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DETERMINATION OF THE MAIN NEEDS OF PALLIATIVE PATIENTS AND WAYS OF THEIR PROVISION IN THE HEALTH CARE SYSTEM OF UKRAINE

Holovanova I.A.¹, Shevchenko A.S.^{2, 3}

¹Poltava State Medical University, Poltava, Ukraine ²Kharkiv National Medical University, Kharkiv, Ukraine ³Kharkiv Regional Institute of Public Health Services, Kharkiv, Ukraine

The organization of medical care for palliative patients of Ukraine, as well as for other categories of patients, should take into account the data on the number of such patients among adults and children, as well as the characteristics of diseases that are included in the list of palliative diseases depending on their stage and the severity of the patients' condition. In Ukraine, the list of palliative diagnoses is smaller than the list recommended by the World Health Organization and adopted in high-income countries. But even those categories of palliative patients, which are included in the list, receive the necessary help in an insufficient amount. This applies both to the therapy of the underlying palliative disease and to effective analgesia. The reform of the health care system of Ukraine, activated since the beginning of the revolutionary events and the beginning of the occupation of Ukrainian territories in 2014, also extends to the provision of Palliative and Hospice Care (PHC). The PHC financing system at the expense of the Medical Guarantee Program has been significantly changed. A greater number of medical institutions are gradually joining the provision of PHC. Therefore, the discussion on clarifying the list of needs of palliative patients is relevant. This short scientific notice is published for the purpose of discussing the list of stated needs. Emphasis is also placed on the connection between the strategy of the reform of the health care system of Ukraine and the possibilities of effective satisfaction of these needs.

Keywords: palliative and hospice care, PHC, the need for medical assistance, health care financing.



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Визначення головних потреб паліативних хворих та шляхи їх забезпечення у системі охорони здоров'я України. Експериментальна і клінічна медицина. 2021;90(3):88-94. https://doi.org/10.35339/ekm.2021.90.3.hos [англійською].

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Відповідальний автор: Шевченко О.С. Україна, 61022, Харків, пр. Науки, 4, ХНМУ E-mail: as.shevchenko@knmu.edu.ua Corresponding author: Shevchenko A.S. Ukraine, 61022, Kharkiv, Nauky av., 4, KhNMU E-mail: as.shevchenko@knmu.edu.ua

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The high and growing need for Palliative and Hospice Care (PHC) all over the world and in Ukraine [1–3] is the basis for a scientific discussion about the organization of medical care for palliative patients, taking into account all their needs. Increased attention to this category of patients is determined by the significant physical suffering of most of them and the large number of children among the hopelessly ill. PHC in Ukraine is provided in specialized medical institutions (hospices), palliative departments, palliative wards and at home. In the latter case, patients are visited by field teams using ambulances [4]. In order to approve medical institutions' applications for PHC funding by the National Health Service of Ukraine under the medical guarantee program, these medical institutions must meet the list of requirements regarding the availability of the necessary personnel and equipment, and must be ready to organize the provision of both medical care and psychological, social and spiritual support [2; 3; 5]. These needs, forms and methods of providing PHC in Ukraine are presented in the *figure*.

Mobile teams that provide medical and social assistance to palliative patients at home may include not only doctors and nurses (in the future, paramedics), but also social workers, psychologists, priests, and volunteers. Social workers, volunteers during the visit together with the doctor and the nurse, who perform the examination of the patient and carry out procedures (for example, treat bedsores, put on drips, administer painkillers), find out the needs of the palliative patient and his family members, can visit the patient in the agreed time on your own, provide necessary things, mobility aids (sticks, crutches, walkers, wheelchair), purchase food, hygiene and care products. A psychologist and a priest can also provide assistance to both the patient and his family members. Unfortunately, with a need for such services at home, which is measured in the tens of thousands per year [3], we are aware of only dozens of such mixed teams that systematically visit a small number of palliative patients.

Provision of PHC requires special training of medical workers. Solving this

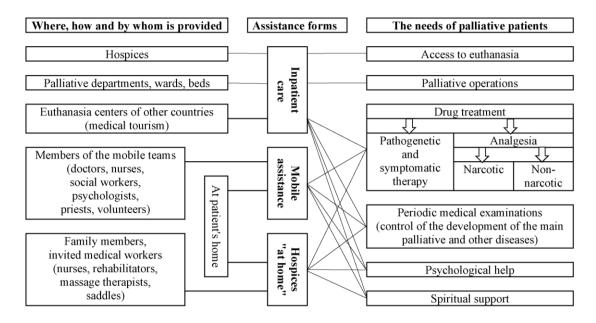


Fig. The main needs of palliative patients, forms and methods of meeting them in Ukraine. © Nesterenko V.G., 2021 (quoted with author's permission).

task is possible either by including PHC issues into the basic curriculum for the specialty "222 - Medicine" for medical students, in disciplines studying palliative nosology, or by creating a new discipline "Palliative care". It is necessary to take into account the high load on medical students when increasing the number of disciplines. However, high-quality modern higher medical education cannot do without information about PHC. It is also necessary to take into account the general trend of decreasing the quality of education in Ukraine. Thus, since the beginning of the russian invasion of Ukraine in 2014, several institutions of higher medical education found themselves in the occupied territories of Crimea, Donetsk and Luhansk regions, and were forced to move to other cities in the territory controlled by Ukraine. The quality of education and scientific work in these higher education institutions has decreased, as evidenced by the decrease in the TOP-200 ranking positions [7; 8]. It is also known that the quality of higher medical education is evidenced by the flexibility of educational programs that quickly adapt to social changes [9]. Until the approval of the educational standard "222 - Medicine", the discussion about the inclusion of PHC issues in the standard is particularly relevant.

Ukraine has a demographic trend similar to the average world and European ones. The aging of the population contributes to an increase in the number of palliative patients, as well as significant problems in the preventive direction of medicine and the low commitment of the population to a healthy lifestyle [6]. The situation can be improved in the course of medical reform. However, it is long-term, inefficient, inconsistent in many ways, and in the last few years it has also been conducted against the background of the global financial crisis and the COVID-19 pandemic [10–13].

These factors contribute to the deterioration of the collection of statistical data necessary for the qualitative calculation of the need for PHC, the planning of public spending on the organization of medical care, and ultimately to better meet the needs of palliative patients, adults and children. The context of this situation is also important. Ukraine belongs to the group of world leaders in digitalization of services to citizens [14]. Electronic health care [15] includes areas such as the medical data monitoring and management system, the HELSI.me appointment service and medical data storage, with the prospect of creating electronic hospital and electronic prescription systems. Electronic health care is administered by the SE "Electronic Health" (eZdorovya). The system is used by more than 3,000 medical institutions of Ukraine. More than 225 thousand users turn to it every day, which exceeds the indicators of similar systems in other countries [16; 17]. The introduction of "e-medicine" in the state using information and communication technologies (ICT) was foreseen by the medical reform program "European Health Strategy-2020", developed by the government together with the EU [18; 19]. The program is aimed at creating a unified (integrated) information and analytical system of accounting for the state of health of citizens of Ukraine, foreigners and stateless persons with the collection of data for their subsequent use in analytical and statistical systems; on the creation of a system of remote counseling and diagnostics using ICT and mandatory compliance with the norms of Art. 8 of the Convention on the Protection of Human Rights and Fundamental Freedoms [20]; on the reorientation of the existing system to the needs of the patient, increasing the ability to provide medical care for all citizens of Ukraine at the level of developed European states [21].

The "Ukraine-2020" strategy itself envisages the creation of a patient-oriented system capable of providing medical care for all citizens of Ukraine at the level of developed European states [2; 11; 21– 23]. This strategy is an integral part of the national reform plan announced by the Government of Ukraine. Among its priority areas, important for our research are the tasks of ensuring free choice of providers of medical services of appropriate quality and providing targeted assistance to the most socially vulnerable sections of the population. It also provides for the improvement of palliative and hospice care. The high digitization of state services clearly contradicts the deterioration of statistical data collection. Digitization should, on the contrary, facilitate both work with medical documentation and automatic settings for recording the actions of medical professionals with all categories of patients.

Within the framework of the ongoing reform, which involves the transformation of the hospital network into a single three-level system (local hospitals – regional hospitals – national reference centers), it will be necessary to correctly determine the location of palliative departments and wards. While the importance and place of individual specialized palliative institutions, hospices, is clear. Also, PHC should be truly free for patients and their families. It is known that at the pre-

sent stage, the patients themselves bear a significant joint participation in the payment of medical services. In Ukraine, one of the largest indicators of out-of-pocket expenses for medical services of patients according to WHO data (2018) [24] is 16.7% of household income. During 2019, this contributed to the increase of impoverished households in the country by 10.8% and allowed Ukraine to be considered one of the anti-leaders in the ranking of countries with "catastrophic expenditures" of households on health care. Numerous appeals by seriously ill children to communities in the mass media and social networks to receive private help (donations) for the patient's survival prove the imperfection of the state's financial mechanisms to ensure the medical needs of the population.

Conclusion

Thus, improving the organization of palliative and hospice care in Ukraine corresponds to the strategy of the health care reform of Ukraine. Funding changes are gradually increasing palliative care coverage. To improve the quality of palliative and hospice care, it is necessary to study the needs of patients and their family members, determine the number of patients with palliative diagnoses according to the list proposed by the World Health Organization based on "best practices", among adults and children.

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Голованова І.А., Шевченко О.С.

ВИЗНАЧЕННЯ ГОЛОВНИХ ПОТРЕБ ПАЛІАТИВНИХ ХВОРИХ ТА ШЛЯХИ ЇХ ЗАБЕЗПЕЧЕННЯ У СИСТЕМІ ОХОРОНИ ЗДОРОВ'Я УКРАЇНИ

Організація медичної допомоги паліативним хворим України, як й іншим категоріям хворих, має враховувати дані щодо кількості таких пацієнтів серед дорослих і дітей, а також характеристики захворювань, які включені до переліку паліативних, залежно від їх стадії та важкості стану пацієнтів. В Україні перелік паліативних діагнозів є меншим ніж перелік, рекомендований Всесвітньою Організацією Охорони Здоров'я та прийнятий у країнах з високим рівнем прибутку населення. Але навіть ті категорії паліативних пацієнтів, які включені до переліку, отримують необхідну допомогу у недостатньому обсязі. Це стосується як терапії основного паліативного захворювання, так і ефективного знеболення. Реформа системи охорони здоров'я України, що активована від початку революційних подій та початку окупації українських територій у 2014 році, також розповсюджується і на надання паліативної і хоспісної допомоги (ПХД). Значно змінена система фінансування ПХД за рахунок Програми медичних гарантій. До надання ПХД поступово доєднується більша кількість медичних закладів. Тому актуальною є дискусія щодо уточнення переліку потреб паліативних хворих. Це коротке наукове повідомлення опубліковано з метою обговорення переліку зазначених потреб. Також зроблено акценти на зв'язок стратегії реформи системи охорони здоров'я України з можливостями ефективного задоволення цих потреб.

Ключові слова: паліативна та хоспісна допомога, ПХД, потреба у медичній допомозі, фінансування охорони здоров'я.

Голованова И.А., Шевченко А.С.

ОПРЕДЕЛЕНИЕ ГЛАВНЫХ ПОТРЕБНОСТЕЙ ПАЛЛИАТИВНЫХ БОЛЬ-НЫХ И ПУТИ ИХ ОБЕСПЕЧЕНИЯ В СИСТЕМЕ ЗДРАВООХРАНЕНИЯ УКРАИНЫ

Организация медицинской помощи паллиативным больным Украины, как и другим категориям больных, должна учитывать данные о количестве таких пациентов среди взрослых и детей, а также характеристики заболеваний, которые включены в перечень паллиативных, в зависимости от их стадии и тяжести состояния пациентов. В Украине

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перечень паллиативных диагнозов меньше, чем список, рекомендованный Всемирной Организацией Здравоохранения и принятый в странах с высоким уровнем доходов населения. Но даже те категории паллиативных пациентов, которые включены в перечень, не получают необходимую помощь в достаточном объеме. Это касается как терапии основного паллиативного заболевания, так и эффективного обезболивания. Реформа системы здравоохранения Украины, которая активирована с начала революционных событий и начала оккупации украинских территорий в 2014 году, также распространяется на оказание паллиативной и хосписной помощи (ПХП). Значительно изменена система финансирования ПХП за счет Программы медицинских гарантий. К предоставлению ПХП постепенно присоединяется большее количество медицинских учреждений. Поэтому актуальна дискуссия об уточнении перечня потребностей паллиативных больных. Это короткое научное сообщение опубликовано с целью обсуждения перечня указанных потребностей. Также сделаны акценты на связь стратегии реформы системы здравоохранения Украины с возможностями эффективного удовлетворения этих потребностей.

Ключевые слова: паллиативная и хосписная помощь, ПХП, потребность в медицинской помощи, финансирование здравоохранения.

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Information about the authors

Holovanova Iryna – Doctor of Medical Sciences, Professor, Head of the Department of Public Health with Medical and Labor Expertise, Poltava State Medical University, Poltava, Ukraine.

Address: Ukraine, 36011, Poltava, Shevchenko str., 23.

ORCID: 0000-0002-8114-8319. E-mail: yaryna.ua@gmail.com

Shevchenko Alexander – MD, Master of Medicine, Pedagogy and Economics, director of the Kharkiv Regional Institute of Public Health Services.

Address: Ukraine, 61022, Kharkiv, Nauky Ave., 4.

ORCID: 0000-0002-4291-3882. E-mail: as.shevchenko@knmu.edu.ua