

**Social Medicine and Public Health**

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**CIVIL SOCIETY AND PALLIATIVE CARE*****Smiiianov V.A., Hornostaieva P.O.****Sumy State University, Sumy, Ukraine*

In Ukraine, the participation of civil society in the development of the Palliative and Hospice Care (PHC) system is not crucial, since professional Non-Governmental (Civil) Organizations (NGOs) do not have the resources and powers necessary for such an impact. However, the experience of other countries shows that the participation of NGOs in the creation of a PHC system, which should be among the "best practices", is mandatory. The study was conducted to identify the areas of work of Ukrainian NGOs for the provision of PHC and influence on state policy. The study was conducted using the method of system analysis and bibliosemantic method, with a search for sources by keywords in Ukrainian and English in Google, Google Scholar and PubMed. PHC consists of medical care, psychological, spiritual, social and legal support for patients. Medical care and psychological support are entrusted to the healthcare system, which should also coordinate other areas. However, the actual overload of medical workers leaves other areas of PHC in the sphere of responsibility of social services and NGOs. NGOs specializing in palliative care are mainly professional associations of doctors and nurses in palliative medicine. Some NGOs also advocate for patients' rights, support patients and their relatives (caregivers), and provide social support. In countries with developed palliative care systems, NGOs specializing in palliative care can organize their own hospices, be coordination centers for palliative care, conduct training, conduct scientific research, and even issue licenses to doctors and nurses to work in palliative care. In many countries where euthanasia is legalized, NGOs have had a significant impact on the legalization process, studied public opinion, and exerted the necessary influence on politicians. Ukrainian scientists are developing models for organizing palliative care, in which NGOs should receive greater resources and powers to play a greater role in the further development of the national palliative care system.

**Keywords:** *palliative and hospice care, social support, psychological support, spiritual support, advocacy.*



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## Introduction

Public (Non-Governmental) Organizations (NGOs) have played an important role in developing national systems of Palliative and Hospice Care (PHC) in all countries, which are included in the list of the best according to the classification of Lynch T., Wright M. and Clark D. (2008/2011) [1] and according to the Quality of Death Index (2015) [2]. At all stages of the development of such systems, NGOs advocated for the rights of medical and social workers, patients, and their relatives, developed educational initiatives, conducted scientific analytical research, maintained public interest in the topic [3], monitored the quality-of-service provision, and influenced politicians who made decisions on legislative changes in the field of PHC. Searching for information about the work of Ukrainian NGOs in the field of PHC gives a preliminary idea of the insignificant influence on state policy and changes in the PHC system during the healthcare reform of both professional associations of palliative medicine specialists and organizations that protect the rights of patients and their relatives, or provide them with services and support.

The activities of NGOs in countries with a low degree of integration of the PHC system into the general healthcare system, to which Ukraine belongs, can be aimed at implementing the general principle of patient-centeredness [4] and at meeting some of the needs of patients. What are these needs? Kotvitska A.A. et al. (2021) found [5] that the vast majority (94.4%) of palliative patients need psychological support, close to 3/4 need pharmaceutical care (75.5%), in particular symptomatic treatment and pain relief, close to 2/3 need professional care (71.6%) and social support (67.4%). 43.2% of patients need spiritual support, and 29.5% need legal assistance.

But an equally important area of NGO's activity is the formation of public opinion,

drawing attention to the problem of the underdevelopment of the PHC system, which is unable to ensure the coverage of a sufficient number of palliative patients and meet their needs. We did not find data on which issues the activities of Ukrainian NGOs had a significant impact on the development of the national PHC system, in comparison with, for example, the work of the Cicely Saunders NGO in the UK [6].

The **aim** of the study was to determine the areas of work of non-governmental organizations in Ukraine to provide palliative and hospice care and influence public policy.

## Materials and Methods

The study was conducted using the method of system analysis and bibliosemantic method, with a search for sources using the keywords "civil society", "non-governmental organizations", "palliative and hospice care", "social support", "psychological support", "spiritual support", "advocacy" in Ukrainian and English in Google, Google Scholar and PubMed.

## Results and Discussion

NGOs in countries with developed PHC systems have an impact on the development and implementation of palliative care development strategies if they lobby for legislative changes and advocacy: they initiate public discussions aimed at improving access to palliative services, improving the quality of services, protect the rights of medical professionals working in palliative medicine, or protect the rights of patients and their relatives (caregivers). In Ukraine, the activity of public organizations is wave-like. Activity lasts for several years, after which there is usually a lull. For example, the State Enterprise "Institute of Palliative and Hospice Medicine of the Ministry of Health of Ukraine" [7], established in 2008 on the initiative of the NGO "All-Ukrainian Council for the Protection of Patients' Rights and Safety", has ceased its activities [8]. The activities of the Public

Organization "Ukrainian League for the Development of Palliative and Hospice Care" are dependent on grants, between which there are breaks [9]. In addition, the organization does not have representatives in all regions of Ukraine, so today it cannot claim the status of a future licensor that could issue licenses to palliative medicine doctors [10].

Periodic public events of NGOs most often only confirm the intention to adhere to a certain strategy in organizing PHC. For example, during the National Congress on Palliative and Hospice Care in 2023, the clinical principles of developing the system of PHC in wartime conditions, the social component of palliative care, the features of its provision to children and at the level of primary health care, as well as the development of palliative care in Ukraine through the prism of law were discussed [11]. According to our forecast, after reviewing the declaration of the meeting, the event will not have an impact on accelerating the widespread use of medical cannabis, which is necessary for palliative patients in conditions of low availability of effective pain relief, on improving chronic pain treatment protocols [12–14], on increasing the safety of palliative patients in wartime conditions [15], on expanding the list of palliative diseases, improving the forecasting of the need for PHC, on returning to the model of providing palliative patients with home hospice care by mobile teams instead of family doctors. Let us dwell on this issue in more detail.

Before the start of the package financing of expenditures on PHC, public organizations implemented new models of providing palliative care at home, which did not ensure a wide coverage of palliative patients with the necessary services, but allowed to work out a model of high-quality care for patients in comfortable conditions for them. This was especially important in conditions of limited funding [16]. Package

financing of expenditures on palliative medicine within the framework of the medical guarantees program and "Affordable Medicines", introduced by the National Health Service of Ukraine, made it possible to develop both inpatient palliative care for adults and children and mobile care at the same time. Funding for the program has grown significantly in recent years (2021–2024), even in conditions of a full-scale war. Heads of medical institutions were willing to order funding packages for palliative patients, but the actual coverage of services for this contingent of patients grew much more slowly. Researchers of the organization of PHC in Ukraine associate this fact with the lack of a clearly defined list of diseases that should be treated as palliative in Ukraine, with the lack of a constant calculation of the need for PHC in a regional context, and the lack of forecasting of this need [17]. Funding for PHC ordered by medical institutions should correspond to the calculated need, as well as be tied to the register of palliative patients of each region and territory, which will correspond to the principle of "money follows the patient". NGOs can also effectively participate in solving the problem of assessing the need for PHC and its forecasting. Their cooperation with medical universities, in particular with departments of palliative medicine and health care organizations, is desirable. Such cooperation will simplify the implementation of the forecast in compliance with the principles of evidence-based medicine and prevent falsifications [18].

But will these research groups have a common opinion on the most important issues of organizing palliative care? We assessed the attitude to these issues based on available (published) data. The results of the search demonstrate both the difference in the understanding of individual issues by Ukrainian researchers and a common vision. Thus, in the issues of assessing the need for palliative care, both the total

number of patients requiring palliative care and the list of nosologies for which such care is required differ [19–21]. Researchers demonstrate common views in the list of services that palliative patients need: treatment (with an emphasis on pain relief), psychological, spiritual, social and legal support [22]. To coordinate efforts, these groups need to work together with the national association of palliative medicine, which should have representatives in all regions of Ukraine, the necessary resources and authority for work.

At the local level, representatives of the association will be required to coordinate the volunteer movement, educational initiatives, and study public opinion on euthanasia of palliative patients [23; 24]. NGO information activities can be aimed at both the general public and professional circles of workers in the PHC system. In the first case, it is possible to disseminate information about palliative care through the media, social networks, and printed materials, which will help raise public awareness of PHC problems and reduce stigmatization of incurable patients. Professional circles will understand the need to consider more diseases accompanied by chronic pain and with a negative prognosis for

treatment as palliative [25; 26]. It is also necessary to intensify cooperation with foreign NGOs and international organizations (for example, USAID) to obtain grants.

### Conclusions

In countries with developed PHC systems, NGOs specialized in palliative medicine are mainly professional associations of doctors and nurses in palliative medicine, as well as NGOs that protect the rights of palliative patients. They can organize their own hospices, be coordination centers for palliative care, conduct training, scientific research, and even issue licenses to doctors and nurses to work in palliative medicine. In many countries where euthanasia is legalized, NGOs have had a significant impact on the legalization process, studied public opinion, and exerted the necessary influence on politicians. Ukrainian NGOs should receive greater resources and powers to play a greater role in the further development of the national PHC system. The final effect of all the proposed areas of work of NGOs in the field of PHC should be to improve the quality of life of palliative patients and increase their coverage with necessary services.

**Conflict of interest** is absent.

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#### **ГРОМАДЯНСЬКЕ СУСПІЛЬСТВО ТА ПАЛІАТИВНА ДОПОМОГА**

В Україні участь громадянського суспільства у розбудові системи Паліативної та Хоспісної Допомоги (ПХД) не має вирішального значення, оскільки професійні НеДержані (громадські) Організації (НДО) не мають необхідних для такого впливу ресурсів та повноважень. Але досвід інших країн свідчить, що участь НДО у створенні системи ПХД, яка має належати до «кращих практик», є обов'язковою. Дослідження було проведено з метою визначення напрямків роботи НДО України для надання ПХД та впливу на державну політику. Дослідження проведено з використанням методу системного аналізу та бібліосемантичного методу, з пошуком джерел за ключовими словами українською та англійською мовами у Google, Google Scholar та на PubMed. ПХД складається з медичної допомоги, психологічної та духовної підтримки, соціального та юридичного супроводу хворих. Медична допомога та психологічна підтримка покладена на систему охорони здоров'я, яка також має координувати й інші напрямки. Але фактичне перевантаження медичних працівників залишає інші напрямки ПХД у сфері відповідальності соціальних служб та НДО. Спеціалізовані на ПХД НДО переважно є професійними об'єднаннями лікарів та медичних сестер паліативної медицини. Частина НДО також займається адвокацією прав пацієнтів, підтримкою пацієнтів та їх близьких (доглядальників), здійснює соціальний супровід. У країнах з розвиненими системами ПХД спеціалізовані на ПХД НДО можуть організовувати власні хоспіси, бути координаційними центрами паліа-

тивної допомоги, проводити навчання, наукові дослідження і навіть видавати ліцензії лікарям та медичним сестрам для роботи у паліативній медицині. У багатьох країнах, де легалізована евтаназія, НДО мали значний вплив на процес легалізації, вивчали громадську думку та вчиняли необхідний вплив на політиків. Українські науковці розробляють моделі організації ПХД, в яких НДО мають отримати більші ресурси та повноваження для виконання більшої ролі у подальшій розбудові національної системи ПХД.

**Ключові слова:** паліативна та хоспісна допомога, соціальний супровід, психологічна підтримка, духовна підтримка, адвокація.

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