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Palliative and hospice care in the Kharkiv region in the first year of the war

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Паліативна та хоспісна допомога в Харківському регіоні в перший рік війни

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Introduction

Palliative and hospice care (PHC) is necessary for patients with terminal illnesses and a limited life expectancy. The development of the PHC system in pre-war times in Ukraine was insufficient in comparison with the best world practices, as evidenced by the inclusion of Ukraine by the World Health Organization (WHO) in group 3a according to the modified classification of countries by the PHC development level of according to Wright, Lynch and Clark, 2008/2011 [1], that is, to countries in which separate palliative care centers operate, but whose work does not have signs of systemic integration into the national health care system. According to the number of beds, Ukraine is provided with palliative care by 40.5%, given the practical absence of hospices at home [2]. The PHC system of Ukraine faces a number of traditional problems, including an insufficient list of diseases for which assistance is provided, difficult access to narcotic analgesics for palliative patients with severe pain, lack of palliative services within walking distance for most palliative patients, etc. [1; 2].

The war added to the list of problems in the PHC organization staff shortage, hospitals and ambulances damaged by shelling, roads along which ambulances reach palliative patients. Thus, according to the WHO [3], during the period from the start of the full-scale war in Ukraine (from February 24, 2022 to September 1, 2023), 1,024 buildings of medical facilities, 18 medical warehouses, 302 laboratories and diagnostic centers ("complexes of medical equipment"), and 133 ambulances were damaged in Ukraine as a result of Russia's military aggression. During 1,147 attacks on medical institutions and transport, patients were injured or killed 27 times, and medical staff – 78 times.

At the same time, 151 people were injured and 104 people died. A significant number of qualified medical workers went abroad to escape the war. The Kharkiv city community and a significant number of other territorial communities of the Kharkiv region are included by the Ministry of Reintegration of the Temporarily Occupied Territories of Ukraine in the list of territories where active hostilities have been taking place since the beginning of the war. At the beginning of the war, a large part of the Kharkiv region was occupied. As of the beginning of September, the city of Kharkiv and many settlements in the Kharkiv region are under constant shelling. At the same time, it should be noted that seriously ill, palliative patients often remain in their homes, because their evacuation is technically difficult for both the social services of the state and the patients' relatives. Moving palliative patients to shelter during air raids is difficult. WHO also notes that palliative patients are one of the most vulnerable categories of patients during hostilities due to their health condition and low mobility [4].

In large cities of Ukraine, hospices have been established that partially meet the needs of palliative care patients. Also, palliative wards or beds operate in multidisciplinary hospitals and specialized hospitals, mainly for infectious, neurological and oncological treatment. Funding for hospices, palliative wards, beds and mobile palliative teams is carried out by the National Health Service of Ukraine (NHSU), which hospitals order, usually per year. The movement of palliative patients across the country due to the war does not allow hospitals to simply redirect funding according to the principle "the money follows the patient", but requires an order for funding from the NHSU and the readiness of the hospital that accepted the new palliative patient to organize everything necessary

for palliative care [5–7]. In this way, funding is to some extent tied to hospitals and territorial communities.

The aim of the study

Our study was conducted to analyze the performance indicators of the hospice of the Kharkiv region, which is the main specialized palliative hospital. The analysis took into account the compliance of the needs for PHC of the Kharkiv region's with the results of the hospice's work and adaptability to the conditions of the first year of a full-scale war.

Object and research methods

The object of the study is the indicators of the annual activity (for 2022, the first year of the full-scale war in Ukraine) of the Communal Non-Profit Enterprise of the Kharkiv Regional Council "Regional Center of Palliative Medicine "Hospice"" (hereinafter – "Hospice"). Bibliosemantic and medical-statistical methods, as well as the method of system analysis, were used for the research.

Statistical reports of "Hospice" for the period 2016–2022, databases on the need for PHC of the Ukrainian Center for Public Data, citizens' appeals for PHC to the Kharkiv Regional State Administration (Kharkiv Regional Military Administration), scientific publications on PHC at Google Scholar and PubMed were analyzed.

Research results and their discussion

"Hospice" started its work in 1999. "Hospice" has two departments – neurological (with 50 beds) and oncology (with 30 beds), a clinical laboratory, a food pantry, a laundry, a centralized sterilization department and a disinfection chamber. Thus, the Hospice can accommodate up to 80 patients at the same time, who are served by 92 staff members: 6 doctors, 26 nurses, 28 junior nurses, and 32 employees of the administrative and economic service. A comparison with the staffing schedule (normative)

shows a shortage of doctors in the Hospice (6 rates instead of 13.75), nurses (26 rates instead of 31), junior nurses (28 rates instead of 32.25) and support staff (32 rates instead of 41). Thus, the personnel deficit is 22.0%, and it has increased in comparison with the pre-war year 2021 by approximately two times (from 11.9% to 22.0%). At the same time, the number of bed days spent by palliative patients in 2022, on the contrary, increased by approximately 5% (from 92.96% of the norm in 2021 to 97.70% in 2022). Analysis of feedback from patients and their relatives about the work of the institution (on the website <https://hospis.in.ua/> and according to complaints to the Department of Health Care of the Kharkiv Regional Administration) shows that the quality of PHC in the "Hospice" in 2022 compared to 2021 did not get worse. Accordingly, it can be concluded that the load on the medical and auxiliary staff of the Hospice increased in 2022 compared to the pre-war year 2021.

The analysis of indicators of the implementation of the plan of bed days in the "Hospice" in 2016–2022 (Fig. 1) shows a gradual increase in the bed days spent by palliative patients during the period 2020–2022, while this indicator, on the contrary, decreased in 2016–2018.

During the period 2018–2022, there was a gradual decrease in the number of patients who applied to the "Hospice" for hospitalization: 178, 167, 152, 148 and 109 new patients per year, respectively. This can be explained by the COVID-19 pandemic, a full-scale war, and the increase in hospitals that have a palliative care department under the contract with the NHSU.

About a quarter of Hospice patients live in rural areas. In 2022, there were 28 such patients (25.7%). During the period 2019–2022, 460 residents of the city of Kharkiv (77.2% of the total number of patients), 117 residents of the Kharkiv region (19.7%), 12 residents of other regions (2.0%), were treated at the Hospice. 6 people without a permanent place of residence (1.1% died in the Hospice). Also, in 2022, 11 (8.9%) patients were discharged home, 113 (91.1%) patients died as a result of their stay at the "Hospice". The number of dead patients is the lowest

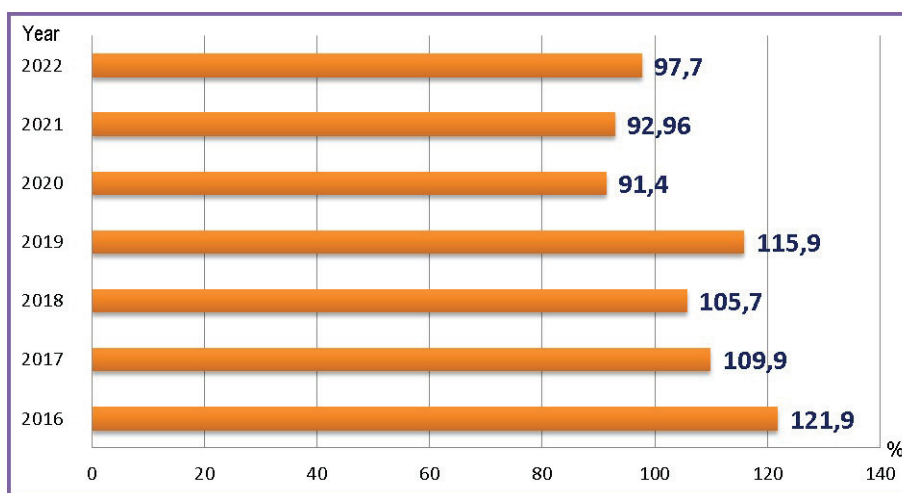


Fig. 1. The indicators of the implementation of bed-day plan in the "Hospice" on 2016–2022

in the last 7 years (the largest number of deaths, 166 patients, was registered in 2016). Over the last 2019–2022, 595 patients were treated at the “Hospice”, of which only 62 (10.4%) were discharged persons, and 533 (89.6%) died, which confirms the fact of treating patients with a severe course of the disease. This confirms the opinion of other researchers that high mortality in hospices is a reflection not of the quality of work of these hospitals, but of the condition of the vast majority of their patients [8; 9].

A comparison of the use of the bed fund in the departments of “Hospice” for 2020–2022 indicates a gradual increase of this indicator (by 7.0% over the last 3 years). However, it should be noted that over the longer previous period of comparison (2016–2020),

on the contrary, it decreased by 33.4%: from 414.3 days in 2016 to 310.6 days in 2020 (Fig. 2). The high length of stay of patients in bed in 2022 compared to the indicators of previous years is due to the presence of severe patients with an unfavorable prognosis for recovery and a long course of the disease. The condition of patients can be more difficult in connection with the stress of war, as well as with the transfer to hospice institutions of difficult patients from the occupied territories [4; 5; 10–12].

An analysis of the age of patients treated at the Hospice for the period 2019–2022 is given in Table 1. The specific weight of patients over 70 years old was 81.7% (486 patients with oncological diseases and degenerative diseases of the nervous system).

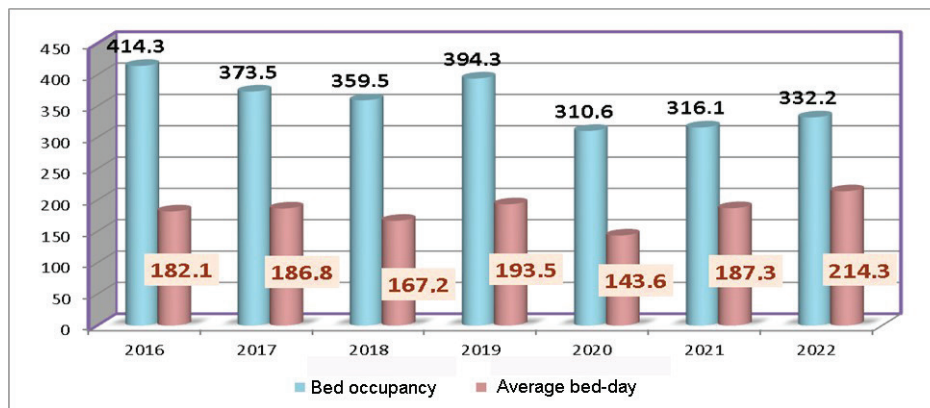


Fig. 2. Indicators of bed occupancy and average bed-day in the “Hospice” on 2016–2022

Table 1

Age composition of “Hospice” patients on the period 2019–2022

Year		Age of patients, years						Total	
		30–39	40–49	50–59	60–69	70–79	80–89		90–99
2019	Discharged	-	-	1	3	3	9	-	16
	Died	-	-	3	14	38	70	22	147
	Treated	-	-	4	17	41	79	22	163
2020	Discharged	-	1	1	4	3	15	4	28
	Died	1	-	7	13	30	74	20	145
	Treated	1	1	8	17	33	89	24	173
2021	Discharged	-	-	1	-	2	4	-	7
	Died	-	5	8	24	28	45	18	128
	Treated	-	5	9	24	30	49	18	135
2022	Discharged	1	-	3	2	5	-	-	11
	Died	-	2	3	12	34	40	22	113
	Treated	1	2	6	14	39	40	22	124
Total treated in 2019–2022		2	8	27	72	143	257	86	595

Out of 595 patients treated in the “Hospice” on 2019–2022, there were 407 (68.4%) female and 188 (31.6%) male. It should be noted that during 2019–2022, the number of female Hospice patients

was always higher compared to the number of male patients (Table 2).

The age and gender composition of “Hospice” patients on the period 2019–2022 roughly corresponds

Table 2

Gender composition of “Hospice” patients on the period 2019–2022

Year \ Sex	Male	Female	Male & Female
2019	59	104	163
2020	45	128	173
2021	48	87	135
2022	36	88	124
2019–2022	188	407	595

to the average Ukrainian indicators for the last decade among palliative patients of neurological and oncological treatment profiles [13]. But it should be understood that the small number of beds of these two treatment profiles compared to the regional need does not allow making reliable judgments. Yes, according to [5; 14] the need for PHC per year among the adult population in the Kharkiv region is 2.6 thousand for neurological and 6.8 thousand for oncological treatment. Therefore, the largest specialized palliative institution of the Kharkiv region provides only approximately 2.0% of the need for PHC for patients of neurological profile and 0.4% of the need for PHC for patients of oncological profile. The question arises about the measures necessary for greater coverage of palliative PHC patients with inpatient and mobile care, moreover, in wartime.

The significant complexity of transporting patients of the specified profiles of palliative treatment [15] in wartime must simultaneously take into account both the need to bring the service closer to patients in remote areas of the Kharkiv region, as well as the safety of patients and medical personnel in conditions of constant shelling. Premises for the inpatient accommodation of palliative patients should be protected to such an extent that during air alarms there is no need to move patients to shelters. Field mobile teams must be provided with protected (armored) transport. Palliative patients from areas of the region where fighting is going on (for example, from the Kupyansk district) must be transferred to the hospice, palliative departments and wards of Kharkiv hospitals. In our opinion, this solution is safer and more realistic compared to providing mobile brigades with armored vehicles.

In our opinion, in the future, regional hospices should be analytical centers that collect data on the needs of PHC in the regions and their provision, create mobile teams to provide PHC needs of patients in the nearest territories according to all profiles of palliative treatment recommended by WHO. Even if the regional hospice itself has only inpatient departments of 1–2 treatment profiles. Thus, according to WHO [1], PHC should be covered:

- among the adult population, patients with malignant neoplasms, cardiovascular diseases, dementia, tuberculosis, diabetes, rheumatoid arthritis, fibrosis and cirrhosis of the liver, chronic obstructive pulmonary disease, HIV/AIDS, kidney diseases;

- among children – with congenital malformations, severe perinatal conditions, cerebral palsy, malignant neoplasms, diabetes, severe and profound mental

retardation, HIV/AIDS, inflammatory diseases of the central nervous system, cardiovascular diseases, tuberculosis, phenylketonuria, cystic fibrosis, chronic hepatitis and mucopolysaccharidoses.

The personnel of mobile teams must be provided with the necessary equipment, means of personal protection against infections, have sufficient qualifications on all issues according to this list of pathology (pass the necessary training and certification).

Prospects for further research

Taking into account the fact that the evaluation of the subjective opinion of patients about the quality of treatment at the “Hospice” was carried out based on reviews on the hospital’s website and complaints (feedback) to the Department of Health Care of the Kharkiv Regional State Administration (Kharkiv Regional Military Administration), we began the evaluation patients’ quality of life according to the standard questionnaire SF-36, recommended by WHO. The first results of the survey of a small group of patients showed the need to modify the questionnaire according to the treatment profile. We are also planning a study to study the need for PHC in patients with different treatment profiles.

Conclusions

Analysis of the work of the largest palliative medical institution of the Kharkiv region “Hospice” allowed to assess the mortality rate, sex-age structure of palliative patients with neurological and oncological treatment profiles. During the period 2019–2022, 96.9% of the patients of the “Hospice” were residents of the Kharkiv region. During this period, women predominated among Hospice patients (407 (68.4%) patients), and 486 (81.7%) palliative patients with oncological diseases and degenerative diseases of the nervous system were older than 70 years, which corresponds to the average Ukrainian indicators.

The work of the “Hospice” provides a small part of the need for PHC of patients with neurological and oncological treatment profiles (2.0% and 0.4% of the estimated need, respectively). However, given the significant size of the Kharkiv region and the need to bring palliative care ambassadors closer to patients, “Hospice” can be an analytical center empowered to analyze the need for PHC and its provision after the war.

The full-scale war had a minor impact on the work of the "Hospice" (objective indicators of work and quality of treatment as assessed by patients and their relatives). Its adaptation was successful due to the fact that Kharkiv was not occupied. For greater coverage of PHC patients in the region (the territories closest to the "Hospice"), it is possible to create more mobile brigades equipped with armored vehicles for wartime, and increase the number

of treatment profiles for palliative patients and, accordingly, the number of beds. Palliative care patients evacuated to Kharkiv from more dangerous areas of the region can be accommodated in the new beds. However, such an organizational measure will require the elimination of the personnel deficit of the "Hospice", which has existed for the past several years both in terms of medical and auxiliary staff of the hospital.

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Palliative and hospice care (PHC) is provided in specialized institutions (hospices), palliative departments and wards of other specialized and multidisciplinary hospitals and mobile teams. In 1999, "Hospice", a communal enterprise of the Kharkiv Regional Council, was established in Kharkiv to provide PHC to patients of the Kharkiv region, which has a neurology and oncology department.

Purpose is analysis of performance indicators of the Kharkiv "Hospice" in the first year of the full-scale war with Russia in comparison with 2016–2021, and assessment of the success of the hospital's adaptation to wartime conditions.

Materials and methods. Bibliosemantic and medical-statistical methods, as well as the method of system analysis, were used for the research.

The results. As a result of the study, it was established that for the period 2019–2022, 96.9% of the patients of the "Hospice" were residents of the Kharkiv region. Among the "Hospice" patients during this period, female predominated (407 (68.4 %) patients), and 486 (81.7 %) palliative patients with oncological diseases and degenerative diseases of the nervous system were older than 70 years. The shortage of personnel of the "Hospice" among medical and auxiliary personnel was revealed (22.0%), which approximately doubled in comparison with the pre-war year 2021 (from 11.9%). At the same time, the number of bed days spent by palliative patients in 2022, on the contrary, increased by approximately 5% (from 92.96% of the norm in 2021 to 97.70% in 2022). In 2022, 113 (91.1%) patients died as a result of their stay in the "Hospice". The mortality rate of "Hospice" patients in the first year of the war slightly exceeded the average for the last 2019–2022 (89.6%).

Conclusions. "Hospice" demonstrated high adaptability to wartime conditions and can increase its contribution to the PCB of the Kharkiv region after the war.

Key words: lethality, need for PHC, staffing, adaptation to wartime conditions.

Паліативна та хоспісна допомога (ПХД) надається у спеціалізованих установах (хоспісах), паліативних відділеннях та палатах інших спеціалізованих та багатoproфільних лікарень та силами мобільних бригад. У 1999 році у Харкові для надання ПХД пацієнтам Харківського регіону був створений «Хоспіс» – комунальне підприємство Харківської обласної ради, що має неврологічне та онкологічне відділення.

Метою є аналіз показників роботи харківського «Хоспісу» у перший рік повномасштабної війни з росією порівняно з 2016–2021 рр. та оцінка успішності адаптації лікарні до умов воєнного часу.

Матеріали та методи. Для дослідження використані бібліосемантичний та медико-статистичний методи, а також метод системного аналізу.

Результати. У результаті дослідження встановлено, що за період 2019–2022 рр. 96,9% пацієнтів «Хоспісу» були мешканцями Харківського регіону. Серед пацієнтів «Хоспісу» за цей період переважали жінки (407 (68,4%) пацієнтів), а 486 (81,7 %) паліативних пацієнтів з онкологічними захворюваннями та дегенеративними хворобами нервової системи були старшими за 70 років. Був виявлений дефіцит кадрів «Хоспісу» серед медичного та допоміжного персоналу (22,0%), який збільшився приблизно удвічі порівняно з довоєнним 2021 роком (з 11,9%). При цьому кількість проведених паліативними пацієнтами ліжко-днів у 2022 році, навпаки, збільшилася приблизно на 5% (з 92,96 % від нормативу в 2021 році до 97,70% у 2022 році). У 2022 році за результатами перебування у «Хоспісі» померло 113 (91,1%) пацієнтів. Летальність пацієнтів «Хоспісу» за перший рік війни незначно перевищувала середній показник за останні 2019–2022 рр. (89,6%).

Висновки. «Хоспіс» продемонстрував високу адаптивність до умов воєнного часу і може збільшити свій внесок у ПХД Харківського регіону після війни.

Ключові слова: летальність, потреба у ПХД, кадрове забезпечення, адаптація до умов воєнного часу.

Conflict of interest: absent.

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