Palliative Care in Kazakhstan

Gulnara Kunirova, MS, and Ainur Shakenova, ML
Kazakhstan Palliative Care Association, Together Against Cancer Foundation (G.K.), Almaty, Kazakhstan; and Soros Foundation-Kazakhstan (A.S.), Almaty, Kazakhstan

Abstract
In Kazakhstan, like most ex-Soviet Union countries palliative care began in the late 1990s with the opening of the Almaty Hospice in 1999. Since that time, several palliative care services have opened in urban centers, but there is little coverage in rural areas. Palliative care has grown because of the collaborative work of Parliament leaders, Ministry of Health, local governments officials, Public Health Higher School, National Center for Health Development, academic medical institutions, oncology and palliative care experts, NGOs, Soros Foundation Kazakhstan, and international experts. A National Palliative Care Strategy provides the legislative framework that mandates the components of palliative care that must be available at no cost for patients living with cancer. Palliative care courses are provided in several of the medical universities and nursing schools with practical training in local hospices who also offer seminars each year to practicing health care professionals. There is no “palliative care” or “palliative medicine” specialty in the national classifier of specialties. There are a number of palliative care specialists who participated in various training courses outside Kazakhstan. Oral morphine is not registered or available in the country, and patients must depend on injectable opioids or patches. Going forward, additional policies, increased public awareness, education of health care professionals, access to oral opioids, and more inpatient, home care, and day care services are needed.

Background
Kazakhstan is an independent republic located in Central Asia. Covering 2.7 million square kilometers, it is the largest country of the former Soviet republics after Russia. It became independent in 1991 and developed its own policy and planning capacity. Policy making is highly centralized in an executive-style government run by the President. National health policies are set by the government and implemented by national and local authorities. Health services are administered by regional departments who have autonomy in their areas.

In Kazakhstan, like most ex-Soviet Union countries, palliative care began with the opening of Almaty Hospice in 1999 with additional hospices opening in five other big cities subsequently. The legislative framework only formed 10 years later, officially incorporating palliative care into the national health care system through the adoption of the Public Health Code (2009), the State Health Care System Development Program (2010), and the new National Cancer Control Program for 2012-2016. These documents established categories of patients eligible for palliative care, categories of medical and nonmedical workers involved in the palliative care process, public health institutions, and hospital departments responsible for services, material supply, and records management.

In spite of this substantial legal framework, palliative care is just beginning to be recognized as an important part of the national health care system. Such problems as the limited access to opioid analgesics, limited number of palliative care beds, inadequate development of home care and outpatient services, lack of trained staff, and poor awareness about palliative care are serious challenges for palliative care development in Kazakhstan.

Publication of this article was supported by Public Health Program of Open Society Foundations. The authors declare no conflicts of interest.
Address correspondence to: Gulnara Kunirova, MS, Kazakhstan Palliative Care Association, Kurnmangazy Strasse 58-75, Almaty 050000, Republic of Kazakhstan. E-mail: palliative.kz@gmail.com
Accepted for publication: March 10, 2017.
The cancer incidence rate is increasing (about 30,000 new cases each year, and the morbidity rate is increasing by 3%-5% each year). The high percentage of terminal stage illnesses (44.2%) indicates the need to develop an integrated palliative care system for incurable cancer patients. In addition to the 140,000 registered cancer patients, about 23,000 people suffer from tuberculosis and 17,000 people are living with AIDS in Kazakhstan.

In 2008, Thomas Lynch, an International Palliative Care consultant carried out a palliative care needs assessment and estimated that 94,200-97,900 patients a year are in need of palliative care (TJ Lynch, 2012, Unpublished). Furthermore, because two or more family members are directly involved in the care of each patient and need support themselves, it is estimated that 282,600 individuals per year would benefit from palliative care. To provide palliative care at home and in hospitals, a large-scale redeployment of professional medical staff will be needed in urban and rural areas. About 6675 medical staff and 825 beds will be required for palliative care to be available to all in need.

**Policy**

In recent years, the development of palliative care in Kazakhstan has been progressing because of the efforts of a few dedicated people and organizations. Collaboration of the Ministry of Healthcare, local and international experts, Soros Foundation-Kazakhstan (SFK), Open Society Foundations' International Palliative Care Initiative, National Center for Health Development, Public Health Higher School, and local NGOs have made change possible.

A number of legislative acts in Kazakhstan have been adopted: for example, the Code of the Republic of Kazakhstan “On health of people and healthcare system” article 52: palliative care and nursing care. To implement the code: the Decision of the Government of Republic of Kazakhstan from November 26, 2009, for no. 1938 “On approval of the list of categories of the population subjected to palliative care and nursing care”, and Order of the Minister of Health of Kazakhstan, dated November 2, 2009, for no. 632 “On approval of the rules for palliative care and nursing care” were adopted. The impact of these policy changes and ways in which they have been important include the development of the health system is the responsibility of the State; this includes the provision of palliative care for the population. These documents laid the foundation for the development of palliative care, and for the first time, the concept of palliative care was highlighted in an official state document.

In December 2013, the Ministry of Health approved the National Palliative Care Standards recognizing both public health institutions and nongovernment organizations as providers of palliative care. Palliative care is no longer seen as a purely medical issue but is also a socio-psychological service. Palliative care is to be available in hospitals, hospices, outpatient settings, day care programs, and at home with the help of mobile cross-disciplinary teams. Bereavement support for family members is included as an important component of palliative care. The standards also emphasize the important role of volunteers and families in providing palliative care. Palliative care providers are obliged to address the legal, social, and psychological needs of their patients in addition to symptom control and pain relief needed by their patients. The Standards pay particular attention to the provision of palliative care for children with life-limiting illness. The psychological needs of seriously ill children are mentioned separately, and their families are called palliative care services beneficiaries.

Of course, the adoption of palliative care standards in itself is insufficient for any substantial changes to be implemented in the clinical practice of health care professionals or health care institutions. Systematic work is needed to change the regulatory framework, implement educational programs, and raise awareness about the benefits of palliative care among the population.

Such activity has been carried out with the assistance of SFK by the Kazakhstan Palliative Care Association (KPCA) which was established in 2013, on the initiative of four NGOs, including “Together Against Cancer” Foundation in Almaty, “Credo” in Karaganda-Temirtau, “Adangershilik” in Karaganda, and “Amazonka” in Taraz. The Association includes NGOs and also government institutions; therefore, the Almaty Oncology Center and the Almaty Palliative Care Center became some of the first members of the Association. The Association’s geographical reach is expanding as well with organizations from Aktobe, Ust-Kamenogorsk, Semey, and other cities joining. Memoranda were signed between the KPCA and several foreign palliative care associations, like the Polish Hospice Association of Lodz, the Russian Association of Palliative Medicine, the Russian Association for Hospice Care, and the Ukrainian League for Promoting the Development of Palliative and Hospice Care.

To date, KPCA is playing a leading role in promoting the ideas and practices of palliative care in Kazakhstan. Each member of the KPCA successfully implements palliative care projects in their regions and is engaged in educational and outreach activities. Because of this, the items related to palliative care development are increasingly included in the agenda of the Parliament sessions, ministerial meetings, and oncology congresses.

**Drug Availability**

Kazakhstan has many barriers that limit the availability of opioid analgesics and effective pain management.
It is among the countries with the lowest consumption of opioids for medical and scientific purposes. This problem is because of the use of an outdated method for estimating the need for narcotic analgesics based on the previous years' consumption. This question continues to be raised with the Ministry of Health and Social Development; however, inconsistency in the actions of various agency departments prevents effective dialogue on this issue. Table 1 illustrates the opioid consumption in Kazakhstan.

The list of the opioid analgesics in the National Drug Formulary has changed very little in the last three years. The available drugs are mainly intravenous forms and oral forms of morphine are still unavailable in Kazakhstan (Table 2).

In 2015, one foreign and one Kazakh pharmacologic company started the process of registering tablet forms of opioids. KPCA made recommendations for the inclusion of these forms in the regulations for the medical use of narcotic drugs, psychotropic substances, and precursors controlled in the Republic of Kazakhstan, order no. 32. The process of registering tablet forms of opioids has been recently finalized in neighboring Russia, and because of the unified rules and regulations for registration and use of drugs for all the members of the Eurasian Economic Union, Kazakhstan may get access to oral opioids soon.

Procedures for licensing, transportation, storage, prescription, dispensing, and disposing of opioid analgesics in Kazakhstan are too stringent. Patients do not have to pay for opioids, but only a small number of pharmacies seek to obtain a license to sell opioids because of the numerous inspections by regulatory authorities.

In 2015, amendments were made to order no. 32 to eliminate the requirement for the patient to return the empty vials and packages to receive a new prescription and to increase the prescription period to 15 days. Currently, the MHSP is preparing a new draft of Order No. 32, which should include further amendments proposed by the KPCA to eliminate other barriers.

Pain relief access in Kazakhstan became the focus of the Round Table on “Availability of Pain Management Drugs: Solutions to the Problem” (December 4, 2012, Almaty) and the Round Table “Access to Opioids: Everybody’s Right” (October 23, 2015, Astana). The discussions, organized by KPCA with support of SFK involved high-profile international experts, representatives of the Ministry of Health and Social Development, Drugs and Narcotics Control Committee of the Ministry of Internal Affairs, members of parliament, oncologists and representatives of hospices, nongovernment organizations, and pharmaceutical companies. Both meetings outlined the current barriers to opioid availability and discussed a plan to resolve them.

Although the average morphine dose in developing countries and low-income countries amounts to 60-75 mg per day, average daily dose in Kazakhstan does not exceed 30-40 mg. This is because of a lack of knowledge about pain assessment and management of opioids by physicians. Fear of addiction is common among physicians, who often ignore the difference between addiction and tolerance and are prone to prescribe lower doses than are effective in relieving pain.

The resolution signed by participants at the most recent Round Table “Stop My Pain!” meeting on September 22, 2016, in Astana contains only one recommendation: to establish an Interagency Committee for the development of a Road Map (Action Plan) on broadening access to opioid analgesics and psychoactive substances for medical use. The first meeting of the group took place on March 3, 2017.

Positive changes are taking place in pediatric palliative care since July 2016 with the introduction of revised Clinical Protocols in Treatment of Solid Tumors and Hematologic Malignancies, which for the first time included palliative care as a separate section of each protocol. Pain treatment was included in these Protocols according to the best world standards and WHO pain management recommendations.

### Education and Training

Kazakhstan had launched a number of initiatives to provide basic palliative care training supported by international and local organizations. About 200 palliative care doctors, nurses, therapists, social workers, and NGO leaders participated in the American Association of Colleges of Nursing’s “End of Life Nursing Education Consortium” courses and seminars at the American Austrian Foundation’s Open Medical Institute in Salzburg, Austria, courses of the European School of Pain, and other world-renowned educational programs. At least three cross-disciplinary teams from Karaganda, Almaty, and Taraz visited hospices in Eastern Europe to gain knowledge about the clinical management of palliative care patients, education and training initiatives, policy development, and program development and management.

Grants provided by SFK and additional support from several international organizations including

### Table 1

<table>
<thead>
<tr>
<th>Types of Opioids</th>
<th>Mg per Capita</th>
<th>Morphine Equivalent (mg per Capita)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fentanyl</td>
<td>0.0110</td>
<td>0.9185</td>
</tr>
<tr>
<td>Hydromorphone</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Methadone</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Morphine</td>
<td>0.2479</td>
<td>0.2479</td>
</tr>
<tr>
<td>Oxycodone</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Pethidine</td>
<td>—</td>
<td>—</td>
</tr>
<tr>
<td>Total morphine equivalents</td>
<td>0.1664</td>
<td></td>
</tr>
</tbody>
</table>
the Eurasian Society for Oncology, the American Society of Clinical Oncologists, U.S. National Cancer Institute, and the Middle East Cancer Consortium enabled KPCA organizations to hold several conferences and seminars in Kazakhstan over the past few years.

The American Society of Clinical Oncology partnered with the Middle East Cancer Consortium to present a three-day International Palliative Care Workshop from May 11 to May 13, 2016, in Almaty, Kazakhstan. One-hundred seventy psychologists, nurses, oncologists, and other health care workers from Kazakhstan attended the International Palliative Care Workshop. The course featured case-based presentations and interactive sessions on different aspects of palliative care. There was a significant increase in interest on the practical aspects of psychological, social, and spiritual care provided to patients and families, the issues of assessment and relief of pain and other symptoms, development of communication skills, and psychological self-help techniques.

Since 2011, Karaganda State Medical University has introduced an elective course on palliative care for fourth year medical students and interns. Palliative care projects in Asfendiarov Medical Kazakh National University are focused on patients suffering from age-related diseases and include development of organizational and functional models of at-home and hospital care for these patients and the development of palliative care clinical guidelines. Short-term training courses are organized on an occasional basis by such educational institutions as Kazakh School of Public Health and the Kazakh Medical Lifelong Learning Institute.

Of course, these educational efforts are not enough to meet the increasing demand for palliative care specialists throughout Kazakhstan. The problem of palliative care specialist training should be recognized at the government level. National Occupation Classification must include such professions as “palliative care” and/or “palliative medicine.” The lack of a legal framework for the inclusion of palliative care into the national standards of education hinders introduction of training programs into medical institutions.

It is necessary to develop and implement a methodologic framework, teaching standards, and an evaluation process for the training of medical (doctors, nurses) and nonmedical (social workers, psychologists) specialists in palliative care on three levels:

- Basic—for all health care professionals providing basic medical care, general practitioners,
- Intermediate—for physicians who care for patients with serious medical illness but are not experts in palliative care, and
- Advanced—for physician and nurses who wish to become palliative care specialists.5

Ideally, practical training for physicians, nurses, psychologists, and social workers should take place in hospices, in patient’s homes, or in inpatient units in hospitals. Additional training for hospital attendants, volunteers, and family members in practical skills of care and psychological support also need to be made available.

### Clinical Service Availability

The Cancer Plan for 2012-2016 included palliative care beds in Astana, Petropavlovsk, Aktobe, and Kyzylorda in 2013 and the establishment of palliative care departments in oncologic hospitals in Taldykorgan, Almaty, Uralsk, Atyrau, Shymkent, and Taraz during the period 2014-2016. To date, approximately 150 new palliative care beds have been deployed as part of the plan, including opening of therapy and
palliative care departments for cancer patients in Astana, Kyzyl-Orda, and Shymkent.

There are 13 institutions in Kazakhstan that provide palliative care, including hospices, nursing centers, and symptomatic treatment and palliative care departments. The total number of beds does not exceed 500, which is still not enough for 17 million of population. Unfortunately, palliative care is virtually inaccessible to patients living in remote areas, and home-based care programs must be developed in rural areas and small towns to meet the needs of these patients.

Patients suffering from common forms of cancer who are discharged from oncologic centers or hospitals become the responsibility of the municipal outpatient clinics. Caring for them becomes the responsibility of general practitioners and residential oncologists who do not have the necessary palliative care skills or the required resources. These health care professionals must receive at least intermediate level of palliative care education.

Four NGOs—“Credo” in Karaganda and Temirtau, “Amazonka” in Taraz, “Together Against Cancer” in Almaty, and “Solaris” in Pavlodar have conducted training for multidisciplinary teams and successfully launched mobile projects for incurable patients at home. The multidisciplinary teams in Karaganda and Temirtau worked for four years from the SFK grant and for one year at the expense of the regional health department. Palliative care specialists provided consultations for cancer patients by telephone and were supported with health department funding. In Almaty, a multidisciplinary team was funded by SFK for one year, and from January 2016, a mobile unit that works under the auspices of Together against Cancer Foundation joined the staff of the Almaty Cancer Center. In addition, the Almaty Center of Palliative Care has launched its own mobile unit.

Challenges and Future Direction

Although there is official government policy and legislation, the provision of palliative care remains irregular and often depends on the patient’s geographic location, local budget, and personal attitude of those who are responsible for the patient’s care on the local level.

Other palliative care service delivery options, such as mobile teams, hospices at home, and daycare centers are included in the legislative statutes but are underdeveloped, if developed at all. The lack of awareness by the public about palliative care and the lack of basic palliative care knowledge by health care professionals, health managers, policy makers, and government officials make the development of palliative care across the country an ongoing challenge. In addition, there are no palliative care services for children, and there are no professionals working in the field of pediatric palliative care.

Palliative care is not included as a mandatory subject in the medical or nursing curricula in Kazakhstan, and there is no such profession as a palliative care physician or nurse. In addition, psychologists and social workers receive little education and training in palliative care.

Because of the unnecessarily strict regulations on opioids and the outdated methodology for estimating the demand for narcotic analgesics, Kazakhstan ranks 115 in the world in opioid consumption per capita, leaving patients with severe cancer pain to suffer needlessly.

Despite positive developments, a great deal of work remains to be done if palliative care is to be provided to all patient and families in need throughout the country.

It is important for the Kazakhstan Palliative Care Association and other stakeholders in Kazakhstan to work cooperatively and make use of the expertise and continued support of the Soros—Kazakhstan Foundation and Open Society Foundation, reputable experts from the American Society of Clinical Oncology, the National Cancer Institute—Center for Global Health, the Middle East Cancer Consortium, and many other partner organizations, and local Parliament members and NGOs.

References


