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Social aspects of the implementation of multidisciplinary approach in palliative and hospice care

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The results of research of the multidisciplinary approach to the provision of the palliative care in Ukraine have been presented in the article. It has been found that the palliative (hospice) care improves the quality of life of patients (adults and children) and their families who face problems, related to life-threatening diseases. The peculiarities in the definition of a «multidisciplinary team» in Ukrainian law (the focus on means of implementation) and international documents on the palliative care (focused on the provision of care components) have been examined. The subjects of the palliative care in Ukraine are palliative institutions, specialized departments of medical institutions, mobile groups (services) of palliative care at home, centers for prevention and combating of AIDS, psychological services, territorial centers of social service for pensioners and lonely disabled people, NGOs and volunteers. The basic medical and non-medical (social, psychological, spiritual) care components of palliative care have been described in the article. The main service users of palliative care are not only terminally ill patients, but also their family members, relatives and palliative care institution employees, who experience high rates of professional burnout.

The results of our empirical research have shown that the palliative care services in the city of Lviv include the functions of social workers, though no social worker positions exists in the service providing working groups. Instead, the functions of the social worker in this area are handled either by other team members (e.g. a chief doctor or other medical personnel, psychologist, priest, etc.), or professionals who do not belong to the service team (mostly psychologist). In some cases most part of the functions of the social worker are not delivered at all. The main social worker's functions while implementing the social component of the palliative care may include the conduction of self-help groups for the terminally ill and their relatives, management of a client's case, drawing up an individual work plan with the client and his/her family, basic legal counseling, provision of the supervision for members of the multidisciplinary team, establishment of contacts with other specialists, conduction of measures to prevent burnout, development of educational and leisure programs for children of different ages with different illnesses, training for teachers how to work with terminally ill children, development of leisure programs for the elderly (taking into account their age and physical condition), training for practitioners to provide these services, research and development of new programs in order to improve social services in the palliative care, establishment of networks with other social organizations, search for partners, grants, and training of clergy to work in palliative care.

Keywords: hospice; multidisciplinary team; the terminally ill; role of the social worker; subjects of palliative care

Соціальні аспекти впровадження мультидисциплінарного підходу в процесі надання паліативної та хоспісної допомоги

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У статті викладено результати дослідження впровадження мультидисциплінарного підходу в процесі надання паліативної допомоги в Україні. З'ясовано, що паліативний (хоспісний) догляд є підходом, який покращує якість життя пацієнтів (дорослих і дітей) і їх сімей, які стикаються з проблемами, супутніми небезпечним для життя захворювань. Виявлено особливості тлумачення поняття мультидисциплінарної команди у міжнародних документах з паліативної допомоги (акцент на меті її надання) та у вітчизняних нормативно-правових актах (акцент на засобах її реалізації). Визначено суб'єкти надання паліативної допомоги в Україні. Встановлено основні немедичні (соціальна, психологічна, духовна) складові паліативної допомоги. Зазначено, що основними користувачами послуг у рамках паліативної допомоги можуть виступати як самі невиліковні хворі, так і їхні родичі, а також самі працівники паліативних закладів у зв'язку з високою ймовірністю професійного вигоряння.

За результатами емпіричного дослідження виявлено, що практика надання послуг паліативної допомоги на рівні Львова включає у себе функції соціального працівника, але не забезпечує посади соціального працівника у складі робочої групи. Встановлено, що має місце суттєве навантаження працівників паліативних закладів додатковими функціями. Відповідно, функції соціального працівника у цій сфері виконуються частково іншими членами команди або не виконуються взагалі.

Ключові слова: хоспіс; мультидисциплінарна команда; невиліковно хворі; ролі соціального працівника; суб'єкти надання паліативної допомоги

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Социальные аспекты внедрения мультидисциплинарного подхода в процессе оказания паллиативной и хосписной помощи

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В статье изложены результаты исследования внедрения мультидисциплинарного подхода в процессе оказания паллиативной помощи в Украине. Выяснено, что паллиативный (хосписный) уход является подходом, который улучшает качество жизни пациентов и их семей, сталкивающихся с проблемами, сопутствующими опасным для жизни заболеваниям. Выявлены особенности интерпретации понятия мультидисциплинарной команды в международных документах по паллиативной помощи (акцент на целях ее предоставления), и в отечественных нормативно-правовых актах (акцент на средствах ее реализации). Определены субъекты оказания паллиативной помощи в Украине. Установлены основные немедицинские (социальная, психологическая, духовная) составляющие ухода паллиативной помощи. Отмечено, что основными пользователями услуг в рамках паллиативной помощи могут выступать неизлечимые больные, родственники, а также работники паллиативных заведений в связи с высокой вероятностью профессионального выгорания.

По результатам эмпирического исследования выявлено, что практика предоставления услуг паллиативной помощи на уровне Львова включает в себя функции социального работника, но не обеспечивает должности социального работника в составе рабочей группы. Установлено, что имеет место существенная нагрузка работников паллиативных заведений дополнительными функциями. Функции социального работника выполняются частично другими членами команды либо не выполняются вообще.

Ключевые слова: хоспис; мультидисциплинарная команда; неизлечимо больные; роли социального работника; субъекты оказания паллиативной помощи

Introduction. Every year in Ukraine up to 600 thousand people the require palliative and hospice care in the final period of their life (hereinafter – PHC). The aim of the public health, social security, charity, civic and religious organizations, volunteers and communities is to achieve the highest possible quality of life of palliative patients and support relatives during their illness and after their death [3, 103-104].

There are positive changes in PHC in Ukraine. For example, Ukraine's first department of palliative medicine was created in 2009 in the Shupyk National medical academy of postgraduate education. And in 2013 the State educational and scientific center of hospice and palliative medicine was created [2, 64]. Regulatory frameworks have gradually improved not only for health, but also for the social aspects of palliative care delivery. In particular, the Ministry of social policy's Order №58 from January 29, 2016, «On approval of the State standard of the palliative supervision» covers the issue of quality of PHC provision [8].

Despite these efforts, the practice of the palliative care for terminally ill patients in Ukraine includes mainly the symptomatic treatment that does not meet modern requirements and needs improvement. Unlike legislative regulation, the existing system of care is usually minimal in nature, and is under the supervision of a general practitioner, who relies often primarily on prescribing of narcotic painkillers.

The process of improvement of the palliative care for patients and their family's needs, requires, above all, the development of patient-oriented support that is based on a multidisciplinary approach and considers the social aspects of PHC. It requires also the creation and the implementation of a new, conceptual and more effective system of care provision.

An important issue is the definition of roles and functions of employees who provide non-medical services in the system of palliative care. Particular attention needs to be given to the role of social workers, who play a key role in the provision of non-medical components of PHC in most countries where long experiences of terminally ill people's assistance exist. Indeed, the lack of clearly defined functions and roles leads to a misunderstanding of tasks that social workers can perform while providing palliative care.

Analysis of studies and publications. Issues related to the provision of palliative care are reflected in the writings of medical, public administration, law and social work sciences. In particular, Yu. Voronenko, Yu Gubsky, A. Tsarenko substantiated scientifically the need for inter-agency and inter-sectoral cooperation and coordination of the development and introduction of modern medical and social palliative and hospice care in Ukraine [2]. N. Goyda, Yu. Gubsky, A. Tsarenko have highlighted the medical and social problems of palliative care in Ukraine [3]. Zh. Zolotareva has studied the health workers' vision on problems of the multidisciplinary approach's implementation to the system of palliative and hospice care [4] C. Lunyachek, A. Melnichenko, V. Melnichenko have studied public administration aspects of development and implementation of the palliative care [5]; T. Semyhina has theoretically described the place of social work in the palliative care model [9].

Aim. To study the current situation and to determine ways of the non-medical part of palliative care's improvement, based on multidisciplinary approach.

Main material. According to the WHO definition, the palliative care is an approach that improves the quality of life of patients (adults and children) and their families who face problems associated with life-threatening illness. It aims to prevent and relieve suffering through the early identification, correct assessment and treatment

of pain and other problems, whether physical, psychosocial or spiritual [7].

According to the Ukrainian law, the palliative (hospice) care is the help with self-service, health surveillance, facilitation in provision of medical services, assistance in provision of technical means of rehabilitation, maintenance of training about their use, training for families about the process of care, representation of interests, psycho-social support of a patient and the members of his/her family, provision of the information on social protection, assistance in obtaining legal aid free of charge, organization and support of self-help groups [8]. The goal of the palliative care is not to eliminate pain in a certain body part, but a complex care of a person.

According to Voronenko Yu., the current poor situation with PHC in Ukraine is the result of the following factors: the lack of modern, science-based affordable model of PHC; imperfection of the legal framework that regulates the PHC delivery, lack of necessary skills and knowledge on approaches and techniques how to provide PHC among medical and social workers; lack of medical and social workers' motivation to work in the institutions of PHC and at patients' home due to low salaries, significant physical, moral and psychological overload; imperfect system of training, specialization of medical and social workers on provision of PHC; lack of inter-agency and intersectoral coordination and cooperation on tape providing health care and social protection at central and local levels, etc. [2, 68].

Multidisciplinary team in the national legislation is composed of at least three persons, including: social worker, medical officer, legal adviser, psychologist, chaplain and other professionals who have been trained by thematic cycles on the palliative care [8]. In addition to the above specialists, the International association of palliative and hospice care also names specialists in nutrition, physiotherapy, occupational therapy, pharmacology, etc. [6]. Palliative care can also be carried out with the assistance of volunteers and community support groups, which makes the international PHC standards to be an important tool [9, 55]. According to the survey of health workers in the city of Ivano-Frankivsk, the main burden of care for terminally ill people lays on their family members [4, 69-70].

The subjects of palliative care may be: palliative institutions (hospices, services and palliative care centers, etc.), specialized departments of medical institutions, mobile group (service) of palliative care at homes, centers for prevention and AIDS, psychological services, territorial centers of social service of pensioners and lonely disabled people, NGOs, volunteers [5, 11].

Integrated palliative care consists of various forms of medical and non-medical care that include general care, symptomatic treatment, anesthesia, rehabilitation, which is aimed to support the possible degree of good physical, psychological and social status, psychotherapy, social and psychological support to the family during the illness of one of its members and the loss period, spiritual support. The important role also takes teaching (of a client, his family, medical and social workers, volunteers) and studies designed to provide information to improve the quality of services and development's assistance [9, 54-55]. Goyda N. has noted that the PHC, according to modern concepts and standards, should provide the four required components (elements): medical, psychological, social and spiritual component. The social component concentrates on financial support of the patients family, legal advice and assistance in the documents completing (registration of a devise, etc.), help in funeral services, etc. [3, 103-104].

Voronenko Y. has indicated that basic non-medical assistance can be provided by professionals (social workers, psychologists, lawyers, etc.), volunteers, friends and relatives of a patient and clergy of different religions and denominations [2, 65]. Some part of the medical personnel understands the importance of involvement and shows their will to work with the following specialists – social workers (68,2%), clergy (45,0%), volunteers (43,6%) etc. [4, 70]. It should be noted that in Ukraine the professional activity of psychologists and social workers in the palliative care is often interconnected and interchangeable due to the presence of only one of these specialists in a single institution. For example, this may include measures aimed at prevention of the syndrome of professional / emotional burnout among employees.

Understanding the central place which a social worker should occupy while providing non-medical component of PHC, in our study, we have focused our attention on the roles and functions performed (or which could be performed) by a social worker.

During our empirical study «Implementation of the multidisciplinary approach in the provision of the palliative care in the city of Lviv», it has been found that the city of about 730 000 inhabitants has only three establishments (branches) of the palliative care: Lviv City Hospital «Hospice» (hereinafter – Hospice) with 30 beds; Department of the Palliative Care at the city hospital # 4 (hereinafter – City hospital # 4) with 30 beds; the Palliative Care Department at the Metropolitan Andrey Sheptytsky Hospital (hereinafter – Sheptytsky Hospital) with 25 beds. In addition, there are also several separate chambers of the palliative care at the Municipal city hospital #5, Lviv regional psychiatric hospitals and geriatric centers.

During our research, conducted in November and December of 2016, we interviewed representatives of the main centers of the palliative care in Lviv. Using the opportunity sampling method, we conducted seven guide interviews. It should be noted, that the only palliative institution, which contains a multidisciplinary team, was at Sheptytsky Hospital. The other two palliative care institutions had only health workers, making it impossible to provide integrated palliative care. Therefore, interviews were conducted with five representatives of the Sheptytsky Hospital multidisciplinary team (doctor, nurse, psychologist, priest, and junior social worker), a «Hospice» therapist and the chief doctor of City Community Hospital #4.

I t has been found that Sheptytsky Hospital's interdisciplinary team includes only a junior social worker who performs his duties according to the contract. These duties consist mainly of provision of the physical assis-

tance to patients, and work with documents – keeping records of patients (those who entered, retired, died), basic accounting. Moreover, the other team professionals do not see the difference between the junior social worker and social worker. In the case of two other centers of the palliative care, it should be emphasized that their team is strictly limited to the medical personnel. Although speaking about Hospital # 4, some involvement of specialists from other departments or external specialists can be seen due to awareness of the need to develop a broader interdisciplinary team that will provide a bigger range of services. All employees of the department had received palliative education abroad and are periodically attending external training and supervision. In the case of «Hospice», quite «closed» systems and unwillingness to engage additional experts to work in the institution can be noted. Referring to the specific customers (such as cancer of the fourth stage), representatives of the team believe that the complexity of care is sufficient. No separate children's palliative department has been found while it needs a bit different services. A single case of accepting child at a later stage in life was found in the «Hospice», but it is rather an exception to the rule. It has been noted that the functions of the social worker are being performed by other members of the multidisciplinary team, and even non-team members. This process takes time from their main duties, causing negative affect on the quality of service. Thus, it demonstrates the need for the involvement of social workers, and other professionals. Furthermore, there are some roles of a social worker that are not enforced at all. That also indicates the lack of international standards to achieve the level of the palliative care.

According to the information received, we have made suggestions for the provision of social services in the palliative care, dividing them into two target groups – children's hospices and the palliative department for persons older than 18 years (table 2).

Conclusion. Palliative (hospice) care is an approach that improves the quality of life of patients (adults and children) and their families who face problems caused by the life-threatening diseases. It has a non-medical component in the implementation of multidisciplinary approach which includes social, psychological and spir-

Table 1. Performing the roles of social worker in interdisciplinary palliative care team

The roles of social worker [1; 6; 7].	Specialist performing social worker roles	Institution name
Therapeutic role – consultant, family therapist (group therapist role is missing)	chief doctor, administrator	Sheptytsky Hospital
	doctor	«Hospice»
	doctor, external psychologist	City hospital # 4
An executive role – social services broker (advocate, case manager are missing)	junior social worker (deputy administrator in social work), doctor	Sheptytsky Hospital
	doctor (if needed)	«Hospice»
	doctor (if needed)	City hospital # 4
The role of coordinator – expert in social services, supervisor, mediator	doctor, psychologist	Sheptytsky Hospital
	according to the hierarchy (chief doctor to doctors, doctors to nurses)	«Hospice»
	external specialist (psychologist)	City hospital # 4
Educational and administrative role – developer of programs of work, researcher, analyst	administrator, priest, senior nurse	Sheptytsky Hospital
	chief doctor	«Hospice»
	chief doctor	City hospital # 4
Additional social worker roles according to respondents' proposals in order to improve the quality of palliative care services	▪ care for meeting of patients' social needs; ▪ organizing of patients' leisure; ▪ search for partners, grants; ▪ contacting other social institutions	Sheptytsky Hospital
	▪ «we do not need a social worker, we provide all the help by ourselves»	«Hospice»
	▪ regulation of the legal aspects of the work with clients and in providing social protection; ▪ organizing of patients' leisure; ▪ establishing of contacts with other social institutions	City hospital # 4

Table 2. Formation of social services as a component of integrated palliative care

The roles of social worker	Functions that perform social worker in this role	
	Children's palliative department	Palliative care department for adults
The therapeutic role – consultant of therapy for groups, family	Conducting self-help groups for families of terminally ill children	Conducting self-help groups for terminally ill and their relatives
An executive role – social services broker, lawyer, case manager	Full guardianship particular case the client – drawing up an individual work plan with the client and his family, legal counseling	
The role of coordinator – expert social services, supervisor, mediator	Supervision for members of the multidisciplinary team, establishing contact with other specialists, conduction of measures to prevent burnout	
Educational and administrative role – developer of programs and areas of work, researcher, analyst	Development of educational and leisure programs for children of different ages and with different illness, training for teachers to work with this target group	Development of the leisure programs for the elderly, taking into account the age and physical condition, trainings for practitioners to provide these services
	Research and development of new programs to improve social services in palliative care	
Additional – providing spiritual support	Providing spiritual support and counseling the client or his/her family (at their request), training of clergy to work with this target group	

itual components. National legal acts are referred to the help with self-care, training for families about the care process, representation of interests, psycho-social support of a patient and the members of his/her family, provision of the information on social protection, organization and support of self-help groups, etc.

Integrated palliative care which meets the needs of patients and their families, is possible to be provided by a multidisciplinary team, which includes at least three persons (social worker, medical officer, legal adviser, psychologist, chaplain and other professionals and volunteers who have been trained by thematic cycles of the palliative care). Palliative care institutions could be palliative institutions (hospices, services and palliative care centers, etc.), specialized departments of medical institutions, mobile groups, palliative care at home, centers for prevention and combating AIDS, psychological services, territorial centers of social service for pensioners and lonely disabled people, NGOs, volunteers.

During the studying of the practice of palliative care in Lviv, an interdisciplinary team was found only in one palliative care institution, while other institutions are limited to medical personnel. This doesn't allow them to provide integrated palliative care. The functions of social workers were often performed by other members of the interdisciplinary team (mostly medical personnel) or even those, who are not the part of the palliative team. This process takes time from their main activities and affects the quality of service. In addition, the roles of social workers are not enforced.

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