення Сумської області. В опитуванні взяли участь 150 респондентів: 33% жінок і 67% чоловіків. За результатами проведених досліджень була підтверджена гіпотеза щодо проблем та потреб в хоспісній та паліативній допомозі. Встановлено, що найбільше її потребують люди пожилого віку та з невиліковними хворобами. Більшість респондентів згодні з тим, що такі люди потребують надання паліативної допомоги в спеціальних закладах.

Ключові слова: паліатив, паліативна допомога, хоспісні, територіальні громади, територіальний маркетинг, брендинг місця.