UDC: 614.2:616.006:616-01

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Scientific and practical grounds for the model of mobile outpatient assistance to incurable cancer patients (short literature review)

Palliative care (PC) is active, comprehensive care for patients whose disease does not respond to therapy. Primary objectives of PC include management of pain and other symptoms, assistance to patients in solving their psychological, social, and spiritual problems. PC is aimed to ensure the highest possible quality of life for both the patient and his family.

PC involves relieving patient suffering throughout his disease (along with radical treatment) and medical care in the last months, days, and hours of life. It would be wrong to think that a dying patient needs only care. Many professional nuances that help alleviate suffering can only be applied by trained specialists.

Mobile palliative outpatient care is one of the modern, humanistic methods of assistance to dying cancer patients and their relatives.

Keywords: *terminal cancer patients, palliative care, mobile team, quality of life.*

The state social policy of Kazakhstan provides for health promotion, increased care, improving the quality of life of the population, and the availability of medical services.

The RK Code on Health of the Population of the Republic of Kazakhstan (of September 18, 2009) states the right of each RK citizen for palliative care (PC) [1].

PC is a complex of medical interventions aimed at relieving pain and alleviating other severe manifestations of the disease, as well as providing psychological, social and spiritual assistance to the patient and his family in order to improve the quality of life of the incurables [2, 3].

The World Health Organization (WHO) has been the sole initiator of the provision of palliative care to patients with incurable malignant tumors. In the 1970s, a small expert team under the aegis of WHO started to promote PC in more than 40 countries headed by Switzerland, United States, United Kingdom, Canada, Netherlands, Belgium, France, and Australia. PC has become a specialized discipline, with its rights, academic and clinical positions, specialized research and literature, and integrated development program [4, 5].

20.4 mln. people all over the world need PC. Of them, 94% are adults, 69% are above 60 years, 25% are aged 15 to 59, and 6% are children (WHO data). 34% of those who died from cancer needed PC at the end of life. 80% of people who need PC live in low-income countries [6].

WHO reports that malignant neoplasms have become one of the major causes of death. GLOBOCAN reports that in 2018, 18.1 mln. people were living with cancer vs. 9.6 million of deaths from cancers [7].

Today, many countries conduct large-scale scientific research, establish large cancer centers that offer diagnostics, prevention, treatment, and specialized services aimed at improving the quality of life of the incurables [8, 9].

According to many scientists, in developed and developing countries many people who suffer from incurable diseases that limit the life expectancy or are associated with acute conditions often dye in fear and loneliness, in anguish, without any actions taken to relieve pain and treat other pathological symptoms [10]. PC can prevent and reduce this suffering. Healthcare workers are ethically obliged to alleviate suffering.

Many foreign researchers have come to a single conclusion that about 90% of incurables would prefer to spend their last days at home [11-13].

A.V. Gnezdilov, Chief Physician of the first Russian hospice, says that the incurables and their family members can not always obtain the necessary attention and assistance of specialists [14]. Improving the quality of life of a suffering patient in his last days is always related to the accessibility of the relevant desensitization [15, 16]. There are several reasons for that:

- Proper characterization of the disease symptoms that is, the use of special scales that determine the symptoms of pain;
- Fear of side effects of drugs that remove the feeling of pain [17];
- Lack of access for many cancer patients to a comprehensive PC due to limited access to pain killers [18, 19].

Kazakhstan has just recently started recognizing PC as an essential part of sociomedical assistance to the population [20, 21]. Though the first hospices were opened in Kazakhstan in 1999, the legal framework for PC development was approved only ten years later, with the introduction into force of the RK Code "On Health of the Population of the Republic of Kazakhstan." Still, a lot is yet to be done today to make PC accessible for the patients who need it. The PC department re-opened at cancer dispensaries and the quality of training of specialized personnel do not meet generally accepted international standards.

The socio-economic conditions raise the importance of providing PC in outpatient settings. Many international studies evidence that providing PC in clinical conditions is too expensive for the state budget [9]. In Kazakhstan, most of the patients prefer to receive PC at home, being surrounded by their relatives and friends.

Mobile PC is one of the most humanistic modern methods of providing care to cancer patients and their relatives. Today, PC is provided all over the world, and providing PC at home by mobile teams takes leadership in this sphere of services.

Unfortunately, Kazakhstan still has no official register of people who need PC. According to an assessment by the international adviser on palliative care, Thomas Lynch, made in 2012, this figure for 2012 amounted to 94,000 to 98,000 people, and at least 15 500 of them needed PC. He also concludes that usually two and more family members are involved in taking care of each patient, so about 283 000 people need PC each year. This massive volume of PC requires rearrangement of medical workers in rural and urban areas, as well as training and retraining of about 6 675 medical workers including doctors, nurses, psychologists, social workers and volunteers, and the provision of 825 beds for PC services.

In his study, Thomas Lynch communicates other PC-related problems shared with him by the representatives of hospices:

- Lack of hospices and services providing PC;
- Lack of possibilities for training and retraining;
- Legal and political obstacles for the development of the discipline;
- Poor awareness of medical workers about PC, lack of public knowledge;
- Problems with access to or lack of opiates;
- Lack of interdepartmental cooperation/coordination (e.g., between the ministries of healthcare and social protection), the absence of the National PC Association;
- Lack of means for agitation and promotion of the introduction of PC in the Kazakhstan healthcare system [21].

In 2018, 179 000 people in Kazakhstan were suffering from various forms of malignancies. 37 000 new cases are registered each year, and more than 17 000 people die. The disease rates add 3-5% each year. The early detection of cancer is improving, but the share of late detection (stage III-IV) is still equal to 44.2% [22, 23].

The Comprehensive Plan to Combat Cancer Diseases for 2018-2022 and the actions under the Roadmap for Improving Palliative Care in the Republic of Kazakhstan assume that every city center, district center, and each city of Republican level shall arrange mobile/multidisciplinary teams to provide home care to incurable cancer patients, with planned training and retraining of specialists.

The analysis and assessment of the current situation, the lack of scientific research in this field in our country necessitate the development of scientifically based recommendations aimed at improving the quality of life of cancer patients.

The lack of real mobile teams providing home care in the settings of the growing demand for their services requires rationalization of PC in our country with the formation of mobile outpatient teams providing medical, social, and psychological assistance.

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