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PALLIATIVE CARE IN THE CONDITIONS OF NEW SOCIAL CHALLENGES: PROBLEMS AND PROSPECTS

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Abstract

Russia's armed aggression against Ukraine, which turned into a full-scale military conflict in February 2022, created serious problems for the entire system of social assistance in Ukraine in general and specialized services providing palliative care, in particular. Significant social problems arose when implementing a comprehensive approach to patient and family care under martial law.

This review aims to summarize the existing positive practices of providing palliative care in conditions of new social challenges and to highlight the main directions of social support in palliative care in conditions of martial law.

The publication provides an overview of modern scientific research and various practices of providing social support abroad, which are provided in the conditions of specialized medical institutions and social institutions that provide palliative care in the conditions of modern social challenges (the COVID-19 pandemic, conditions of social distancing, etc.). Prospective practices in the provision of palliative care using community resources have been identified. The domestic experience of providing social rehabilitation services is analyzed, and the main directions of social support services provided to clients within the social service of palliative care in the Kharkiv Regional Charitable Fund "Social Assistance Service" under martial law are given.

To identify problematic issues and improve the quality of palliative care social service provision, a survey of recipients of the relevant social service was conducted regarding the level of life satisfaction as an important prerequisite for the psychosocial state of clients and client satisfaction with the level of palliative care service provision as a promising way to improve further work with clients, focused on their needs. Data on the processing of the survey results using the methods of statistical evaluation of the central tendency of the sample and correlation analysis are given. Based on the analysis and generalization of the research results, the main ways to improve the social service of palliative care for the elderly in the conditions of martial law and promising directions of research are determined.

Keywords: palliative care, elderly people, palliative help, martial law, charity fund, social well-being, statistical evaluation, central tendency of the sample, correlation analysis.

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51

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Introduction

According to the website of the International Organization for Migration, 6.2 million people are refugees and 5.1 million people are forced migrants in Ukraine. Based on the data provided in the 28th round of the report (September 2023), according to the basic assessment of the territory of registered IDPs, among the regions with the officially largest number of registered IDPs, the maximum share of registered IDPs of elderly and elderly age (28%) is observed in the Kharkiv and Donetsk regions (International Organization for Migration, 2023), which confirms the relevance of the problem of improving the quality of social services for this vulnerable category of the population in general and the need to find new ways and means of improving the quality of life of elderly people who are palliative patients and need special care in conditions of martial law, in particular.

According to the Constitution of the World Health Organization, social well-being is recognized as a component of optimal human health (World Health Organization, 1946), therefore palliative care is one of the basic needs that must be provided by the state in accordance with the foundations of Ukrainian legislation on health protection (Verkhovna Rada of Ukraine, 2020; Verkhovna Rada of Ukraine, 2014; Verkhovna Rada of Ukraine, 2023).

Analysis of studies has shown that social support is a resource that can be obtained through interpersonal interactions (emotional support, companionship, information, advice, etc.) (Uchino, 2004, Rutkowski et al., 2018), which is necessary for both physical (provides opportunities to maintain physical condition) and mental health (protects against the negative effects of prolonged stress (Hostinar, 2015). Also, in modern society, the role of art therapy is growing, the use of which in social rehabilitation work is considered one of the important aspects of improving the system of providing social services on the basis of the formation of a new concept of social services for the population of Ukraine with increased attention of society to people with special needs (Smerechak, 2020, p. 219).

With the beginning of the full-scale military invasion of Russia in Ukraine, the conditions and possibilities of providing palliative care changed radically. Researchers (Shcherbakova & Kostina, 2022, p. 203-206) proved that this led to a further deterioration of the difficult life circumstances in which this population group was living before. Specialized social institutions in Ukraine are trying to respond to the scale of the disaster, are involved in social projects for the provision of humanitarian aid and the provision of services in emergency/crisis intervention conditions, but the issue of increasing the effectiveness of the provision of palliative care social services in conditions of martial law requires additional research. Therefore, the purpose of the study was to generalize the existing positive practices of providing palliative care in the conditions of new social challenges, to conduct an empirical study among the recipients of palliative care social services and, based on the statistical processing of its results, to highlight the main directions of social support for palliative care clients in the conditions of martial law.

Materials and Methods

To study the practices of providing social assistance to clients in need of palliative care, a content analysis of scientific publications was used in the relevant field of research. To determine the needs of the target group, the 9-item Social Service Recipient Needs Assessment Questionnaire (NAQ-9) was used to comprehensively assess the needs of a palliative care social service recipient and ways to improve the quality of social service provision for the client, and the Life Satisfaction Scale (SWLS-5) of 5 points that allow identifying the peculiarities of the client's perception of the objective circumstances of life and state of the social service. The study was conducted among the recipients of the palliative care social service of the Kharkiv Regional Charitable Foundation "Social Assistance Service" in October 2023 by conducting an oral survey with data recording in the appropriate Google forms, 100 respondents, recipients of the palliative care social service, took part in the survey. Processing of the results was carried out using the methods of statistical evaluation of the central tendency of the sample and correlation analysis.

Results

The analysis of scientific studies on palliative care showed that the term "palliative" has an archaic origin, which is associated with the ritual of burial on the one hand and care for people who are terminally ill and need help, looking after them, on the other (Danyliuk, 2018). The researcher defines palliative care as an approach that improves the quality of life of palliative patients and their families, by preventing and alleviating suffering using early detection and clear assessment, treating pain and other physical symptoms, providing psychosocial and spiritual support.

According to research results (Bradley, et al., 2018, p. 7-9), during a survey of hospice day services in the United Kingdom and the Republic of Ireland in order to determine the spectrum of social support offered by hospices to palliative care patients, multicomponent interventions, activity groups (physical exercises, music, art or relaxation), formal support groups (functional rehabilitation groups, therapy groups, etc.), friendships and informal social activities (cafe clubs, some friendly and charitable community projects oriented around the home, etc.) became the most widespread.

Experts of the European Association for Palliative Care (EAPC) (Radbruch & Payne 2009, p. 283-289) distinguish various forms of palliative and hospice care, including supportive care, end-of-life care, terminal care, respite care, each type of which has its own characteristics and depends on the type of social institution that provides palliative services and the personal needs of clients, which require its provision. Therefore, in palliative social work at the level of the client in need of palliative care, the family is a unit of care that requires a complex influence in order to maximize efforts, because all family members can play an important role as caregivers.

The analysis of scientific studies has shown that new social challenges pose serious problems for specialized palliative care services, which are associated with significant limitations arising from the application of a holistic approach to a patient and family care. Thus, researchers (O'Brien & O'Brien, 2022) prove that at the beginning of the COVID-19 pandemic, serious problems appeared for specialized palliative care services, which were associated with significant ethical dilemmas that arose during the organization of patient care and family interaction due to the imposition of restrictions on visiting related to COVID. Analysis of the practice of providing social rehabilitation assistance showed that since the beginning of the war in Ukraine, the representatives of the target group have had additional social problems (Shcherbakova & Kostina, 2022, p. 205): the problem of a partial shortage of food products in the city and the impossibility of purchasing them on their own; loss of work due to hostilities has significantly affected the financial condition of beneficiaries, especially families, property damage, etc. This necessitated the search for new types of social support and assistance to beneficiaries at this time: drawing up logistical routes for the drivers to deliver humanitarian kits; sending volunteers to the place of residence to obtain the necessary medicines and deliver them to the beneficiaries; assistance in repairing damaged and destroyed housing; evacuation transportation of beneficiaries within the city to more "safe" areas, to relatives or guardians, to sanatoriums or homes for the elderly, etc.

In this context, we find the pilot project "Compassionate Communities Connectors for care at the end of life" interesting in this context, which was carried out in Western Australia in 2020-2022 and aimed to develop, implement and evaluate a model of care provided by volunteers from communities (Aoun et al., 2022, p. 1-14). The main task of Connectors, as caring helpers recruited from the local community, was to support people in need of palliative care by expanding their support networks. The implementation of the project was able to eliminate gaps for people who could not receive official services because they lived alone or were socially isolated in remote rural communities, which are often beyond the reach of official services. The researchers suggest implementing a comprehensive model of care that includes a combination of four subsystems of care: specialized palliative care, general palliative care, community action, and natural networks. Important types of support provided by Caring Helpers and Connectors were: personal care, medical services, house and yard work, transportation services, social connections, nutrition counseling, help with pets, help with preparation of the latest cases. Researchers provide a description of interesting innovative practices: palliative care in the community as the use of volunteers to improve access to rehabilitation services in the community in palliative care (Preston et al., 2023, p. 1-3) and the combination of efforts of health care representatives with volunteers and social institutions of the community (Peeler et al., 2023 p. 1-4, 15-17); providing additional social rehabilitation and social adaptation and support services to clients in the community in the face of new social challenges (Kostina, 2023a; Kostina, 2023b, p. 36-43, 47-50, 58-72, Melnyk et al., 2021, p. 297).

Content analysis of information from the websites of medical institutions and social institutions that provide palliative care in Ukraine proved that the leading providers of relevant services are: hospices and centers of palliative and hospice care; specialized departments of palliative medicine of multidisciplinary hospitals, oncological, geriatric, psychoneurological, anti-tuberculosis dispensaries; specialized social institutions of the public sector (charitable foundations, social institutions, etc.). The provision of palliative care is based on a comprehensive approach, the goal of which is to ensure the highest possible quality of life for palliative patients and their family members by maximizing the efforts of various specialists.

The main directions of palliative care in Ukraine, according to modern standards of the relevant type of professional activity, are as follows: medical (provides effective control of chronic pain syndrome, treatment of disease symptoms and professional care of patients); psychological (allows to improve the psychological state of clients by reducing the feeling of fear and anxiety, prevention and control of depressive states and stress in palliative patients and their relatives); social (creates conditions for ensuring social support for the family of a palliative patient, provision of household and ritual services, legal counseling and assistance in drawing up documents, etc.); spiritual (performed by clergy and aimed at meeting the religious needs of the palliative patient and their family members).

The following types of palliative care are distinguished: primary palliative care (provided to palliative patients at the primary level of receiving health care in a hospital or at home by doctors of general practice and family medicine, etc.); general palliative care (provided to palliative patients by specialist doctors in accordance with their specialization on an outpatient basis and in inpatient health care facilities of the second and third level); specialized palliative care (provided to palliative patients in hospices, palliative care departments and wards of inpatient treatment and prevention institutions by doctors and junior medical staff, as well as at home by specialists of specialized multidisciplinary mobile palliative care teams with the involvement of medical psychologists, social workers and other specialists, volunteers, the patient's next of kin or guardians).

An analysis of the practice of providing palliative care in Ukraine under martial law showed that in order to overcome the challenges of the war, its provision was somewhat simplified according to April 18, 2022, requiring only the application of a person (Government Portal, 2022). This service is provided by various social institutions of both the state and public sector, competing on issues of quality provision of social services in terms of their procurement. As the director of the Department of Social Policy, Ruslan Svitly, notes, through the social order, palliative care services are currently being purchased in Kyiv at the expense of the city budget, provided by "multidisciplinary teams, which include a social worker, a social worker, a medical worker (paramedic, doctor), legal counsel, a practical psychologist, clergymen (Masters or PhD of theological sciences), catering technologist (cook), which travels to the person in their own transport" (Kyiv Official Portal, 2023).

The Kharkiv Regional Charitable Fund "Social Assistance" (2023) implements various charitable projects, in particular the "Home Care" and "Palliative Care" projects, which are aimed at providing assistance to the elderly and palliative patients. Since 1999, the foundation has implemented a medical and social direction of work with elderly people who are lonely, deprived of attention from their relatives, and since 2011, the foundation has started implementing the "Helping Hand" project – end-of-life care for terminally ill and elderly people, who were left without guardianship in Moldova and Ukraine. To date, thanks to the support of the ICF "Caritas of Ukraine" and the charitable organization "Caritas Vienna", social services are provided within the framework of the "Palliative care" and "Domestic care" projects. The overall goal of the projects is to improve the quality of life of socially disadvantaged population groups by facilitating access to professional home care/palliative care services. Currently, more than 210 elderly people and people in need of palliative care receive social services within these projects. In particular, these are cancer patients, patients with severe cardiovascular and neurodegenerative diseases, patients in the late stages of diabetes, people who have suffered a stroke, lonely elderly people, people with limited mobility who live alone, people with limited physical capabilities, people with temporary disability who cannot work. Support is also provided to family members (if any) of our wards. These projects currently provide the following types of services: 1) social and household support for patients (sanitary and hygienic services (rubbing, washing, hygienic baths, nail clipping, hairdressing, changing underwear and bedclothes, etc.), as well as assistance in everyday life (purchase and delivery of medicines, food, basic necessities, cooking, washing and ironing, etc.); 2) moral and psychological assistance to patients and their relatives (provided by a practical psychologist of the project both at the patient's home and by phone, which allows to improve and stabilize the emotional state of seriously ill people and their family members); 3) borrowing of rehabilitation equipment and providing consultations on the use of rehabilitation equipment (anti-decubitus mattresses, wheelchairs, walkers, etc.); 4) sanitary and educational work with relatives of palliative patients, teaching them the basic methods of caring for seriously ill people. Social workers of the fund have a special education and/or have completed training under a program certified by the European Reference Center For First Aid Education, as a result of which they received certificates of international standards, and also constantly improve their professional level and work on improving knowledge and sharing experience.

Therefore, the goal of modern palliative care is to create conditions to prevent the emergence of additional problems and alleviate the suffering of people with a life-limiting disease and their families by comprehensively responding to their physical, psychological, spiritual, social, cultural and situational needs, as well as helping the people close to them to better adapt to the life situation and maximize efforts to find and restore common resources. Generalization of the practice of providing palliative care showed that most modern social service providers of palliative care combine both medical care and social support. But the latter is still at the stage of developing the established foundations of its provision and remains only an additional part of the former, which actualizes the need for its theoretical research and practical solution.

In order to improve the quality of providing social services to clients who receive them within the framework of the above-mentioned projects, we prepared materials for a diagnostic study consisting of two stages: determining the level of life satisfaction as a basis for influencing the psycho-social state of clients and identifying the level of client satisfaction with the level provision of palliative care services as a promising way of further work with the client, focused on their needs. 73% of women and 27% of men participated in the diagnosis. According to the age of the respondents, the sample is characterized by the following indicators: respondents under 60 years old -17%; respondents 60-80 years old 60% and respondents older than 80 years old -23%.

During the first diagnosis, using the Life Satisfaction Scale (SWLS) technique, it was found that: only 16% of the surveyed respondents consider their life close to ideal or almost close; only 20% of respondents agree or partially agree that their life circumstances are exceptionally favorable; 3) only 18% of respondents were satisfied or partially satisfied with their lives; 4) regarding the question of having everything that is necessary in life, only 23% of respondents answered affirmatively, or rather affirmatively; 5) 27% did not agree or rather did not agree to the question regarding the desire to live their life in the same way. Therefore, based on the results of the first survey, it can be concluded that the majority of clients are not very satisfied with the quality of their own life, which undoubtedly affects their psychological state and social relationships, and confirms the need to improve the quality of palliative services as an important component of supporting their social well-being.

After statistical processing of the results of the survey using the Life Satisfaction Scale (SWLS) methodology and using the method of statistical evaluation of the central tendency of the sample, it was found that the majority of respondents are generally at the stage of uncertainty regarding the quality of their own life, as evidenced by the data shown in Fig. 1.

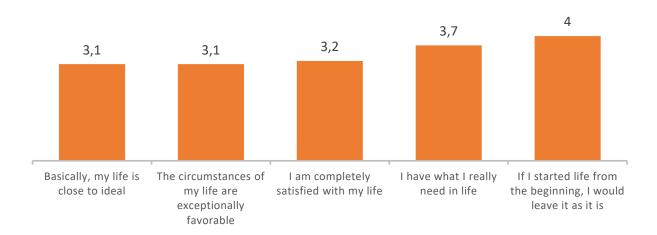


Figure 1 – Distribution of respondents' generalized assessments regarding the quality of their life (according to the method of statistical evaluation of the central tendency of the sample)

The analysis of the survey results showed that the majority of respondents rate the quality of their own life with sufficiently low ratings, but there are certain discrepancies regarding the ratings of interviewees of different ages. The processing of the research results showed that the respondents under the age of 50 rated the quality of their life the lowest, even with palliative care, while the respondents aged 50 to 80 rated

the quality of their own life the most optimistically and, even if something could be changed, then would leave everything as it is, which is confirmed by the statistical data shown in Fig. 2.

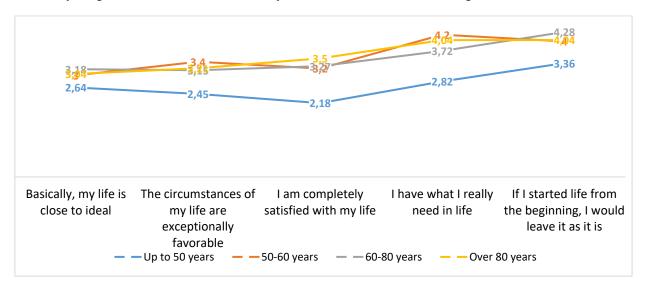


Figure 2 – Distribution of respondents' generalized assessments by age regarding the quality of their life (according to the method of statistical evaluation of the central tendency of the sample)

Calculating the Pearson correlation coefficient regarding the presence of a relationship between respondents' answers according to the quality of life criteria defined in the Life Satisfaction Scale (SWLS) methodology allows us to assert that all criteria in the respondents' assessments are closely related to each other and a direct connection between them can be traced. (See table 1).

Table 1

Pearson's correlation coefficients regarding the relationship

between quality of life criteria in respondents' assessments

(** - correlation is significant at the 0.01 level)

Quality of life criteria	Basically, my life is close to ideal	The circumstances of my life are exceptionally favorable	I am completely satisfied with my life	I have what I really need in life
Basically, my life is close to ideal	1	0,851**	0,712**	0,614**
The circumstances of my life are exceptionally favorable	0,851**	1	0,761**	0,662**
I am completely satisfied with my life	0,712**	0,761**	1	0,710**
I have what I really need in life	0,614**	0,662**	0,710**	1

The statistical analysis also made it possible to state that the quality of their life is highly related to certain circumstances and that their lives do not have everything that they really need (0.614), but no significant differences were found in the answers of respondents of different genders, at the same time, a significant discrepancy in satisfaction with one's own life is observed in the answers of respondents of different ages (see Table 2).

During the generalization of the results of the second diagnosis according to the method of assessing the needs of the recipient of social services of palliative care, which was carried out in order to determine the level of satisfaction of the needs of clients, as well as to determine the possible prospective directions of their social support in the conditions of palliative care, the following data were obtained: the majority

Table 2

The relationship between quality of life criteria in respondents' assessments by age
(Pearson correlation coefficients)

The relationship between quality of life criteria and the age of respondents	Your age	A positive assessment of all circumstances of life	A high level of satisfaction with one's life	Having everything you really need in life
Basically, my life is close to ideal	Up to 50 years old	0,923	0,708	0,650
	50-60 years old	0,922	0,968	0,645
	60-80 years old	0,805	0,727	0,620
	over 80 years old	0,895	0,686	0,615

of respondents, 82%, answered, that they are fully satisfied with the service they receive; 79% of respondents are completely satisfied with the quality and frequency of service provision; 95% of clients noted that they are completely satisfied with the attitude of social workers; 83% of clients are fully satisfied with the provider's list of social services; 27% of clients wish to improve the quality of social services in the context of martial law. Among the additional social services that recipients of palliative care social services need, the following were identified: general care (49%); rehabilitation aimed at maintaining, as far as possible, a good physical, psychological and social state (21%); psychotherapy (28%); social and psychological support of the family during illness (27%), 15% of respondents have specific additional individual needs. Therefore, based on the results of the second survey, it can be concluded that the quality of the provision of social services of palliative care within the scope of the work of the specialists of the Social Assistance Service "Social Assistance Service" is high.

Statistical processing of the results of the second survey using the method of statistical evaluation of the central tendency of the sample made it possible to state that the respondents were generally satisfied with the quality and frequency of the provision of social services. The respondents gave the highest ratings to the following criteria in the provision of social services: attitude towards oneself in the work of social workers (3.91); conformity of the service to customer needs (3.78); and satisfaction with the quality and frequency of service provision (3.73), which is a confirmation of the generally positive assessment of the quality of social service provision shown in Figure 3.

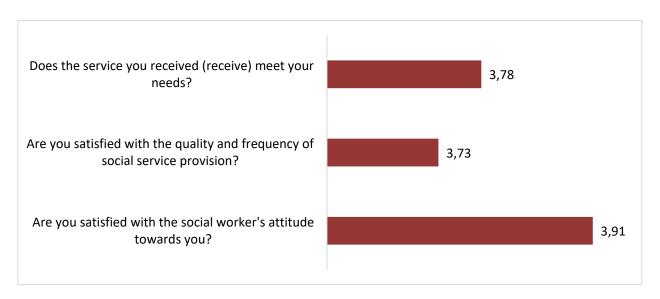


Figure 3 – Distribution of respondents' assessments of the quality of social services received (according to the method of statistical evaluation of the central tendency of the sample)

Meanwhile, the relationship between the respondents' comprehensive assessment of the quality of their own life and the quality of social services provision is almost not observed or is observed in the opposite direction. What is connected, in our opinion, first of all, with the respondents' low assessment of the quality of their own life and high assessment of the quality of the provision of social services, which confirms the need to improve the conditions of the quality of life of recipients of palliative services through the provision of palliative care (See Table 3).

Table 3

The relationship between the generalized quality of life criterion in respondents' assessments and the assessment of the quality of social services (Pearson correlation coefficients)

Relationship between criteria	Evaluation of the quality of the provision of social services				
	Conformity of the social service to the needs of the recipient	Satisfaction with the quality and frequency of social service provision	Satisfaction with the social worker's attitude towards themselves	Satisfied with the provider's list of social services	
Comprehensive assessment of quality of life	-0,096	0,002	-0,085	-0,043	

Meanwhile, there are differences between the correlation of respondents' assessments of the quality of their own life and the quality of the provision of social services by age. For respondents under the age of 50, the connection is direct and sufficiently strong (0.466). For people aged 50 to 60 years, it is strong, but reversed (- 0.722). For interviewees over 60 years of age, the relationship is not observed (see Table 4).

Table 4

The relationship between the generalized criterion of quality of life in the ratings of respondents by age and the assessment of the quality of the provision of social services (Pearson correlation coefficients)

	Age of respondents	Evaluation of the quality of the provision of social services			
Relationship between criteria		Conformity of the social service to the needs of the recipient	Satisfaction with the quality and frequency of social service provision	Satisfaction with the social worker's attitude towards themselves	Satisfied with the provider's list of social services
Comprehensiv e assessment of quality of life	Up to 50 years old	0,466	0,455	0,295	0,319
	50-60 years old	-0,722	-0,297	-0,297	-0,295
	60-80 years old	-0,216	-0,132	0	-0,127
	over 80 years old	0,037	-0,003	-0,333	-0,008

The statistical analysis of the processing of answers regarding the sources of obtaining information about the social service "Palliative care" also made it possible to determine that the largest number of respondents learned about the social service from acquaintances, and only a very small number (2%) received information from the Internet, which confirms the need to develop a quality social service advertising and digital distribution of this information (see Fig. 4).

How did you find out about the social service you receive?

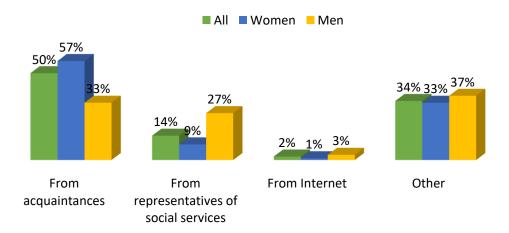


Figure 4 – Sources of information about social services in general among respondents and by gender

Discussion

The conducted research made it possible to confirm the presence of additional social needs of palliative care social service clients (Shcherbakova & Kostina, 2022) in improving their quality of life, especially in the conditions of martial law.

In addition, we saw that there is a particularly vulnerable category of clients (respondents under the age of 50) who need to expand the range of social services. The experience of multi-component intervention, the creation of activity groups, formal support groups, the organization of informal social activities (Bradley, Lloyd-Williams & Dowrick, 2018), as well as the provision of social services using the experience of compassionate community connectors that spread social support in the community on a volunteer basis, can be useful here (Aoun, et al., 2022).

Conclusions

Therefore, based on the obtained research results, and taking into account the additional needs of palliative care social service recipients, it can be determined that the appropriate social service is an important condition for preserving the health and maintaining the social well-being of the aged and elderly people, especially in the conditions of martial law. The following are the promising areas of activity of specialists in the social sector that will be able to improve the quality of providing palliative care services: increasing the list of services related to general care and social and psychological support of the family; the addition of social rehabilitation and psychotherapy services as important aspects of maintaining the state of social well-being, especially in the conditions of martial law; involvement of volunteers from available resources of the community to increase the breadth of coverage of social services, especially in terms of creating additional social support centers.

There is an important direction of further research in identifying the possibilities of combining the efforts of specialized social institutions of hospice and palliative care of state and communal forms of ownership in interaction with the public sector at the level of the territorial community through the implementation of complex social projects and programs.

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in conducting research within the educational program of the second (master's) level of higher education in the specialty 231 "Social work" within the educational and professional program "Social pedagogy".

Conflicts of Interests. None.

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