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Analytical review of the demand and satisfaction of the population with in-home palliative care services provided by mobile teams for cancer patients in Almaty

Relevance: Patients with advanced malignant neoplasms require constant monitoring and care. Mobile palliative care (PC) is one of the modern humanistic methods of supporting terminal cancer patients, as well as their relatives.

The purpose of this study was to analyze the demand and satisfaction of the population with in-home PC services for cancer patients provided by mobile teams.

Results: According to WHO, the number of people who need PC services at the end of life is 20.4 million, of whom 94% are adults (69% are over 60 years, 25% are at the age of 15 to 59), and 6% are children. 34% of patients dying from cancer need PC services at the end of life. 80% of people in need of PC services live in lower-middle-income countries. At the end of 2018, the total number of palliative beds deployed in the Republic of Kazakhstan amounted to 415 (vs 373 in 2017).

Conclusion: Given the practical relevance and topicality, there is an urgent need to develop evidence-based recommendations for optimizing the provision of PC services, as well as improving the quality of life of cancer patients.

Keywords: oncology, palliative care, mobile teams, incurable patients, malignant neoplasms.

Introduction: In 2018, GLOBOCAN reported 18.1 million new cases of cancer worldwide and 9.6 million deaths from cancer. In the Republic of Kazakhstan (RK), as of January 01, 2019, 181 344 patients are registered with malignant neoplasms (MN). In 2018, 752 cancer diagnoses were established postmortem (vs 819 in 2017), what amounted to 2.1% (2.3%) of the total number of patients newly diagnosed with cancer that year [1].

Caring for public health, improving the quality and accessibility of medical services for the population of Kazakhstan are the priorities of social policy of the state. The Code of the RK "On the Health of the People and the Health Care System" dated September 18, 2009 guarantees every citizen of the RK the right to receive palliative care (PC) [2].

Based on the WHO definition, palliative treatment starts from the moment when the possibilities of special antitumor treatment have been exhausted, or it is not advisable since will not lead to prolongation of life or improvement of quality of life (QOL) in a particular patient. WHO claims that cancer is one of the most common causes of morbidity and mortality today. On the other hand, there is convincing clinical evidence that palliative and supportive care in oncology should start from the moment of diagnosis, continue during all phases of the tumor process and be integrated into the overall structure of cancer service. This contradiction is one of the reasons for the fact that providing care (in this or that model of PC) to patients with very advanced forms of MNs remains a difficult and unsolved issue.

The purpose of PC is to improve the QOL of the patients and their relatives facing the life-threatening disease. The purpose is achieved by preventing and alleviating suffering, early detection, a thorough assessment and relief of pain and other painful physical symptoms, and the provi-

sion of psychosocial and spiritual support.

Mobile palliative care (MPC) is one of the modern humanistic methods of support for dying cancer patients, as well as their relatives. Patients with advanced forms of MNs require constant monitoring and care.

It should be noted that only an inter-disciplinary approach to solving the problems of incurable patients who need PC, based on the integration of professional, financial, HR, spiritual and moral resources of society will help optimize PC for incurable patients in the RK on the basis of close cooperation between the healthcare and social protection institutions in providing PC and medical-social support.

Analysis of the need of the population for PC for cancer patients

Today, there is an urgent need for scientific justification of the model of providing PC to incurable patients with severe progressive diseases in the terminal stage to ensure the QOL adequate to their state.

PC is overall active support provided to patients with diseases unresponsive to treatment. PC performs the following primary tasks: anesthesia and elimination of other symptoms, helping the patient in solving psychological, social and spiritual problems. The purpose of PC is to ensure the highest possible QOL for both the patient and his family members [3].

According to WHO, 20.4 million people need PC at the end of life. 94% of them are adults (69% – above 60 years, 25% are aged 15-59 years), and 6% are kids. 34% of those dying from cancer diseases need PC at the end of life. 80% of those who need PC live in lower-middle-income countries [4].

PC is aimed to reduce pain and other painful symptoms; it claims the value of life but treats death as a natural event, not trying to either precipitate or delay it. PC includes psy-

chological and moral support aimed to help the patient keep life as active as possible until the last day. The system of care for the patient's relatives is aimed to help them cope with the tragic situation, with the use of psychological counselling after the patient's death, if necessary. Using a complex approach, PC sensitively responds to the needs of patients and their relatives. It helps to improve the QOL and can have a positive effect on the course of the disease. It can be applied in the early stages of the disease in parallel with other types of treatment aimed at prolonging life (like chemotherapy or radiation therapy) [5].

Today, many countries of the world carry out large-scale research, establish new large cancer centers. Along with the diagnosis, prevention and treatment of MNs, such centers take actions aimed at creating a special service to improve the QOL of incurable patients [6, 7]. The studies report that both in developed and developing countries many patients with incurable, life-limiting, progressing diseases live and die in unjustified suffering, without adequate management of pain and other pathological symptoms, often in a state of constant fear and loneliness [8]. Palliative medicine helps to prevent and relieve such suffering. Relieving suffering is the ethical duty of healthcare providers.

There is growing scientific evidence on the type of care people need in the terminal period of their life. Most of the researchers report that about 75% of respondents would prefer to die at home. A share of those who would prefer an inpatient hospice is a bit higher among the people who lost their relatives recently. Some studies show that 50 to 70% of severely ill people would prefer to die in private (though, as they approached death, a certain part of that group has changed its attitude in favor of hospital conditions). Though most of the people would prefer to die at home, in practice, death in hospital is still common in many countries [9].

Different countries have a different structure and practice of providing PC depending on the historical traditions, national policy and financing. In many countries, a large volume of PC is provided by primary medical staff and hospitals. Some countries pay special attention to the development of inpatient PC services and hospices. Others attach greater importance to home-based care, providing care together with other services or at hospitals. In some cases, hospices or PC services completely take care of the patient.

Nearly every study informs that the patients and their relatives consider it particularly important to have a well-coordinated package of services. The results of pilot use of different forms of coordination (sometimes, via the PC services) of providing various services offered by hospitals, home-based care structures, lead us to a conclusion that in many cases we could help people create necessary conditions to let the patient stay at home till the end of his life if he wants and die in his bed. Scientific data also confirms that providing a coordinated PC can improve the QOL of the relatives taking care of the patient [10].

In Kazakhstan, PC has just been recognized as an important part of medical-social support to the population [11, 12]. Though the first hospices appeared in Kazakhstan back in 1999 and the legal framework for PC development was laid over the next decades with the adoption of the Code of the RK "On the Health of People and the Health Care System," PC

is still far from being available for the patients in need. The quality of provided care and the level of training of care providers in the newly opened palliative wards in cancer dispensaries do not meet the widely recognized global standards.

The problem of providing outpatient PC, taking into account the socioeconomic conditions, is gaining relevance. Providing inpatient PC costs a lot for the state, as evidenced by many studies [13]. On the other hand, most patients in Kazakhstan prefer receiving outpatient PC at home, surrounded by family and relatives.

Unfortunately, Kazakhstan still lacks an official registry of people in need of PC. In 2012, Thomas Lynch, an international PC consultant, estimated the number of those in need as 94 000 to 98 000 patients a year [4]. Besides, since, usually, two or more family members provide care to every patient, the number of PC beneficiaries should approximate to 283 000 people each year. Providing PC on such a scale will require not only reallocation of medical staff in urban and rural areas but the teaching of about 6 675 staff units - doctors, nurses, psychologists, social workers and volunteers, and allocating 825 beds for PC [15].

As of the end of 2018, RK possessed 415 palliative beds in total (vs 373 in 2017) (Table 1).

Table 1 – Number of palliative beds deployed in the Republic of Kazakhstan by the end of 2018

Name of the region	Number of deployed palliative beds (including those in hospices)	
	2017	2018
The Republic of Kazakhstan	373	415
Akmola	20	20
Aktobe	20	20
Almaty	15	30
Atyrau	7	7
East Kazakhstan	21	26
Zhambyl	5	30
West Kazakhstan	10	10
Karaganda	20	20
Kyzylorda	30	30
Kostanay	15	10
Mangystau	10	10
Pavlodar	30	30
North Kazakhstan	20	25
South Kazakhstan	20	20
The city of Almaty	100	100
The city of Nur-Sultan	30	27
Kazakh Institute of Oncology and Radiology	0	0
Also, by regions:		
Almaty region	5	20
Turkestan region	10	10
East region	11	11
Semey region	10	15

The analysis and current situation assessments, the lack of domestic scientific research on the topic, urge the necessity to develop evidence-based recommendations for optimizing the provision of PC services, as well as improving the QOL of cancer patients.

Analysis of population satisfaction with the provision of PC for cancer patients at home by mobile teams in Almaty

MPC is one of the modern humanistic methods of support for dying cancer patients and their relatives. Today, providing PC by mobile teams at home is a preferred method all over the world.

Materials and methods: The level of satisfaction of the patients and their relatives with the provision of PC at home was studied by continuous anonymous questioning using a specially developed questionnaire. The study involved 88 respondents: 46 (52.3%) women and 42 (47.7%) men.

Results: In the total structure of the respondents, 32 (36.4%) were caregivers, 42 (47.7%) – a patient with a caregiver, and 14 (15.9%) patients.

Demographic features of the cohort were established by questioning (Figure 1).

The distribution of patients by age showed that most of the primary patients (42, 47.7%) were aged 60 years and above.

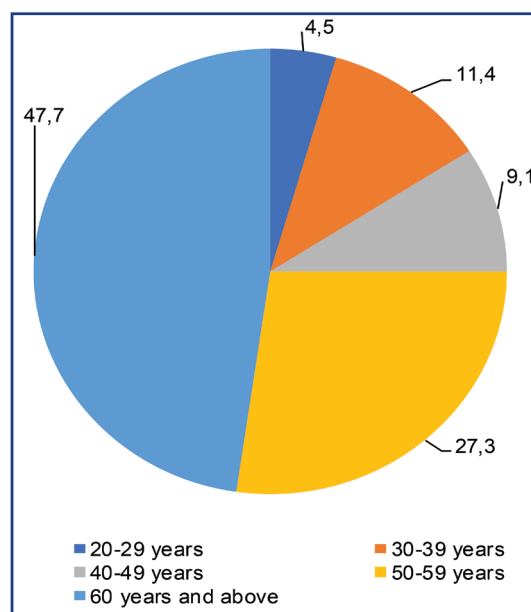


Figure 1 – Distribution of patients by age

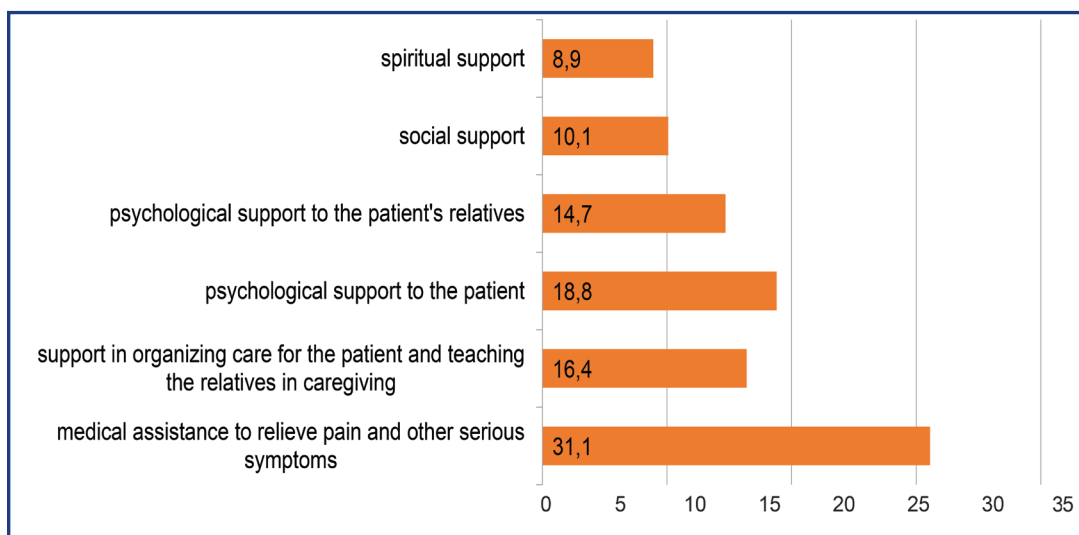


Figure 2 – Analysis of the patients' needs at the first visit

Being asked if they were aware before the visit about mobile teams providing PC care at home, 36 (40.9%) respondents answered positively, and 52 (59.1%) respondents answered negatively.

The analysis showed that by the first visit of the mobile team all 88 (100%) respondents needed medical assistance to relieve pain and other serious symptoms, support in organizing care for the patient and teaching the relatives in caregiving, psychological support to the patient and the relatives, as well as social support. At that, only 12 (13.63%) needed spiritual support (Figure 2).

Being asked how the provision of care by the MPC team at home influenced the patient, 78 (88.6%) of the responding patients reported improving condition, 8 (9.1%) reported no change in condition, 2 (2.3%) reported a worsening condition (Figure 3).

Assessing the accessibility of information provided by MPC team on a 5-point scale, the respondents answered as follows: 5 points – 79.5% (70), 4 points – 15.9% (14), 3 points – 4.6% (4) (Table 2).

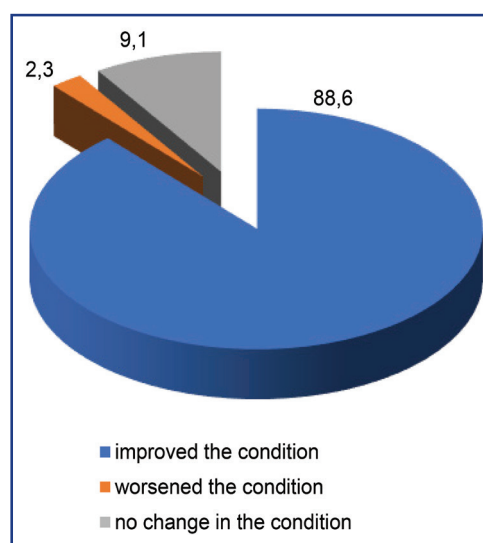


Figure 3 – The analysis of the influence of PC provision on the patient's condition

The study revealed a high assessment of the level of professional knowledge of MPC medical workers by 74 (84.1%) respondents (5 points on a 5-point scale), a good assessment – by 10 (11.4%) respondents (4 points), and a satisfactory assessment – by 4 (4.5%) respondents (3 points).

The overall satisfaction with MPC team service was assessed as follows: 5 points – 84.1% (74), 4 points – 11.4% (10), 3 points – 4.5% (4).

The following wishes were expressed to improve the quality of care provided: to expand staff – 25% (22), provide care round-the-clock – 59.1% (52), organize the timely provision of opioid drugs – 15.2% (7) (Figure 4).

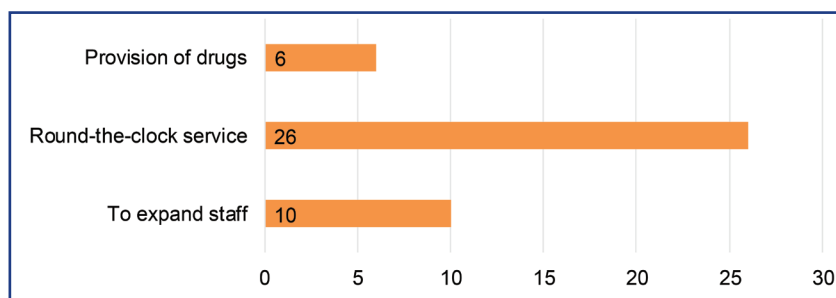


Figure 4 – Wishes of the respondents on the improvement of quality of provided palliative care

Table 2 – Assessment of the accessibility of information and the level of overall satisfaction

Points on a 5-point scale	Assess the accessibility of information provided by the MPC team (% of scores)	Assess the level of professional knowledge of MPC medical workers (% of scores)	Assess the level of your overall satisfaction with MPC team service (% of scores)
1	0	0	0
2	0	0	0
3	1.6	4.5	4.5
4	15.9	11.4	11.4
5	79.5	84.1	84.1

Conclusions: The principle of providing PC only at the terminal stage of life is obviously not suitable for those common situations when the patients need PC immediately after establishing the diagnosis, even though in parallel and till the last day they receive treatment against the primary disease. New views on PC link it more closely to known patterns of the course of certain types of diseases.

Taking into account the growing demand for mobile team operations in our country, all the above necessitates the optimization of providing PC at home. Such a team shall provide medical, social, and psychological services. Determination of satisfaction with home-based care is an integral part of providing PC to cancer patients.

References:

- Code of the Republic of Kazakhstan. On the Health of the People and the Health Care System: *appr. on September 18, 2009, No. 193-IV*;
- Pokazateli onkologicheskoy sluzhby Respubliki Kazakhstan za 2018 god (statisticheskie i analiticheskie materialy) [Indicators of the Oncological Service of the Republic of Kazakhstan for 2018 (statistical and analytical materials)]. – Almaty, 2019. – P. 209 [in Russian];
- Cleminson B. Vvedeniye v palliativnyuyu pomoshch' [Introduction to Palliative Care] / transl. from English by O. Tseitlina, E. Bakunina; ed. D.V. Nevrozova. — M.: Hospice Charity Foundation "Vera", 2016. — 276 c [in Russian];
- Saunders C. Foreword // In: Palliative care for noncancer patients / eds. Addington-Hall J.M., Higginson I.J. – Oxford, Oxford University Press, 2001;
- National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 2004. – Pittsburgh, 2004;

- National Health Services UK. What end of life care involves // www.nhs.uk/Planners/end-of-life-care/Pages/what-it-involves-and-when-it-starts.aspx. 09.06.2001;
- World Health Organization. Cancer. Palliative care // www.who.int/cancer/palliative/en/. 09.06.2020;
- Palliative care to cancer patients / eds. G.A. Novikov, V.I. Chissov. – M.: OOD "Medicine for the quality of life", 2006. – 192 p. [in Russian];
- Weizen S.M.S. et al. Factors associated with site of death: a national study of where people die // *Medical Care*. – 2003. – Vol. 41. – P. 323–335;
- Higginson I.J. et al. Is there evidence that palliative care teams alter end-of-life experiences of patients and caregivers? // *J Pain Symptom Manag.* – 2003. – Vol. 25. – P. 150–168;
- Shakenova A. Kazakhstan: approved National Palliative Care Standards. - Soros Foundation-Kazakhstan, February 28, 2014 [in Russian];
- Kaidaroda D.R., Afonin G.A. Sovremennaya sistema palliativnoy pomoshchi v onkologii [The modern system of palliative care in oncology]. – Almaty, 2017 [in Russian];
- Kaidarova D.R., Kunirova G.Zh. Palliativnaya pomoshch' v Kazakhstane: Etapy razvitiya i tekushchiye vyzovy [Palliative care in Kazakhstan: Stages of development and current challenges] // *Onkologiya i radiologiya Kazakhstana [Oncology and Radiology of Kazakhstan]*. – 2016. – №3. – P. 114-121 [in Russian];
- Lynch T. Assessment of the need for palliative care in the Republic of Kazakhstan [Otsenka potrebnosti v palliativnoy pomoshchi v Respublike Kazakhstan]. – Open Society Foundation Public Health Program, International Palliative Care Initiative (Ipcl), October 2012 [in Russian];
- Kunirova G.Zh. Dokladnaya zapiska Kazakhstanskoy Assotsiatsii palliativnoy pomoshchi (KAPP) po sostoyaniyu na oktyabr' 2017 [Report of the Kazakhstan Association of Palliative Care (KAPP) as of October 2017] // www.palliative.kz/pp_v_kazahstane/hospisy_i_dr_organizacii_okazyva. 09.06.2020. [in Russian].