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THE ISSUE OF PATIENT-ORIENTED ORGANIZATION OF PALLIATIVE AND HOSPICE CARE IN UKRAINE

Holovanova I.A.[1], Shevchenko A.S.[2, 3]

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

The quality of the provision of palliative and hospice care (PHC) depends on regulatory, legal and logistical support, the practice of implementing laws, and the support of society. The need for PHC is growing both worldwide and in Ukraine, which is associated with the aging of the population and global medical advances, thanks to which people live to a greater age and continue to live even with serious diseases and severe disabilities. Patients with incurable diseases most often need analgesia, which in low- and middle-income countries the population either does not receive at all, or has limited access to narcotic analgesics. The task of the PHC organization corresponds to the European integration obligations of Ukraine at a high level, and is in the sphere of responsibility of the Ministry of Health. The insufficient level of development of the national PHC system depends on imperfect legislation, non-implementation of adopted laws, lack of public results of calculating the need for PHC among adults and children. The system of training medical workers to work in hospices and palliative care departments, which concerns both doctors and nurses, also needs improvement. The routes of movement of palliative patients during the provision of assistance to them in the institutions of the health care system require public discussion. Instructions regarding the movement of these patients should be understandable to a doctor of any specialty, and contain step-by-step algorithms of actions. The practice of euthanasia, which is not allowed in Ukraine, is important for palliative patients. The PHC system should become one of the key components of the health care system, provided at the place of residence of patients (in hospices and palliative departments of hospitals) in the area where they live, or in "hospices at home". The development of the national PHC system, in which all known shortcomings will be taken into account and corrected, will be able to reduce the level of suffering of terminally ill patients and their relatives, and ensure their standard of living at the average European level.

Keywords: *PHC, need for medical assistance, health care financing.*

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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 palliative direction of social care is applied to patients with severe incurable diseases and a limited projected life expectancy [1]. 40 million people need it every year, of which 78% live in low- and middle-income countries. At the same time, approximately 14% of those who need it receive palliative and hospice care (PHC). WHO predicts an increase in the need for PHC in connection with the aging of the global population and the burden of non-communicable (to a greater extent) and infectious diseases. The social phenomenon of "extra years of life" associated with the successes of medicine in developped countries has its reverse side in the form of the need to care for people whose lives continue despite advanced and senile age, severe disability and a number of incurable diseases. At the same time, timely provision of palliative care reduces health care costs associated with hospitalizations.

A significant number of certain categories of patients need palliative care: about 1/3 of cancer patients and patients with cardiovascular diseases, 1/10 patients with chronic respiratory diseases, 1/20 patients with diabetes and HIV-infected. The main symptom that requires attention in providing palliative care is pain. Opioid analgesia is needed by 4 out of 5 cancer patients in the terminal stages of the disease, 70% of AIDS patients.

However, in many low- and middle-income countries, PHC are either not provided at all, or their provision is not integrated into national health care systems. In 2019, only 40% of almost 200 countries in the world reached PHC coverage of half of all patients who need it [2].

Along with the low coverage PHC of the population, low- and middle-income countries are characterized by the low availability of narcotic pain relievers [3], drugs for providing specialized medical care in cases of system and organ failure (respiratory, cardiovascular, etc.) and insufficient training of medical workers in the principles and methods of specialized medical and social care for palliative patients. Thus, in 2018, 4/5 of the world's population (mostly from low- and middle-income countries) consumed only 1% of all medical morphine produced in the world for pain relief (which is approximately 388 tons per year).

Many countries need to overcome numerous cultural and religious barriers related to ideas about the processes of dying and death to organize high-quality PHC. Representatives of the political establishment also need training in international principles and best practices of PHC organization. People who make decisions should be clearly aware of the right to palliative care not only of representatives of the elites and the middle class, but also of marginalized sections of the population.

The PHC system should be integrated into the system of primary health care for the population, aimed at palliative patients and their family members. According to the recommendations of the WHO, the PHC system should be one of the key components of all national health care systems, should be provided at the place of residence of patients, should be based on a clear calculation of the needs of different categories of patients, adults and children, should provide the necessary level of analgesia for all palliative patients who in need [4]. For its part, the WHO declares constant monitoring of the actual provision of PHC in different countries of the world, study of national models of PHC provision and methodical assistance to countries in disseminating information on the best practices of PHC organization.

Most of low- and middle-income countries (including Ukraine) needs improvement of legislation and educational programs for medical personnel. An urgent issue is determining the need for PHC for adults and children. According to Hu-

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man Rights Watch (2011) and [5] (2014), in 2009–2012 in Ukraine approximately 425 thousand people per year need for PHC. Ukrainian society needs a broad discussion of citizens' right to euthanasia. This discussion must be based on an understanding of death as nothingness, which is contrary to the religious beliefs of a large number of the population. But these beliefs should not stand in the way of ending life with dignity in a secular state [6; 7]. Technical (safety) and ethical issues of euthanasia lie in the field of medical law, a separate direction in administrative and civil law. Administrative and legal regulation concerns both the general rules of human behavior and the rights and obligations of participants in specific legal relationships, and also establishes responsibility for violations of such rules. A developed legal system creates conditions for preventing abuses during euthanasia. However, many researchers consider both the regulatory and legal acts of Ukraine and the practice of their application to be imperfect for providing PHC [8; 9].

So, for example, the provision of PHC in Ukraine is regulated by the Order of the Ministry of Health of Ukraine No.1308 on June 4, 2020 "On improving the organization of palliative care in Ukraine" [10], which states the need to "approve clinical routes for patients of all age categories … to ensure the continuity of provision" of such assistance. The task of creating routes is entrusted to the "Coordination Centers of the Regional Palliative Care Network". However, on the websites of the coordination centers of the regions of Ukraine, we did not find a single route that would be step-by-step understandable to a practical doctor to whom a palliative patient turned for an appointment. There are only lists of medical and preventive facilities that serve the territories of settlements.

The development of a package financing scheme for these types of medical care under the medical guarantee programs of the National Health Service of Ukraine (NHSU) is definitely a positive moment for the organization of PHC in Ukraine. Thus, according to the notification of the NHSU [11], as of the end of March 2021, 483 medical institutions of Ukraine (mostly from Dnipropetrovsk, Lviv and Kharkiv regions), and among them 12 multidisciplinary hospices, multidisciplinary hospitals, cancer centers, AIDS centers, anti-tuberculosis, infectious diseases hospitals, children's hospitals, etc. However, the problem is the lack of a public calculation of the need by categories of patients in regional and age categories at the state level. At the same time, some researchers are already trying to make similar calculations, and they do not coincide with the official ones [12; 13]. Calculations of the need for PHC of the Ukrainian Center for Social Data (UCSD) for 2018 were well-reasoned and easy to use, but the state did not use them to constantly recalculate such needs for the following years, and the work of the UCSD was not continued in the public field after the end grant funding.

But at the same time, there is still some progress in increasing the coverage of the population by PHC. Thus, in 2018, PHC in Ukraine were provided by only 2 specialized palliative centers, 7 hospices and 60 palliative departments, there were only 1,500 inpatient palliative beds compared to the 3,500 recommended by WHO, and field teams met only 15% of the need for mobile care ("hospices at home").

The medical education system of Ukraine should also be improved to train "palliatively competent" both doctors and nurses [14] who are able to relieve the patient in the last days of his life from pain, reduce vital activity disorders, severe mani-

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festations of the disease, organize or provide adequate care, psychological, social and spiritual support for patients and their relatives in hospice, specialized palliative departments or at home. The basic scientific-methodical and clinical institution for PHC in Ukraine is the State Enterprise "Institute of Palliative and Hospice Medicine of the Ministry of Health of Ukraine", established by order of the Ministry of Health of Ukraine No.159-0 in 2008. Also, training in the specialty "Palliative and Hospice Medicine" takes place in most medical universities of Ukraine.

Improving the PHC organization in Ukraine is one of the important steps in the implementation of the country's plans for its European integration. Such improvement is foreseen by the activity program of the Cabinet of Ministers of Ukraine, the section of tasks for the Ministry of Health of Ukraine, the goal of "people living longer" [15; p. 56]. So, among the planned actions are the following: reducing the suffering of palliative patients, improving their quality of life, providing them with medical care on a multidisciplinary basis, taking into account international approaches and recommendations, training specialists (medical workers) in the direction of "palliative care", developing the PHC system, information campaigns about PHC for the population, involvement of the patient himself, his relatives and the public in the PHC process.

Conclusion

The problem of palliative and hospice care in Ukraine requires constant discussion with scientists and the public. Despite the fact that Ukrainian legislation on these types of assistance is being improved, not all issues have been resolved. In addition, the practical implementation of the adopted laws has significant drawbacks. In addition, there are no public results of calculations of the need for palliative and hospice care for the main categories of patients to whom such care is recommended by the World Health Organization, regionally and by age, which would be updated annually and used by the state as a basis for planning expenditures for these needs at the national level. Ukrainian society also needs a dialogue on the issue of the right of palliative patients to euthanasia, and patients – sufficient access to narcotic pain relievers.

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Голованова І.А., Шевченко О.С.

ПИТАННЯ ПАЦІЄНТООРІЄНТОВАНОЇ ОРГАНІЗАЦІЇ ПАЛІАТИВНОЇ ТА ХОСПІСНОЇ ДОПОМОГИ В УКРАЇНІ

Якість надання паліативної і хоспісної допомоги (ПХД) залежить від нормативного-правого та матеріально-технічного забезпечення, практики реалізації законів, підтримки суспільства. Потреба в ПХД зростає як у всьому світі, так і в України, що пов’язано зі старінням населення і глобальними успіхами медицини, завдяки яким люди доживають до більшого віку і продовжують жити навіть із важкими захворюваннями та важкою інвалідністю. Пацієнти з невиліковними хворобами найчастіше потребують знеболення, якого у країнах з низьким та середнім рівнем прибутків населення або не отримають взагалі, або мають обмежений доступ до наркотичних анальгетиків. Завдання організації ПХД на високому рівні відповідає євроінтеграційним зобов’язаннями України, і знаходиться у сфері відповідальності Міністерства охорони здоров’я. Недостатній рівень розвитку національної системи ПХД залежить від недосконалого законодавства, невиконання прийнятих законів, відсутності публічних результатів розрахунку потреби

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у ПХД серед дорослих і дітей. Вдосконалення потребує також система навчання медичних працівників для роботи у хоспісах та паліативних відділеннях, що стосується як лікарів, так і медичних сестер. Маршрути руху паліативних хворих при наданні їм допомоги в установах системи охорони здоров'я, потребують публічного обговорення. Інструкції щодо руху цих хворих мають бути зрозумілі лікарю будь-якої спеціальності, містити покрокові алгоритми дій. Важливою для паліативних хворих є практика евтаназій, яка не дозволена в Україні. Система ПХД має стати одним з ключових компонентів системи охорони здоров'я, надаватися за місцем проживання хворих (у хоспісах та паліативних відділеннях лікарень) на місцевості, де вони мешкають, або у «стаціонарах на дому». Розбудова національної системи ПХД, в якій будуть враховані та виправлені всі відомі недоліки, буде спроможна знизити рівень страждань паліативних хворих, їх близьких, забезпечити рівень їх життя на середньоєвропейському рівні.

Ключові слова: *ПХД, потреба у медичній допомозі, фінансування охорони здоров'я.*

Голованова И.А., Шевченко А.С.

ВОПРОСЫ ПАЦИЕНТООРИЕНТИРОВАННОЙ ОРГАНИЗАЦИИ ПАЛЛИАТИВНОЙ И ХОСПИСНОЙ ПОМОЩИ В УКРАИНЕ

Качество паллиативной и хосписной помощи (ПХП) зависит от нормативно-правового и материально-технического обеспечения, практики реализации законов, поддержки общества. Потребность в ПХП растет как во всем мире, так и в Украине, что связано со старением населения и глобальными успехами медицины, благодаря которым люди доживают до большего возраста и продолжают жить даже с тяжелыми заболеваниями и тяжелой инвалидностью. Пациенты с неизлечимыми болезнями чаще всего нуждаются в обезболивании, которого в странах с низким и средним уровнем доходов населения либо не получат вообще, либо имеют ограниченный доступ к наркотическим анальгетикам. Задача организации ПХП на высоком уровне отвечает евроинтеграционным обязательствам Украины и находится в сфере ответственности Министерства здравоохранения. Недостаточный уровень развития национальной системы ПХП зависит от несовершенного законодательства, несоблюдения принятых законов, отсутствия публичных результатов расчета потребности в ПХП среди взрослых и детей. В усовершенствовании нуждается также система обучения медицинских кадров для их работы в хосписах и паллиативных отделениях, что касается как врачей, так и медицинских сестер. Маршруты движения паллиативных больных при оказании им помощи в учреждениях системы здравоохранения также требуют публичного обсуждения. Инструкции по движению этих больных должны быть поняты врачу любой специальности, содержать пошаговые алгоритмы действий. Паллиативных больных важна практика эвтаназий, которая не разрешена в Украине. Система ПХП должна стать одним из ключевых компонентов системы здравоохранения, предоставляться по месту жительства больных (в хосписах и паллиативных отделениях больниц) на местности, где они проживают, или в стационарах на дому. Развитие национальной системы ПХП, в которой будут учтены и исправлены все известные недостатки, будет способна снизить уровень страданий паллиативных больных, их близких, обеспечить уровень их жизни на среднеевропейском уровне.

Ключевые слова*: 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