

DOI <https://doi.org/10.30525/2592-8813-2024-4-33>

THE INFLUENCE OF NGOS ON THE PALLIATIVE AND HOSPICE CARE POLICIES IN UKRAINE IN 2011–2024

Oleksandr Volf,

*PhD in Political Sciences, Assistant at the Department of Palliative and Hospice Medicine,
Shupyk National Healthcare University of Ukraine (Kyiv, Ukraine)*

ORCID ID: 0000-0003-3425-5346

oncohema@ukr.net

Abstract. The author has analyzed the role of non-governmental organizations (NGOs) in the development of palliative and hospice care in Ukraine from 2011 to 2024. Using such research methods, as bibliosemantic and systems analysis, it has been determined that the need for such care remains high, with NGOs playing a crucial role in its provision. Special attention is given to projects supported by the International Renaissance Foundation. However, NGO activities are often fragmented, complicating the systemic development of palliative care. The necessity of an integrated approach is emphasized, encompassing medical, social, and legal support for patients, along with enhanced coordination between governmental and non-governmental structures to ensure compliance with international standards. Additionally, conditions must be created in the state for active civil society participation in shaping policies within this sphere.

Key words: hospice and palliative care, social work in palliative care, Ukraine, clinical social work, social care, hospice and palliative care in developing countries, NGO in developing countries.

Introduction. Palliative and hospice care are essential components of any country's healthcare system, addressing the needs of individuals with serious illnesses and their families. The number of elderly individuals and those with severe, incurable diseases in Ukraine remains high. Due to martial law, complete mortality statistics for 2022 and 2024 remain inaccessible. However, based on available data, general trends can be identified. For instance, in 2017, the total number of deaths was 583,600, while in 2021, considering the impact of COVID-19, it reached 714,263. The number of cancer-related deaths in 2019 was 61,289, decreasing to 53,012 in 2021 and 42,660 in 2022 (excluding temporarily occupied territories). Palliative and hospice care can be provided to these individuals. The type of assistance described extends beyond healthcare and generates scholarly interest in related fields such as political science, social work, psychology, and economics (Volf, 2024: 50–51).

Analysis of recent research and publications. Studying the practical experience of palliative and hospice care providers, particularly non-governmental organizations (NGOs), can foster the development of social work in this sector. As of December 2023, Ukraine had 208,385 registered non-profit organizations (Kaplan et al., 2024: 5). Civil society in Ukraine is actively evolving, with the number of charitable organizations increasing by 43% between 2021 and 2023 (Tygnyriadno, 2024). Therefore, Ukraine's non-governmental sector represents a significant segment whose various aspects of activity require further research.

The activities of non-governmental organizations (NGOs) in the context of social policy and social work – especially in the specialized field of palliative and hospice care – have been insufficiently studied in Ukraine. Oleg Kondratenko examined the broader relationship between NGOs and authorities from the 1990s to the present (Kondratenko, 2023). Formal and informal support networks for addressing the needs of elderly individuals were discussed in a monograph by Dzhuhan (Dzhuhan, 2023). Authors of another monograph briefly mention the role of NGOs in palliative and hospice care (Moiseienko, 2022). However, a more detailed and focused analysis of the role of NGOs in this field was conducted by O.O. Volf. In his doctoral dissertation in political science, he introduced the concept of the humanization of social policy, which he defined as a process that imparts a human-

centered direction to policy, expressed through enhanced democracy and an increased role for civil society structures, ultimately improving citizens' quality of life (Volf, 2014).

According to the relevant scholarly literature, key standards for NGO activities include transparency, citizen engagement in democratic processes, and the protection of human rights.

The article's purpose is analysis of the role of non-governmental organizations (NGOs) in the development of palliative and hospice care in Ukraine from 2011 to 2024.

Research methodology: bibliosemantic and systems analysis.

Main part. It is unsurprising that one of the most influential players in palliative and hospice care during the studied period was the International Renaissance Foundation. Founded by George Soros (USA) in April 1990, it has become one of Ukraine's largest charitable foundations. The Foundation fosters an open society characterized by citizen participation in state-building and transparent, accountable governance. A critical priority for the Foundation is the robust protection of human rights. Until 2022, one of its programs was «Public Health». According to the Foundation's website, the program aimed to «promote the development of an economically efficient and non-discriminatory healthcare system, ensure transparent and rational use of budget funds, and guarantee equal access for citizens, including vulnerable groups, to essential medicines and appropriate treatment» (Hromadske zdorovja, 2022).

Unfortunately, much of the information regarding project activities (reports on project implementation) of organizations receiving financial support from the Renaissance Foundation for assisting the seriously ill has not been published.

Between 2011 and 2016, with funding from the International Renaissance Foundation, a local NGO, Charitable Organization «Network 100 Percent Life Rivne», implemented the project «Ensuring Access to Pain Relief Medications for Palliative Care Patients in Rivne and Volyn Regions» (Nadani Granty). This initiative aimed to uphold the right of individuals requiring palliative care to alleviate pain and suffering by monitoring procedures related to prescribing, dispensing, and acquiring opioid analgesics (Diialnist iz Zabezpechennia..., 2014).

During this period, particularly between 2015 and 2017, one of the primary focuses for NGOs was ensuring adequate pain management for patients with chronic pain. Access to appropriate medications and medical procedures is one of the most critical aspects of palliative care. Without adequate pain relief, patients face significant barriers to a dignified life and social integration. Supported by the Renaissance Foundation, projects like «Palliative Care: Our Common Pain» were implemented by the Sumy Regional Public Organization «Source of Life». Since 2017, the campaign «Time to Take Off the Rose-Colored Glasses» has been underway (Nadani Granty). This initiative aimed to help healthcare professionals and patients properly assess pain and appropriately prescribe and use analgesics. Key partners included the NGO «Institute for Legal Research and Strategies», the International Charitable Foundation «Sobornist», the Charitable Foundation for Helping the Incurably Ill «Mother Teresa», «Chance Club», «Institute for Social Development», «Ukrainian Legal Initiatives», and «Network 100 Percent Life Rivne» (Husij, 2017).

Some projects supported by the Renaissance Foundation in 2016–2017 were implemented at the local level and involved active public participation in shaping local palliative care policies. A short-term outcome of such projects was the adoption of the Regional Programs for Palliative Care Development.

Another focus area for NGOs during this period was their collaboration with the Office of the Ukrainian Parliament Commissioner for Human Rights as part of the National Preventive Mechanism. Monitoring visits were conducted to closed institutions, including hospitals, hospices, and palliative care units, involving civil society activists (Uzahalnena Dopovid, 2017: 7). NGO representatives highlighted numerous violations of patients' rights, such as inadequate pain relief, lack of informed consent for hospitalization, substandard care, and breaches of privacy (Uzahalnena Dopovid, 2017: 2).

One of the key centers providing assistance to terminally ill citizens from 2011 to 2018, supported by funding from the International Renaissance Foundation, was Ivano-Frankivsk. Here operated the Charitable Foundation for Helping the Incurably Ill «Mother Teresa». According to the Foundation's reports, a Training and Methodological Center for Palliative Care functioned within the organization from 2009 to 2017, funded by the International Renaissance Foundation. The target audience for these trainings was medical professionals. Analyzing the issues addressed in the trainings, for example, in 2016, it can be noted that they primarily focused on enhancing the professional qualifications of medical personnel. Issues related to democracy, public monitoring, human rights, and the participation of civil society (including professionals) in shaping public health policy were addressed only marginally. The primary outcome of these numerous activities was the general dissemination of information to specialists about palliative care as a modern form of support for terminally ill patients. The analysis of the reports does not indicate that long-term results were achieved for community development or the actual protection of human rights (Zvit pro diialnist navchalno-metodychnoho tsentru, 2018).

Thus, the activities of non-governmental organizations largely depended on international funding (primarily from the United States) and were aimed at spreading information about this new type of support for terminally ill patients – palliative and hospice care – as well as addressing the protection of these individuals' rights.

As a result of this NGO activity, there was, according to the authors of the manual «Optimization of the Palliative and Hospice Care System in Ukraine: Realities and Prospects», an «uncontrolled» (Moiseienko, 2022: 83) increase in hospices and home care departments by 400% and 200%, respectively, during 2019–2020 (Rohanski, 2020). In subsequent years, the number of palliative care facilities continued to grow, while the quality of services provided remained questionable (Struk, 2024).

Since approximately 2020, the activities of most non-governmental organizations funded by the International Renaissance Foundation have ceased, due to the lack of international grants.

Due to such unsystematic activities by civil organizations, the state was forced to reconsider its role and approaches to regulating this sector. In the Analytical Note of the National Institute for Strategic Studies, non-governmental organizations are not mentioned as key players in the field of palliative care; instead, the leading role is assigned to the state, with one of the main barriers to the development of palliative care cited as the absence of an appropriate law in Ukraine (Boiko, 2019).

Thus, the activities of non-governmental and state organizations were unsystematic and not always coordinated, resulting in inconsistent quality of services provided in palliative care institutions.

Since 2011, Ukraine has had a public organization called the «League for the Development of Palliative and Hospice Care». This organization was established on December 17, 2010. The first initiative meeting aimed at creating the organization took place in November 2010 in Ternopil during the seminar «Opening of a Hospice in Ternopil: Opportunities and Prospects». During the event, participants reached a consensus on the need to establish an organization that would unite representatives from various fields – medical professionals, public activists, academics, clergy, volunteers, and philanthropists – to develop palliative care in Ukraine. One of the key areas of the organization's work is improving existing legislation in the field of palliative care, as well as developing plans and programs aimed at providing comprehensive medical, psychological, social, physical, and spiritual support for patients with incurable diseases (Ukrainska liha rozvytku paliatyvnoi ta khospisnoi dopomohy). In subsequent years, the League continued its activities to regulate care for terminally ill patients legally. Notably, representatives of the League are among the members of the multidisciplinary working group developing sectoral standards for medical care in «Palliative Medical Care», approved by the Ministry of Health of Ukraine on August 18, 2020 (Derzhavnyi ekspertnyi tsentr MOZ Ukrainy, 2024).

Analyzing the activities of this public organization, it can be noted that its specialists primarily focus on the medical component of palliative care. This is explained by the organization's staff com-

position, which mainly consists of doctors. This leads to the medicalization of palliative care, turning this field into an exclusively medical domain where even nurses have no decisive role. The roles of social workers, psychologists, medical chaplains, and volunteers are diminished. Specifically, according to the League's official website and social media presence, issues related to nursing, social work, psychology, and volunteerism in palliative care were only marginally addressed.

Therefore, the «Ukrainian League for the Development of Palliative and Hospice Care» is one of the non-governmental organizations working to develop palliative care. The organization focuses on improving the regulatory framework, with most changes concerning the medical component of palliative and hospice care.

The experience of the charitable organization «Association of Palliative and Hospice Care» founded in 2010, provides valuable insights into the operational methods of NGOs and their impact on policies for the terminally ill. Notably, this organization did not receive funding from the International Renaissance Foundation between 2011 and 2024.

Upon its establishment, the organization quickly became an active player in developing palliative medicine in Ukraine. From the outset, it identified one of its key tasks as implementing integrated multidisciplinary educational programs for professionals and volunteers, including medical workers, social workers, psychologists, and patients themselves. The Association's educational activities aimed not only at enhancing specialists' qualifications but also at promoting a comprehensive approach to palliative care that considered the needs of both patients and their families (Volf, 2019).

The educational programs implemented by the Association integrated fundamental theoretical concepts of social work, particularly the socio-ecological theory and the Life Model of social work practice developed by C. Germain and A. Gitterman. This theory viewed palliative care as a holistic system in which each element – medical staff, patients' families, psychologists, and social workers – plays a crucial role in improving patients' quality of life. It helped develop a training approach focused on creating a supportive network for patients and their families.

The primary educational activities conducted by the Association of Palliative and Hospice Care were informal education initiatives. In 2012, as part of a project to develop pediatric palliative care, the Association organized training sessions for parents at a medical facility in Kyiv. The training program covered topics such as basic care for terminally ill children, psychological support for families, and communication between families and medical staff. During these sessions, the Association promoted innovative care models for the terminally ill, such as home-based pediatric care in collaboration with volunteer organizations and state social services.

Patient rights and the participation of civil society organizations in shaping policies to uphold these rights were essential pillars of the Association's activities. For example, in 2012, the «Association of Palliative and Hospice Care» conducted a training session titled «Protection of the Rights of Terminally Ill Citizens» for civil activists (managers of civic and charitable organizations, socio-political movements, and associations) in the Kyiv region. This event was supported by the Democracy Support Fund of the U.S. Embassy in Ukraine. The primary objective of the training was to enhance the knowledge and practical skills of managers in civic and charitable organizations, socio-political movements, and associations in areas such as access to social and medical services, adequate pain management, and educational opportunities for terminally ill children (Treninh dlia hromadskykh aktyvistiv, 2012).

The training was linked to the Association's hotline for protecting the rights of terminally ill patients. According to the hotline's findings in 2013, there were numerous violations of terminally ill patients' rights to pain relief, information, social guarantees (including housing and necessary transportation), hospitalization, and the rights of terminally ill individuals with special needs. Even when certain rights appeared adequately defined in legislation, practical implementation often revealed violations, indicating the need for better enforcement (Govda, 2013: 23).

A significant area of focus for the Association was the implementation of educational visit programs for Ukrainian healthcare professionals to European countries, including Poland, Slovakia, and Sweden, between 2012 and 2013. These visits, lasting one to two weeks, provided insights into European hospice practices, which led to the establishment of new hospice departments in Ukraine. In 2016, educational visits to healthcare, social protection institutions, and charitable organizations in Poland, Sweden, Norway, Hungary, and Belgium were organized, involving approximately 50 specialists. These international visits and exchanges of experience with European colleagues promoted the development of palliative and hospice care (PHC) at the local level. During these visits, discussions extended beyond medical care for the terminally ill to include professional education, public awareness campaigns, and multidisciplinary collaboration between medical and social services (Zvit pro diialnist blahodiinoi orhanizatsi, 2024).

A significant milestone was the partnership with the international volunteer organization PRIME, established in 2013. This partnership facilitated the arrival of volunteer doctors to Ukraine, who shared practical palliative care experience during week-long programs. This collaboration enabled the creation of effective training programs based on advanced international practices. Cooperation with the Shupyk National Medical Academy of Postgraduate Education, particularly the Department of Palliative and Hospice Medicine, allowed Association specialists to integrate international experience into educational programs that continue to be successful today (Zvit pro diialnist blahodiinoi orhanizatsi, 2024).

In 2016–2017, the Association contributed to the creation of Ukraine's first textbooks on palliative and hospice care, with particular emphasis on social work in palliative medicine. This marked an important step toward systematizing knowledge in this field and improving the professional skills of specialists working with terminally ill patients. These textbooks, developed in close cooperation with the Shupyk National Medical Academy of Postgraduate Education, became crucial tools for educational institutions training social workers and medical professionals (Istorychna dovidka, 2024).

Between 2011 and 2015, the Association actively collaborated with Ukraine's Ministry of Social Policy and Ministry of Health to improve existing regulatory frameworks and implement educational programs. As a result of this long-term work, in 2014, a joint order titled «On Approval of the Procedure for Interaction of Entities in Providing Palliative Care Services at Home for Terminally Ill Patients» was developed by the Ministry of Social Policy and the Ministry of Health (Pro zatverdzhennia Poriadku). In 2015, the Ministry of Social Policy, in collaboration with public sector experts, developed the State Standard for Palliative Care, which defined the content, scope, norms, conditions, and quality indicators for providing palliative care services (Pro zatverdzhennia Derzhavnoho standartu). This ensured that NGOs must now deliver social services in compliance with state standards, whether on a paid or free basis.

Between 2017 and 2020, the Association conducted numerous training sessions for professionals under the Ministry of Social Policy, including topics such as «Fundraising and Project Management in the Field of Terminal Patient Rights Protection» (for instance, in the Mykolaiv region) (Na Mykolaivshchyni vidbuvsia treninh, 2018). The primary goal was to strengthen cooperation between governmental and non-governmental institutions and to initiate social projects aimed at improving conditions for terminally ill patients. This trend was influenced by the political and socio-economic situation in Ukraine. Since the onset of the war with Russia in 2014, there has been an acute need for fundraising initiatives due to reduced state funding. One of the leading trainers engaged by the Association from 2011 to 2018 was Yakiv Rogalin, head of the «Dobrota» foundation, who continued fundraising efforts despite the occupation of Donetsk and its surrounding region.

During this period, the Association also organized educational events focused on resource acquisition and closely collaborated with leading medical institutions, such as the «Okhmatdyt» National Children's Specialized Hospital and the Institute of Pediatrics, Obstetrics, and Gynecology. These

institutions frequently hosted training sessions for patients on effective care, psychological support, and interaction with medical personnel (Treninh «Fandreizynh i proektnyi menedzhment...», 2016).

Ensuring the rights of seriously ill patients, particularly children, to receive proper palliative and hospice care has been an important focus for this non-governmental organization. Between 2016 and 2019, the Association conducted relevant training sessions for representatives of non-governmental patient organizations and professional communities. As part of the project «Children's Rights in Palliative Care», which was implemented in 2016 with the support of the British Embassy in Ukraine, training sessions were organized on the rights of seriously ill children (Khvori dity, 2016). Participants included representatives of non-governmental organizations and volunteer groups (Treninh «Zakhyst prav tiazhko khvorykh ditei», 2016). During these events, the initiative «Second April,» dedicated to protecting the rights of children with disabilities, was launched and continues to operate in 2024. In 2016, a report on «The Rights of Seriously Ill Children» was published (Volf et al., 2016).

A key aspect of these activities was the involvement of specialists from various fields, including psychologists, social workers, and doctors, which allowed for an integrated approach to training and facilitated knowledge exchange. For instance, in 2018, in cooperation with the Ukrainian Association of Young Political Scientists, training sessions were held using future modeling technologies to predict the development of palliative care (Volf, 2019a).

An important part of the work of the Charity Organization «Association of Palliative and Hospice Care» was its membership in the Ukrainian side of the EU-Ukraine Civil Society Platform. This platform, established under Articles 469–470 of the Association Agreement between Ukraine and the EU, consists of representatives of Ukraine's civil society and members of the European Economic and Social Committee (EESC). The Association is part of Working Group 4 «Employment, Social Policy, Equal Opportunities, and Health» (Ukrainska storona).

In 2020, the Association conducted an online school for nurses, in recognition of the Year of Nursing (Zminy v okhorony, 2020). Since 2020, the Association has actively participated in the ISAR Ednannia program, which aims to strengthen the institutional capacity of organizations founded by parents of seriously ill children. This initiative included training events on organizational development, strategic planning, advocacy, marketing, communications, and fundraising (Psykhokolohiia, 2020).

In 2021, the Association became an official provider of continuous professional development educational services for healthcare workers (Tsentr testuvannia pry MOZ Ukrainy). From 2013 to 2020, the Association also worked closely with educational institutions that train social workers to raise awareness about palliative care. Special training programs and internships in medical institutions helped future professionals gain practical skills for working with seriously ill patients (Zvit pro diialnist blahodiinoi orhanizatsi, 2024).

The Association's intensive educational, scientific, and humanitarian activities have continued since 2022. Thus, the work of the Association of Palliative and Hospice Care has played a crucial role in the development of palliative medicine in Ukraine. Programs focused on training and professional development of specialists have helped improve the level of medical and social support for patients and their families. Through innovative approaches, interdisciplinary training, and effective cooperation with international organizations, the Association has become a leading educational platform in the field of palliative care. The Association views its educational activities as a tool for influencing state and local policies. According to the Association's report, between 2011 and 2024, over 4,000 specialists, 2,000 patients and their families, and nearly 80 volunteers were involved in educational events (Zvit pro diialnist blahodiinoi orhanizatsi, 2024).

Other non-governmental organizations active during this time included the charitable foundations «LaVita» and «Svoi» which primarily focus on targeted assistance to families. From 2022 to 2024, these organizations have directed their efforts towards providing direct support to individuals with serious illnesses, supplying hygiene products and food to about 100 people each month (Volf, 2024a: 38).

Conclusions. Based on the presented material, the following conclusions can be drawn.

The demand for palliative care remains high, driven by the significant number of individuals with incurable diseases. Providing quality palliative care is an urgent social and medical issue that requires a systematic solution at both the state and public levels.

In Ukraine, a substantial number of NGOs play a crucial role in the development of palliative and hospice care. Some of these organizations conduct systematic activities in this field, while others contribute to the implementation of individual projects.

The International Renaissance Foundation has become one of the key players in the development of palliative care in Ukraine. Thanks to funding from the USA, a number of important projects were implemented, aimed at ensuring the accessibility of pain-relieving medications and enhancing the qualifications of healthcare workers. However, the impact of these measures on the long-term development of palliative care remains limited, as the focus was primarily on the medical component, while social aspects and human rights were less emphasized.

The activities of non-governmental organizations in the field of palliative care are often fragmented. The lack of a systematic approach and coordination between state and non-state structures leads to uneven development in this field. A significant challenge remains the medicalization of palliative care, which narrows the role of social workers, psychologists, and volunteers within multidisciplinary teams.

An important aspect of NGO activities is the educational programs aimed at improving the qualifications of specialists and volunteers. The activities of the charity organization «Association of Palliative and Hospice Care» demonstrated the effectiveness of applying socio-ecological theory and the life practice model of social work to create a comprehensive system of support for patients and their families. The further development of palliative care in Ukraine requires an integrated approach that takes into account not only medical, but also social, psychological, and legal support for patients. Systematic cooperation between the state, non-governmental organizations, and international partners must be ensured, as well as enhanced monitoring of service quality.

For the effective development of palliative care in Ukraine, it is essential to implement comprehensive standards based on international experience, as well as create conditions for the active participation of civil society in shaping policies in this area.

References:

1. Boiko S. H. (2019). Shchodo rozvytku paliatyvnoi ta khospisnoi dopomohy. Analitychna zapyska [About development of palliative and hospice care. Analytical review]. In: *Seriia «Sotsialna polityka». Natsionalnyi instytut stratehichnykh doslidzhen. Issue 2*. Retrieved from <https://niss.gov.ua/sites/default/files/2019-11/analit-boiko-soc-policy-2-2019.pdf> (10.11.2024) [in Ukrainian].
2. Derzhavnyi ekspertnyi tsentr MOZ Ukrainy. Mulydystsiplinarni robochi hrupy ta temy (2024). [Ministry of health State expert center. Multidisciplinary taskforces and topics]. Retrieved from <https://www.dec.gov.ua/mtd/mulydyscyplinarni-robochi-grupy> (11.11.2024) [in Ukrainian].
3. Diialnist iz zabezpechennia dostupnosti zneboliuvalnykh preparativ dlia paliatyvnykh patsientiv Rivnenskoï i Volynskoi oblasti (2014) [Activities on better availability of pain management for patients in Rivne and Volyn regions]. Retrieved from <https://www.network.rv.ua/news/120> (18.10.2024) [in Ukrainian].
4. Dzhuhan R. (2023). *Potreby liudei pokhlyloho viku ta yikh realizatsiia v umovakh suchasnoho ukrainskoho suspilstva (sotsiologichnyi dyskurs) [Needs of elderly and their realisation in modern society]*, Uzhogord, RIK-U. [in Ukrainian].
5. Govda N. I. (2013). Typovi vypadky porushen prav tiazhkokhvorykh hromadian [Typical cases of seriously ill rights violation]. In: *Sotsialna polityka shchodo tiazhkokhvorykh (nevylikovnykh) Materialy II-yi shchorichnoi naukovo-praktychnoi konferentsii (23–26)* [in Ukrainian].
6. Hromadske zdorovja (2022) [Public health]. Retrieved from <https://www.irf.ua/program/health/> (29.10.2024) [in Ukrainian].

7. Husij O.V. (2017). Pravo na hidnu smert. Vidverta rozmova pro bil ta paliatyvnu dopomogu [Right to dignity death. Honest talk about pain and palliative care]. Retrieved from www.umj.com.ua/uk/publikatsia-111182-pravo-na-gidnu-smert-vidverta-rozmova-pro-bil-ta-paliativnu-dopomogu (11.10.2024) [in Ukrainian].
8. ISAR «Ednannia» (2024). Retrieved from <https://ednannia.ua/> (01.10.2024) [in Ukrainian].
9. Istorychna dovidka. Kafedra paliatyvnoi ta khospisnoi medytsyny (2024). [Historical review. Department of palliative and hospice medicine]. Retrieved from <https://www.nuozu.edu.ua/s/np/k/paliatyvnoi-ta-khospisnoi-medytsyny/istoriia-kafedry#gsc.tab=0> (30.10.2024) [in Ukrainian].
10. Kaplan Y., Skvotskova V., Valevski O. (2024). Stan rozvytku hromadianskoho suspilstva v Ukraini u 2023–2024 rokakh [Development of civic society in Ukraine in 2023-2024]. In: Potapenko V., Kaplan Y., Tyshechnko V. (Eds.). Kyiv, NISD. [in Ukrainian].
11. Khvori dity maiut pravo zhyty [Ill children have a right to live] (2016). Retrieved from <https://www.ukrinform.ua/rubric-presshall/1985887-hvori-diti-maut-pravo-ziti.html> (16.10.2024). [in Ukrainian].
12. Kondratenko O. (2023). Vzaiemovidnosyny vlady ta neuriadovykh orhanizatsii v Ukraini: vytoky ta suchasnyi stan [Relations of power and NGOs in Ukraine: sources and the modern situation], *Naukovi pratsi Mizhrehionalnoi Akademii upravlinnia personalom. Politychni nauky ta publichne upravlinnia*, 3 (69), (31–41) [in Ukrainian].
13. Moiseienko R. O., Hojda N. G., Tsarenko A. V., Knyazewich V. M., Tsajkowska V. V. (2022). *Optimizatsiia systemy paliatyvnoi ta khospisnoi dopomohy v Ukraini: realii i perspektyvy* [Optimisation of the palliative and hospice care in Ukraine: reality and perspectives]. Kyiv [in Ukrainian].
14. Na Mykolaivshchyni vidbuvsia treninh na temu «Fandreizynh i proektnyi menedzhment u sferi zakhystu prav vazhkokhvorykh» (2018) [In Mykolaiv oblast was made training on the topic Fundraising and project management in the sphere of protection of rights of seriously ill]. Retrieved from <https://www.msp.gov.ua/news/14799.html> (12.09.2024) [in Ukrainian].
15. Nadani granty [Grants provided] Retrieved from https://www.irf.ua/grants/awarded_grants/ (27.10.2024) [in Ukrainian].
16. Pro zatverdzhennia Derzhavnogo standartu paliatyvnoho dohliadu [Order about the approval of the Standard of palliative care] Retrieved from <https://zakon.rada.gov.ua/laws/show/z0247-16#Text> (15.09.2024) [in Ukrainian].
17. Pro zatverdzhennia Poriadku vzaiemodii subiektiv pry nadanni sotsialnoi posluhy paliatyvnoho dohliadu vdoma nevylikovno khvorym [Order about the cooperation between provider during provision of palliative care] Retrieved from <https://zakon.rada.gov.ua/laws/show/z0625-14#Text> (14.09.2024) [in Ukrainian].
18. Psykhoonkolohiia. Stratehiia rozvytku nauky ta dopomohy [Psychooncology. Strategy of development of science and support] (2020). Retrieved from <https://www.prostir.ua/?news=psyhoonkolohi-ya-stratehiya-rozvytku-nauky-ta-dopomohy> (29.10.2024) [in Ukrainian].
19. Rohanski A. (2020). Paliatyvna dopomoha: vazhlyva reforma, yaku nikhto ne pomityv [Palliative care: important unnoticed reform]. Retrieved from <https://rubryka.com/blog/paliatyvna-dopomoga/> (01.09.2024) [in Ukrainian].
20. Struk O. (2024). Paliatyvna dopomoha. Na paperi maiemo vse, shcho treba, ale v zhytti vono ne zavzhdy tak [Palliative care. On the paper we have all what is needed, but in life it is not always so]. Retrieved from https://lb.ua/society/2024/03/12/602752_paliativna_dopomoga_na_paperi.html (18.11.2024) [in Ukrainian].
21. Treninh dlia hromadskykh aktyvistiv na temu zakhystu prav tiazhko (nevylikovno) khvorykh [Training for civic activists on protection of rights of seriously ill] Retrieved from <https://gurt.org.ua/news/trainings/15228/> (20.10.2024) [in Ukrainian].
22. Treninh «Fandreizynh i proektnyi menedzhment u sferi zakhystu prav vazhkokhvorykh ditei» [Training Fundraising and project management in the sphere of rights protection of seriously ill children] (2016). Retrieved from <https://gurt.org.ua/news/trainings/34973/bull/> (18.10.2024) [in Ukrainian].
23. Treninh «Zakhyst prav tiazhko khvorykh ditei» [Training «Protection of rights of ill children»] (2016). Retrieved from <https://naiu.org.ua/trening-zahyst-prav-tyazhko-hvoryh-ditei/> (23.10.2024). [in Ukrainian].

24. Tsentr testuvannia pry MOZ Ukrainy [MoH Center of testing] 2024. Retrieved from <https://www.testcentr.org.ua/uk/bpr> (12.10.2024) [in Ukrainian].
25. Tygnyriadno L. (2024). Chym zhyve hromadianske suspilstvo protiahom dvokh rokiv viiny – doslidzhennia [How lives the civic society during 2 years of war]. Retrieved from <https://zmina.info/articles/chym-zhyve-gromadyanske-suspilstvo-protyagom-dvoh-rokiv-vijnydoslidzhennya1/> 17.11.2024 [in Ukrainian].
26. Ukrainska liha rozvytku paliatyvnoi ta khospisnoi dopomohy. Misii ta pryntsypy [Ukrainian League of palliative and hospice care development. Mission and Principles]. Retrieved from <https://ligalife.com.ua/ua/pro-nas/misiya-i-principi> (19.10.2024). [in Ukrainian].
27. Ukrainska storona Platformy gromadyanskogo suspilstva Ukraine-EU [Ukrainian side of the Platform of the civil society Ukraine-EU] Retrieved from <https://eu-ua-csp.org.ua/what-is-eu-ua-csp/> (10.09.2024). [in Ukrainian].
28. *Uzahalnena dopovid pro rezultaty monitorynhu shchodo dotrymanna prav patsientiv, shcho potrebuut paliatyvnoi dopomohy, u zakladakh okhorony zdorovia Ukrainy* (2017). [Report on results of the monitoring about rights of seriously ill patients who need palliative care, in medical facilities]. Retrieved from https://issuu.com/irf_ua/docs/_____2018____.docx (12.11.2024)[in Ukrainian].
29. Volf O. (2024). Dosvid roboty neuriadovykh orhanizatsii shchodo rozvytku dopomohy tiazhkokhvorym hromadianam u 2022-2024 rr. [Experience of NGOs about development of care to seriously ill citizens in 2022-2024]. In: *Suchasni realii ta perspektyvy sotsialnoho vykhovannia osobystosti v riznykh sotsialnykh instytutsiakh: materialy vseukrainskoi naukovo-praktychnoi konferentsii, prysviachenoj 220-richchju vid dnia zasnovannia Universytetu, m. Kharkiv, 7 lystopada 2024 r.* (36–39). Kharkiv, Skovoroda University. [in Ukrainian].
30. Volf O. (2019). Futuristychni aspekty v sferi sotsialnoi polityky shchodo tiazhkokhvorykh v Ukraini, Velykobrytanii ta Avstralii v 2030–2040 rr. [Futuristical aspects in the sphere of social policy concerning seriously ill in Ukraine, UK and Australia], *Nauki Społeczno-Humanistyczne. Polsko-ukraińskie czasopismo naukowe*, № 4 (24), 25–32. [in Ukrainian].
31. Volf O. (2019). Paliatyvna ta khospisna dopomoha v Ukraini. Chastyna 1. [Palliative and hospice care in Ukraine. Part 1]. Retrieved from <https://www.nuozu.edu.ua/n/p/4576-paliatyvna-ta-khospisna-dopomoha-v-ukraini-chastyna-1-mynule-ta-sohodennia-svitlii-pamiati-profesora-yuriiia-hubskoho-01101945-18052019-rr#gsc.tab=0> (10.10.2024) [in Ukrainian].
32. Volf O. (2024). Socio-ecological theory and the «Life model of social work practice» in practical social work in the field of palliative and hospice care. *Psychology and social work*, 1(59), 50–62, DOI <https://doi.org/10.32782/2707-0409.2024.1.5>
33. Volf O. (2014) Struktury hromadianskoho suspilstva ta yikh rol u humanizatsii sotsialnoi polityky derzhavy [Structures of the civil society and their role in the humanisation of social policy of country], Odesa, University «Juridical Academy» [in Ukrainian].
34. Volf O. O., Gedeon I. V., Golovachova K. G., Zamorska T. I., Ostrolutska L. I. (2016). *Zvit za rezultatamy doslidzhennia shchodo dotrymanna prav tiazhkokhvorykh ditei v Ukraini [Report on results of the study of rights of seriously ill children]*. Kyiv: Talkom. [in Ukrainian].
35. Zminy v okhorony zdorovia zalezhat vid nas samykh [Changes in the healthcare dependant on us]. Retrieved from <https://www.prostir.ua/?news=zminy-v-sferi-ohoroni-zdorovya-zalezhat-vid-nas-samyh> (01.11.2024) [in Ukrainian].
36. Zvit pro diialnist blahodiinoi orhanizatsi «Asotsiatsiia paliatyvnoi ta khospisnoi dopomohy» za 2022-traven 2024 rr. (2024). [Report on activities of charity Association of palliative and hospice care]. Retrieved from <http://palliativ.kiev.ua/gallery/zvit-ukr1.pdf> (12.11.2024) [in Ukrainian].
37. Zvit pro diialnist navchalno-metodychnoho tsentru Oblasnogo klinichnoho tsentru paliatyvnoi dopomohy m.Ivano-Frankivska (2005–2017 rr) (2018). [Report on activities of educational center on palliative care in Ivano-Frankivsk] Retrieved from <http://palliative.if.ua/ua/charity-foundation/reports/view/194/> (28.10.2024) [in Ukrainian].