

in PC providing. It requires special training and motivation of GP-FP, the relevant regulatory framework and adequate financial and political support of the Government of Ukraine, regional and local authorities, and the interest and support of the whole society.

Keywords: palliative and hospice care; health care system; primary health care

Rezumat

Argumentări medicale și sociale pentru crearea unui model funcțional și organizatoric de acordare a îngrijirilor paliative și a asistenței de tip hospice la nivelul medicinei primare în Ucraina

Situația medicală și cea demografică nefavorabilă din Ucraina impune implicarea furnizorilor de asistență medicală primară și a specialiștilor din domeniul sănătății în îngrijirea paliativă și de hospice (PC), cum ar fi facilitățile sanitare (HF) ale diferitor ministere și departamente, diferite forme de proprietate. Sistemul PC optim în Ucraina a fost creat în baza modelului conceptual al AMP și este susținut, în special, de așa instituții PC implicate cum ar fi: 1) PHC HF; 2) echipe multidisciplinare PC; 3) facilități de farmacie licențiate; 4) facilități de asistență socială. La nivelul AMP, acesta oferă: 1) identificarea și înregistrarea pacienților paliativi (PP); 2) asigurarea îngrijirii medicale paliative, organizarea spitalizării PP în PC HF staționară; 3) PP și membrii familiilor acestora, membri ai organizațiilor de suport psihologic, social și religios/spiritual; 4) PP și membrii familiilor acestora, consiliere, informare și educație; 5) coordonarea și cooperarea medicilor generaliști – medicilor de familie (GP-FP) cu o echipă multidisciplinară PC sau PC HF staționară, specialist în sănătate, instituții de asistență socială, ONG-uri, voluntari etc. Modelul funcțional și organizatoric prezentat al sistemului PC la nivel de AMP vizează asigurarea disponibilității și calității asistenței medicale și sociale pentru pacienții incurabili în ambulatoriu și la domiciliu, pentru a determina rolul și interacțiunea dintre profesioniștii din domeniul sănătății AMP și alți specialiști implicați în furnizarea de PC. Aceasta necesită o pregătire și o motivare specială a GP-FP, un cadru de reglementare relevant și sprijinul financiar și politic adecvat al Guvernului Ucrainei, al autorităților regionale și celor locale, dar și interesul și sprijinul întregii societăți.

Cuvinte-cheie: îngrijire paliativă și de tip hospice; sistem de sănătate; asistență medicală primară

Резюме

Медицинские и социальные обоснования для создания функционально-организационной модели системы паллиативной и хосписной помощи на уровне первичной медицины в Украине

Неблагоприятная медико-демографическая ситуация в Украине требует участия поставщиков первичной медико-санитарной помощи (ПМСП) и специалистов здравоохранения в паллиативной и хосписной помощи (ПК), таких как медицинские учреждения различных министерств и ведомств, различные формы собствен-

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MEDICAL AND SOCIAL GROUNDS FOR THE FUNCTIONAL AND ORGANISATIONAL MODEL OF PALLIATIVE AND HOSPICE CARE SYSTEM AT THE PRIMARY HEALTH CARE LEVEL IN UKRAINE

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Summary

The unfavorable medical and demographic situation in Ukraine requires of Primary Health Care (PHC) providers (GPs) and health specialist's involvement in palliative and hospice care (PC), such as Health Facilities (HF) of various Ministries and Departments, different forms of ownership. The optimal PC System in Ukraine at the PHC level conceptual model is substantiated; in particular, the PC involved institutions are substantiated: 1) PHC HF; 2) PC multi-disciplinary teams; 3) Licensed Pharmacy Facilities; 4) Social Care Facilities. At the PHC level it provides: 1) Identification and registration of palliative patients (PPs); 2) Providing palliative medical care, organization of PPs hospitalization to stationary PC HF; 3) PPs and their families members of psychological, social and religious/spiritual support organization; 4) PPs and their families members counseling, information and education; 5) Coordination and cooperation of the General Practitioners-Family Physicians (GP-FP) with a PC multi-disciplinary team, or PC HF stationary, health specialist, social care institutions, NGOs, volunteers etc. The presented functional and organizational model of the PC System at the PHC level is aimed at ensuring the availability and quality of medical and social care to incurable patients in outpatient settings and at home, to determine the role and interaction of PHC health care professionals and other specialist involved

ности. Оптимальная система ПК в Украине обоснована на уровне концептуальной модели ПМСП, в частности, обоснованы учреждения, вовлеченные в ПК: 1) ПМСП ХФ; 2) ПК многопрофильных команд; 3) лицензированные аптеки; 4) социальные учреждения. На уровне ПМСП она обеспечивает: 1) идентификацию и регистрацию паллиативных пациентов (ПП); 2) оказание паллиативной медицинской помощи, организация госпитализации ПП на стационарном ПК ХФ; 3) ПП и члены их семей являются членами организации психологической, социальной и религиозной/духовной поддержки; 4) ПП и члены их семей консультируют, информируют и просвещают; 5) координация и сотрудничество семейных врачей общей практики (СВ) с междисциплинарной командой ПК или стационарным ПК, специалистом здравоохранения, учреждениями социального обеспечения, НПО, волонтерами и т.д. Представленная функциональная и организационная модель системы ПК на уровне ПМСП направлена на обеспечение доступности и качества медицинской и социальной помощи неизлечимым пациентам в амбулаторных условиях и дома, на определение роли и взаимодействия медицинских работников ПМСП и других специалистов, занимающихся предоставлением ПК. Это требует специальной подготовки и мотивации СВ, соответствующей нормативно-правовой базы и адекватной финансовой и политической поддержки со стороны правительства Украины, региональных и местных органов власти, а также заинтересованности и поддержки всего общества.

Ключевые слова: паллиативная и хосписная помощь; система здравоохранения; первичная медицинская помощь

Introduction

Around the world now, most patients with serious chronic diseases or life-threatening health problems and a lot of elderly people lack access to palliative and hospice care (PC), especially people in low- and middle-income countries (LMICs). It is estimated that 40 million terminally ill people and millions of others not imminently dying, need PC every year. But 86% of palliative patients (PPs) do not receive it, including 98% of children in need in LMICs [1–3].

According to modern concepts, the PC is an innovative patient-family-oriented medical-social and humanitarian approach that most adequately provides the needs and proper quality of life of PPs and their relatives, contributes to the preservation of human dignity at the end of life. An important part of reforming the healthcare sector in Ukraine is the creation and implementation of an accessible, high-quality and efficient PC System, which has led to the need to find new ways of inter-agency and inter-sectoral interaction and rational forms of or-

ganization of medical and social assistance to PPs, including limited life expectancy, optimization of the provision of PC at the primary health care (PHC) level, in particular the involvement of general practice-family doctors (GP-FD), the new Declaration of Astana (2018) which highlights PC as one of the key components of PHC [4–13].

The purpose of the research was to create the medical and social grounds of the optimal functional and organizational model of the PC System at the PHC level.

Research materials and methods

Medical statistics data, national and international literary sources, results of sociological research, bibliosemantic, statistical and sociological research methods, methods of systemic and structural-functional analysis were used in this work.

Results and discussion

The analysis of literature shows that the main objective of the PC is to ensure the highest possible quality of life and to preserve the human dignity of incurable patients and their families' members. Due to the holistic approach to the patient as a person, PC can most effectively relieve the physical and moral suffering of PPs and his relatives [5, 8, 9, 12, 13]. WHO defines PC as the prevention and relief of suffering of adult and children patients and their families facing the problems associated with life-threatening illness. These problems include physical, psychological, social and spiritual suffering of patients and their family members [14].

With the aging of populations and the growing burden of long-term chronic and incurable illness and multiple morbidities, include not only cancer and major organ failure, but also HIV/AIDS and mental health conditions such as substance use disorders, depression and dementia. PC should be integrated at all levels of Health Care Systems [15, 16]. Attention to the social determinants of ill health, and responding to social suffering with programs such as these, are fundamental both to PHC and to PC and reveal their interfusion [17–21].

The Astana Declaration on Primary Health Care (2018) about the importance of providing the PC at the PHC level: «Promotive, preventive, curative, rehabilitative services and palliative care must be accessible to all» and «PHC will be implemented in accordance with national legislation, contexts and priorities. (...) We will prioritize disease prevention and health promotion and will aim to meet all people's health needs across the life course through

comprehensive preventive, promotive, curative, rehabilitative services and palliative care» [22]. PHC and PC have in common an emphasis on continuity of care and solidarity (accompaniment), respect for patients' values and attention not only to patients, but also to their families [6, 8, 18, 19, 23].

According to most domestic politicians, healthcare organizers, scientists, the state of health of the population in Ukraine over the last decades is unsatisfactory and continues to deteriorate. The peculiarities of the medical and demographic situation in Ukraine over the past decades are the rapid aging of the population, high rates of morbidity and mortality from cancer and severe complications of chronic NCDs, HIV/AIDS, TB and TB/HIV co-infection, viral hepatitis B and C, and the Chernobyl accident consequences etc.

As you can see, one of the highest mortality rates in Europe is observed in Ukraine [24, 25], which substantially actualizes the problem of creating and developing an affordable, high-quality, and efficient PC System (see *figure 1, 2*). An analysis of the causes of mortality in Ukraine has shown that in 2017, as in the last 5 years, the first 5 places have been occupied by: CVDs (392,300 people, which is 67,2% of the total number of deaths); oncological diseases (79,0 thousand people – 13,5%); external causes of death (31,7 thousand people – 5,4%); diseases of a digestive system (22,0 thousand people – 3,8%); diseases of a respiratory system (13,8 thousand people – 2,4%).

The results of our analysis allowed us to determine the need of PC in Ukraine, in accordance with the Order of the Ministry of Health of Ukraine dated July 15, 2011 no. 420 *On Approval of Methodological Recommendations for Calculation of the Population's Need for Medical Care*. According to the order, not less than 80% of patients with incurable forms of oncological and other chronic diseases in terminal stages require PC.

At the same time, one of the most important factors determining the growth of the demand for PC is that during the last half-century, in the most developed countries of the world, including Ukraine, there are profound demographic and social changes characterized by rapid aging population and significant accumulation in the populations of the elderly (on average – from 20 to 30% or more). Today, Ukraine is one of the 30 oldest countries in the world. Analysis of data from the State Statistics Committee of Ukraine and the Center for Medical Statistics of the Ministry of Health of Ukraine [24, 25] shows that as of January 1, 2018, in Ukraine about

1,337 million people were aged 70-74 years, 1,588 million people – 75-79 years old, and 1,678 million people – 80 years and older. If in 2000 in the general structure of the population the proportion of people older than the working age was 20,7%, then in 2017 this figure increased to 22,9%. The analysis of medical and demographic data made it possible to determine the need in PC in the age aspect, as well as the estimated amount of PPs in Ukraine, that in 2017 amounted to 457.4 thousand people, or 1078,4 per 100 thousand people in population (see *table*).

According to our data, there are 2 PC Centers (in Kharkiv and Ivano-Frankivsk) and 17 hospices (567 beds in total), as well as 68 PC units/departments in hospitals, which have 1626 beds for PPs, and also 543 beds for PPs in different profiles hospitals. In total in Ukraine there are 2736 beds for PPs, which is 64,3% of the need. Establishments of the PC pediatric profile HF operate in only 5 cities of Ukraine. In Ukraine, only 11 PC mobile teams, including 5 PC mobile teams for children, are provided PC at home. This is extremely insufficient, and it predetermines a situation in which most of the PPs are dying at home, under the supervision of PHC physicians and, in particular, GP-FDs.

Thus, PPs and their family members can receive PC outpatiently, including at home, or permanently by GP-FDs of any form of property. At the same time, different organizational forms of PC can be used. Organizational forms of PC System (see *figure 3*):

Outpatients (do not provide round-the-clock medical care and treatment), including at home:

- involvement of health care professionals at the PHC HF (in particular, GP-FP), with support (counseling, patronage) of specialists of specialized PC HF;
- involvement of social workers;
- outpatient multidisciplinary PC teams at home, which are based on specialized PC HF, PHC HF or specialized HF (oncological, pediatric, geriatric, psycho-neurological profiles, etc.);
- multidisciplinary teams of palliative care at the home of social care territorial centers for the population;
- PHC consultancy rooms and pain control cabinets, which are based on specialized PC HF and specialized HF (oncology, geriatric, psycho-neurological profiles, etc.);
- day-care hospitals/day-care hospices, which are based on specialized PC HF, multidisciplinary and specialized HF and non-state-owned institutions.

Stationary (provide round-the-clock medical care and treatment):

- PC beds/department/units in the HF (specialized or general profile);
- specialized PC HF – hospices, PC centers;
- PC beds/departments in the social protection system inpatient institutions (social care houses for the elderly, children, persons with disabilities, veterans of wars and labor, territorial centers of social services, etc.);
- PC units/PC beds in nursing hospitals/long-term care departments;
- PC institutions of non-state ownership (private, charitable and community organizations, etc.).

The main GP-FP's tasks when providing the PC at PHC level are:

- palliative/symptomatic treatment, in particular, relief or complete control of pain and other severe symptoms of diseases that impair PP's quality of life, and, when necessary, to provide hospitalization PP to PC HF;
- affirmation of life and death as a natural process, ensuring the maximum achievable for PPs full active life, working capacity and social activity;
- ensuring the maximum possible quality of life for PPs and their families members;
- organization of psychological, social and spiritual support to PPs and their family's members during PPs illness and in the period of severe loss/sorrow after PP death;
- informing a PPs and their family members about a course of the disease;
- training PPs and their family members on the rules and methods of providing hygiene, nutrition and care and relieving the suffering of PP;
- making a partnership relations between PP, members of a family and GP-FP and other specialists involved in the PC;
- ensuring PP's right to autonomy and making informed decisions;
- co-ordination and collaboration with a PC multidisciplinary team or stationary PC HF;
- co-ordination and cooperation with health specialists of specialized HF according to nosology of PP;
- co-ordination and cooperation with the social protection institutions;
- co-ordination and cooperation with NGOs, charitable foundations, volunteers.

An important condition for the effectiveness of GP-FP PC is the improvement of special PC trainings for students, interns and doctors specialized in fa-

mily medicine, at under- and post-graduate level of medical education that were issued in our previous articles [9, 12, 26-28]. PC Training Courses for GP-FP are conducted at the Department of Palliative and Hospice Medicine of the Institute of Family Medicine of the Shupyk National Medical Academy of Postgraduate Education now.

According to the proposed conceptual model of the PC System, GP-FPs at the PHC level, specialist doctors or physician's assistant detect PPs with progressive incurable diseases, diagnose/confirm the patient's palliative status in stationary HF secondary and tertiary levels, register a PP in the electronic registry. At this stage, the incurability of the diagnosis of the underlying disease is verified, if necessary – the pain syndrome control and symptomatic therapy are provided, consultations of specialists in the corresponding nosological profile, the consultations about an appropriateness and extent of surgical intervention, special treatment methods (chemo- and radiation-therapy, etc.) are provided. Next, an incurable patient is under the control of a GP-FP or a physician's assistant who provides general PC, as determined by the Order of the Ministry of Health of Ukraine dated January 21, 2013, no. 41 *On the organization of palliative care in Ukraine*.

By worsening of a PP's health status, PP may be hospitalized, if necessary, to a specialized hospital for secondary or tertiary level of medical care.

Thus, a systematic analysis of the current state of Ukrainian PC, literary sources, regulatory and statistical data makes it possible to make the following

Conclusions

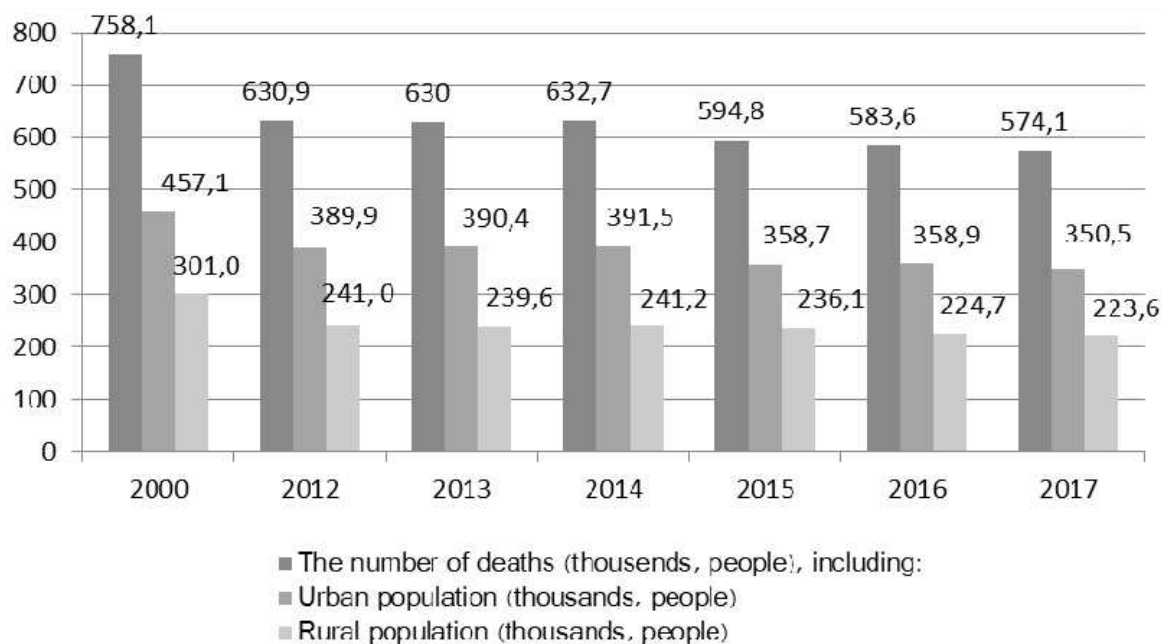
1. The main goal of the proposed conceptual PC System model is to maximize a relief of suffering, to preserve human dignity and to provide appropriate quality of life for incurable patients and their family members. The presented PC System functional-organizational model of at the PHC level is aimed at ensuring the availability and quality of medical and social assistance to incurable patients, including at the terminal stage, in outpatient settings and at home, to determine the role and interaction of PHC health specialist and other physicians, involved in the PC, that should improve PPs' and their families the quality of life.

2. The proposed functional and organizational PC System model at the PHC level of requires special professional training, professional development and motivation of GP-FP, the relevant regulatory

framework and, of course, an adequate financial support and political support of the Government of Ukraine, regional and local authorities, and interest and support of the whole society.

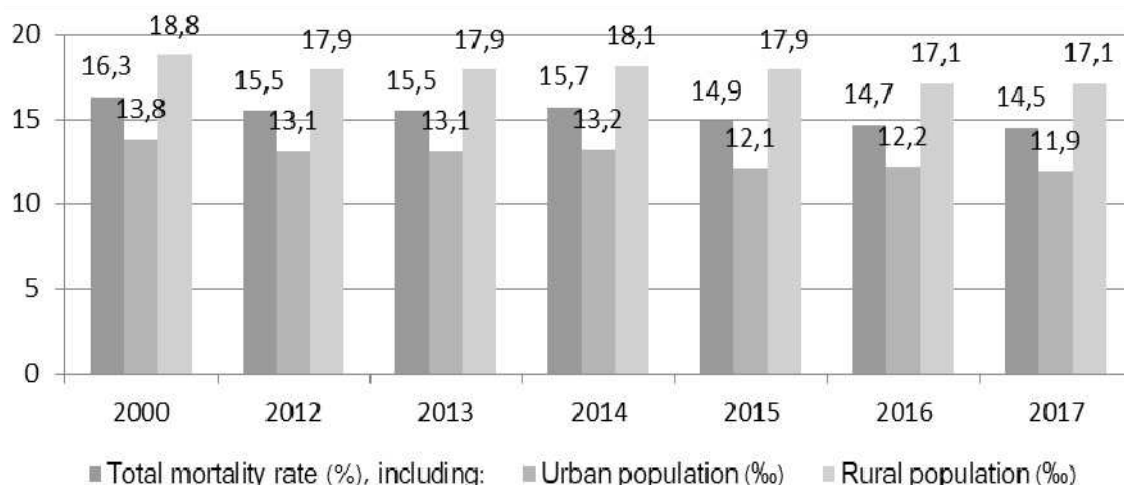
3. The one of a main conditions for the provision the PHC to incurable patients in outpatient

settings and at home is the work of GP-FDs as a part of a PC multidisciplinary team to combine the efforts, coordination and collaboration of GP-FPs and specialist doctors, social protection institutions, volunteers, private sector representatives, public organizations and priests etc.



Note. Excluding the temporarily occupied territory of the Autonomous Republic of Crimea and the City of Sevastopol and part of the combat zone on the territory of regions of Donetsk and Lugansk.

Figure 1. Dynamics of the deaths number (thousand people) in Ukraine (2000, 2012–2017)



Note. * Excluding the temporarily occupied territory of the Autonomous Republic of Crimea and the City of Sevastopol and part of the combat zone on the territory of regions of Donetsk and Lugansk.

Figure 2. General mortality rates (%) in Ukraine and their dynamics (2000, 2012–2017)

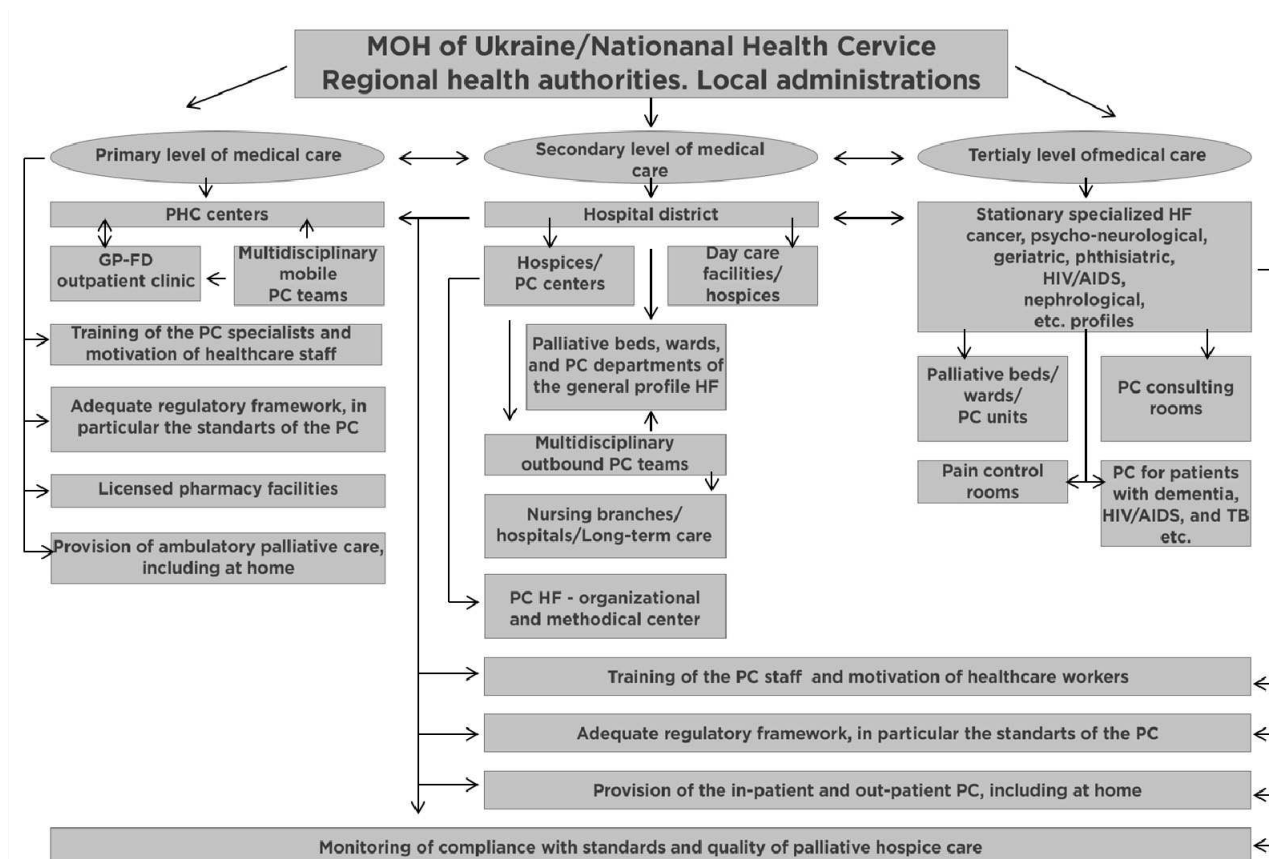


Figure 3. Functional-organizational model of PC System in Ukraine

The calculated need in PC in terms of age and gender structure of mortality from diseases of the Ukraine population in 2017*

Age category (years)	Number of deaths (men)	The estimated PC need (men) at a coefficient of 0.80	Number of deaths (woman)	The estimated PC need (woman) at a coefficient of 0.80	The estimated PC need (men and women) at a coefficient of 0.80
0-9	2177	1742 (0.78%)	1596	1277 (0.55 %)	3019 (0.67 %**)
10-19	887	710 (0.32 %)	405	324 (0.14 %)	1034 (0.23 %**)
20-29	4576	3661 (1.63 %)	1390	1112 (0.48 %)	4773 (1.06 %)
30-39	13350	10680 (4.77%)	4428	3542 (1.52 %)	14222 (3.15 %)
40-49	22384	17907 (7.99%)	8208	6566 (2.82 %)	24473 (5.41 %)
50-59	43080	34464 (15.39%)	17385	13908 (5.97 %)	48372 (10.68 %)
60-69	66209	52967 (23.65%)	38029	30423 (13.06 %)	83390 (18.36 %)
70-79	69199	55359 (24.71%)	79581	63665 (27.32 %)	119024 (26.02%)
80 and older	58423	46738 (20.87%)	140059	112047 (48.09 %)	158785 (34.48%)
Total	280285	224228	291081	232865	457093 (100%)
Total number of deaths (men and women) – 571366					
The estimated PC need at a coefficient of 0.80 counted based on the number of deaths – 457093 and pro 100 thousand of population – 1078,4					

Note. * Excluding the temporarily occupied territory of the Autonomous Republic of Crimea and the City of Sevastopol and part of the combat zone on the territory of regions of Donetsk and Lugansk.

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