Palliative Care Development in Ukraine
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Background
Before Ukraine’s independence in 1991, it followed the highly centralized Semashko health care model. Since independence, it has undertaken several attempts at health care reform that were launched in parallel to decentralization of the system and passing managerial authority to the 27 regions (oblasts) and the local level. Local (city and rayon) and regional (oblasts) health authorities are responsible for the polyclinics and hospitals in their regions and report to the Ministry of Health (MoH), but management and financing departments report to the regional and local government as of 2014.1

Ukraine is the second largest country in size in Europe and borders Russia, Belarus, Poland, Slovakia, Hungary, Romania, and Moldova. The population is roughly 46 million with more than 700,000 deaths per year—460,000 to cardiovascular disease and 90,000 to cancer.2 Twenty-five percent of the population is older than 60 years, and the death rate exceeds the birth rate (480 vs. 280.) Life expectancy for men is 64, female 75, and while the population is aging, the number of births is decreasing.3 There are more than one million cancer patients in Ukraine with 30%—35% diagnosed in Stage III or IV. Eastern Europe has some of the highest rates of HIV, but Ukraine has the most severe in the region with more than 200,000 persons living with HIV/AIDS and 6000—10,000 deaths annually. There are roughly 41,000 orphans (0—17 years) because of AIDS in Ukraine.4 It is estimated that more than 500,000 patients would benefit from palliative care.5

The first palliative care association was established in 2006 to raise awareness of the need for palliative care. The Coordinating Council for Palliative and Hospice Care was created, and the Institute of Palliative and Hospice Medicine was established by the MoH.

In 2011, the nongovernmental organization All-Ukrainian League on Palliative and Hospice Care was created as the national palliative care association. The league was begun by a group of individuals, medical institutions, charitable organizations, and representatives of the scientific community, health care professionals, elected deputies to regional and district councils, city mayors and authorities, and palliative care providers and organizations interested in palliative care development. The league was established to facilitate the development of palliative care by improving the regulatory framework, facilitating access to palliative care medications, implementing education and training programs for health care professionals and volunteers, developing the volunteer movement, and raising public awareness.

The first national palliative care congress was held in Kiev in 2012, and the first national forum on pediatric palliative care took place in December 2015. At the same time, the National Association of Pediatric Palliative Care was established. The 2013 European Association for Palliative Care Atlas of Palliative Care Europe ranked the development of palliative care in Ukraine at the level of 3a—isolated provision.6

Policy
One of the foundational documents for palliative care development in Ukraine was the Concept of the National Palliative Care Program, which was elaborated by national palliative care champions with technical assistance from international palliative care experts and supported by the International Renaissance Foundation (IRF) and the International Palliative Care Initiative. The concept was submitted into the standard approval process with the MoH as the entry point followed by multiple ministries making changes and
recommendations. Political instability and economic crises put the final approval on hold, but palliative care activists continue their advocacy efforts to gain final approval.

Although this foundational document lacks final approval, several other policy and regulatory documents, protocols, standards, and guidelines have been approved and are being implemented albeit unevenly. Some are as follows:

**Policies**
- No. 463, June 26, 2009. *On approval of palliative care development in Ukraine for 2009–2010*, which became the basis for the creation of the Department of Palliative Care and Hospice Medicine at the National Medical Academy of Postgraduate Education.\(^7\)
- April 2011, State Service of Ukraine on Drug Control (National Competent Authority) established a central body of executive power coordinated by the Cabinet of Ministers.
- National program on HIV prevention, treatment, care, and support for HIV/AIDS patients 2009–2012, followed by a similar program for 2013–2018.\(^8\)
- In 2013, the Law of Ukraine *On Amendments to the Basic Laws of Ukraine about public health to improve health care provision* included the chapter related to palliative care as a medical service (34.8) was adopted by the Parliament of Ukraine.\(^9\)

**Standards, Guidelines, and Protocols**
- The National Standard for Social Service for Palliative Care was approved by the Ministry of Social Care in 2016.\(^10\)
- The National Protocol for Chronic Pain Management was approved in 2012.\(^11\)
- No. 483, June 2010. MoH order *On suggested equipment of the hospice (palliative care ward or unit) for tuberculosis patients*.\(^12\)

**Drug Control Policies**
- Ukraine National Strategy on Narcotics until 2020 was approved in August 2013.\(^13\)
- Cabinet of Ministers Decree on Narcotics no. 333 on May 13, 2013. *Procedure for acquisition, transportation, storage, delivery, use, and disposal of narcotic drugs, psychotropic substances, and precursors in health care institutions*. Major changes included the following: individual physicians can prescribe opioids to patients with panel review; empty vials can be destroyed without commission oversight; per the discretion of chief doctors, facilities can stock up to one month’s worth of drugs; physicians must ensure that the patient receives an adequate supply of opioid medications through a prescription that can be filled in local or hospital pharmacies; patients and/or family members can pick up their medications directly from the health care facilities and store at home.\(^14\)

  - MoH Order no. 77 on February 1, 2013. *On registering oral morphine sulfate and allowing its use in Ukraine*.\(^15\)
  - MoH Decree no. 494 on August 7, 2015. *On some aspects of narcotics and psychotropic medications use in health facilities*. It offered additional explanations on the responsibilities of the health staff who are prescribing, dispensing, and storing controlled medications.
  - MoH Decree no. 360 established on July 19, 2005 and updated on July 25, 2016. *On the rules to prescribe medicines and medicinal products; the order of dispensing of medicines and medicinal products from pharmacies and their structural subunits; instructions on the order of storage, management, and of destroying of the prescription forms*.\(^16\) Its major changes include the following: permission to all doctors irrespective of their specialty to be able to prescribe controlled medications, the minimum allowed dosages were increased, the validity of the prescription form for controlled medications was extended to 20 days, and the amount of medications prescribed per prescription form was increased up to one month supply. The number of signatures was reduced from three to two, whereas three stamps are required to verify the prescription form.
  - Minister of Interior Decree no. 216 approved on May 15, 2009 was last updated on October 28, 2013. *On approval of construction norms for facilities and units designated for operation with narcotics, psychotropic medicines and precursors as well as storage of these substances were withdrawn from illicit circulation*.\(^17\) Even after revision, the order contains some burdensome requirements for the facilities and wards to store and dispense controlled medications being a significant barrier to store and supply these medications to patients.

**Drug Availability**

Slow progress is taking place to reduce or eliminate the barriers to controlled pain medications. The table
provides some examples of the barriers and advances that have taken place.

Despite the progress being made, 75% of palliative care patients receive inadequate pain management, including the number of patients in rural areas who have little or no access to opioid analgesics for pain management. The lack of a drug procurement budget, limited funding for provider training, low prestige of the palliative care provider/specialty, and persisting myths and fears about opioids severely limit

<table>
<thead>
<tr>
<th>Barriers</th>
<th>Advances</th>
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<tr>
<td>Morphine tablets were not registered, imported, or produced in Ukraine. Only injectable morphine was registered and produced in Ukraine by one national producer</td>
<td>Morphine sulfate tablets (5 and 10 mg immediate release) were registered and produced by the Ukrainian pharmaceutical company InterChem in January 2013</td>
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<td>Patients received an opioid prescription for a maximum of three days. The maximum daily dosage limit for injectable morphine was 90 mg</td>
<td>In December 2013, another Ukrainian pharmaceutical company Zdorov'e Narodu started production of immediate-release morphine hydrochloride</td>
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<td>A prescription form was valid for only three days</td>
<td>Patients may receive an opioid prescription for a 10–15 day supply, and there is no maximum daily dosage limit</td>
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<td>Patients could only fill their prescriptions in the designated pharmacy (by the health facility) or according to their registration</td>
<td>A prescription form is valid for 10 days, for all forms, including ampoules, tablets, and patches</td>
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<td>Most pharmacies are reluctant to supply morphine because of the licensing requirements, which stipulate a separate room for supplies, a locked safe, reinforced walls, and costly alarm systems. The number of licensed pharmacies is very low because of excessive requirements for the premises to store and dispense controlled medicines. The sales volume is low, and profits are minimal for controlled medications. No incentives exist for pharmacies to get licensed and to ensure a range of controlled medications available. No regulations exist to ensure even geographical coverage of licensed pharmacies</td>
<td>A prescription for an opioid may be filled at any licensed pharmacy in the country but must be paid for by the patient</td>
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<td>A panel of at least three physicians was needed to allow a patient to get opioids for more than three days. A special form for opioids (pink form or Form 3) had to be used and be signed by the chief of the hospital/institution or vice-chief and the head doctor of the ward and certified by the stamp of the institution, the individual stamp of the head doctor of the ward, and the individual stamp of the treating physician</td>
<td>Minimal progress has been made. Very few pharmacies are getting licenses to operate with controlled medications. There are some regions (oblasts) that have one or two pharmacies with the population of around one million, e.g., Kirovograd'ska oblast</td>
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<td>Any change in dosage or administration needed must be verified by the same panel of three doctors each time a change is made</td>
<td>A panel is no longer needed to verify an opioid prescription. One treating physician can prescribe. Two signatures are required, the treating physician and the chief doctor of the facility. Three stamps, the triangle stamp of the facility for documents, and the individual stamp of the treating physician, are needed to verify the opioid prescription. There are slightly different requirements for private practices, but private practices are very reluctant to be prescribed</td>
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<td>A commission of officials including police officers had to verify that every single vial was destroyed</td>
<td>Restrictions on the provider's specialty were eliminated. Now all physicians are allowed to issue a prescription form for an opioid</td>
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<td>Only oncologists were able to prescribe strong pain-relieving medications (opioids), and psychiatrists, narcologists, and some neurologists were allowed to prescribe psychotropic medicines used as adjuvants</td>
<td>Family practice physicians are being trained to assess pain and how to prescribe strong pain-relieving medications</td>
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<td>Physicians lack the necessary training to prescribe opioids for pain relief</td>
<td>As of October 2016, pediatric forms of oral morphine were included into the procurement list of medicines for oncology patients by the MoH. Pediatric forms of oral morphine are submitted for registration to the State Authority on Drug Registration</td>
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<td>There are no pediatric forms of opioid analgesics in the country</td>
<td>This practice still takes place, although on a smaller scale, as emergency teams are banned from serving as mobile opioid delivery teams</td>
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<td>When oral morphine is not available, home care service nurses, when available, go to the patient’s home to administer a morphine injection</td>
<td>Now there is a relatively simple mechanism for family members/caregivers to obtain vials/tablets or fill the prescription for the patient and administer the drugs according to the doctor’s prescription</td>
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actual availability. Payments for opioid analgesics remain an issue; although there are legal provisions for free opioids for cancer patients, they still have to pay for their morphine or other controlled medications as there is no central or local procurement of these medications. These medications are available for free for patients in hospitals. Patients suffering from HIV/AIDS and/or tuberculosis (TB) must pay for their opioid prescriptions. Often doctors are hesitant to prescribe any controlled medications to these patients because of their history of drug use, or suspects of continued use, or if they are on substitution treatment. Currently, the MoH is developing a reimbursement mechanism for essential medications, but opioids are not considered in the first group of medicines that will be eligible for reimbursement.

The first precedent of national-level procurement of opioids was made by the MoH in October 2016—when pediatric oral morphine was included on the procurement list. Activists among pediatricians and parents are closely monitoring the situation to ensure that the procurement will take place, and medicines will be distributed to the facilities that had ordered them.

Pricing of opioids also became an issue as prices have tripled since 2013, after the local currency devaluation and unprecedented hikes on prices for utilities, imported goods (pharmaceutical substances), and others. Health facilities’ budgets were drastically reduced, and they were able to offer fewer medications. The burden was placed entirely on patients and families.

Education and Training

Health care professionals interested in palliative care visit palliative care centers of excellence in Romania, Poland, Belarus, U.S., Austria, and the Czech Republic for training and observation. Attendance at regional and international conferences provides Ukrainian palliative care specialists with the opportunity to network with other colleagues working to develop palliative care and to gain new knowledge.

The Department of Gerontology at the P.L. Shupyk National Medical Academy of Postgraduate Education in Kiev began offering palliative care seminars in 2009. In 2010, the Department of Palliative and Hospice Medicine was created at the P.L. Shupyk National Medical Academy of Postgraduate Education in Kiev. A palliative care curriculum was developed for doctors and nurses working in primary and secondary facilities as well as hospices, inpatient units, specialized cancer clinics, AIDS control centers, TB dispensaries, and other specialized medical settings. The department offers one- and two-week courses for oncologists, general practitioners, and nurses.

Regional and international palliative care experts have participated in local and national palliative care seminars and workshops throughout Ukraine. The U.S. National Cancer Institute’s training program, Educating Physicians in End of Life Care in Oncology, was presented to the emerging leaders in palliative care in the country, and the American Association of Colleges of Nursing’s End of Life Nursing Education Consortium train the trainer program (End of Life Nursing Education Consortium) for nursing leaders to integrate basic palliative care skills into nursing education. Additional educational programs were provided by the Global Fund to Fight AIDS, TB, and Malaria, by experts from the U.K, and others. Educational initiatives provided the opportunity for students to learn at the bedside and in the classroom. This work was made possible by the International Palliative Care Initiative of the Open Society Foundation’s Public Health Program, meeting local needs with available international resources.

The first Ukrainian Palliative Care Training Center was established in 2010 at the Ivano-Frankivsk oblast’s hospice with support from the IRF and the Mother Theresa Charitable Foundation. The hospice has training facilities, provides limited on-site student housing, and has a computer library with palliative care publications. The hospice offers a variety of short- and long-term courses that include clinical training in the hospice facility. The hospice medical director teaches palliative medicine to medical and nursing students at the Ivano-Frankivsk National Medical University, and students do rotations at the hospice. Students also volunteer at the hospice during their free time. The hospice also provides technical expertise to local and national government officials and health care professionals from within Ukraine and the region who are interested in establishing palliative care inpatient- or home-based care programs, as well as training to health care professionals from across the country and the region, and is highly regarded by the entire European palliative care community.

A similar Palliative Care Training Center was established in Kharkiv in 2013 and has gained recognition. It offers a range of training options for doctors, nurses, psychologists, and social workers.

The first pediatric palliative care freestanding hospice was opened in Ivano-Frankivsk on December 21, 2013 after an enormous local fundraising campaign. The Medical Director of the Hospice, Dr. Luidmila Andriyshyn, is a major palliative care leader in the country and has driven the development of palliative care from its inception.

Although there are numerous lectures and seminars on palliative care offered by hospices throughout the country, there are no mandatory basic or advanced courses on palliative care for physicians, nurses, or
Services

The lack of a national strategy and implementation plan to integrate palliative care into the public health system has led to hospices operating either on their own or as a part of a public health care facility. The decree governing public health facilities assigns a certain number of doctors and nurses for a certain number of beds in the facility, often irrespective of the real need in staffing and supplies. This is inappropriate for hospice patients who require more care than aggressive treatment.

The first hospices in Ukraine were established in 1996–1997 in Lviv, Korosten, and Ivano-Frankivsk, which is the oldest operating hospice in Ukraine. These hospices operated outside the health care system and lacked sufficient funding for staff, equipment, and supplies. Palliative care departments and hospices now exist in many Ukrainian cities. Most of them are funded by health care departments and municipalities, churches, and charities. In some regions, public social care institutions have put in place home care programs containing some elements of palliative care. Palliative care is offered in a variety of settings, in a patient’s home, stand-alone facilities, or part of a larger health institution as an inpatient unit or ward. There are 50 inpatient palliative care units, seven freestanding hospices, and five mobile teams, but there is no uniformity in service provision and no certification or licensing of services. Most hospices have 20–30-bed facilities with two to three physicians and 12–20 nurses as well as aid positions. Almost all are understaffed and underfunded, except for a few who secured connections to the religious communities and/or through international links. These services focus on cancer, HIV, multidrug-resistant TB, neurologic, and geriatric patients. In general, these programs provide symptom management but little psychological or bereavement support. Some facilities are not licensed to provide opioids for pain relief. Long-term care and geriatric care continue to be combined with palliative care. Pediatric palliative care is still widely unavailable with one inpatient unit and four mobile teams for the entire country. As in many countries around the world, palliative care is mainly provided in patient’s homes by their families (www.nowinylekarskie.ump.edu.pl/index.php/JMS/article/viewFile/80/81).

Public Awareness

The Stop the Pain campaign was launched in late 2011 to illustrate the need for adequate pain control. Access to oral morphine became the centerpiece of the campaign. Activities included round table discussions, petitions, open letters to the President, Prime Minister, the Cabinet, and MoH. Support groups for patients and family members who dealt with pain across the country were mobilized to talk about access to pain management and oral morphine in particular. The Web site http://stoppain.org.ua/en was established to provide a toolkit for families with terminally ill patients and offered a list of licensed pharmacies and instructions on how to obtain a prescription for opioids (or actual supply). The Web site also provided sample forms to write a petition to local departments of health or other controlling bodies or human rights groups in cases when pain management was denied.

Hospice providers sponsor a wide range of fundraising activities, including marathons, concerts, and auctions, and there are regular events to engage families and volunteers. Internet resources on palliative care provide information for health care professionals, government officials, volunteers, and families.

Ukrainian palliative care advocates and organizations participate in annual World Palliative Care Day activities with programs used to inform and educate the public about palliative care and as fundraising activities to support local hospices.

Human Rights

In an effort to give voice to patients and families about the suffering they experience because of the lack of opioid analgesics for pain relief, IRF and the Rivne Branch of the Network of People Living with HIV/AIDS, Charitable Foundation “Light of Crimea,” Kharkiv Institute of Legal Research and Analysis, conducted a project to document patients’ records and interviewed patients and families on their experiences. The resulting report, We have the right to live without pain and suffering, on the rights of palliative care patients in Ukraine was published in 2012.

Advocacy efforts related the Human Rights Watch report entitled Uncontrolled Pain sparked national and international media and led to IRF launching the short film 50 Milligrams is Not Enough (https://www.youtube.
com/watch?v=sWeUDNyqo1I), featuring a 27-year-old cancer patient in terrible pain whose mother went to extremes to get pain relief for her bedridden son. This work culminated in the Cabinet of Ministers passing Decree 333, lifting burdensome procedures for prescribing and accessing opioids. In 2017, the same advocacy and human rights groups are working on an update of the situation with access to pain management and opioids in Ukraine, documenting the best practices and gaps in services’ and medicines’ provision that result in patients’ suffering. The full text was submitted in November 2017.

Legal Aid

In addition to human rights advocacy for access to pain medications and palliative care, providing legal services to patients and families living with life-limiting illnesses is an essential element in palliative care. End-of-life issues, such as advanced care planning, power of attorney, writing a will, childcare, inheritance rights, and property rights, are all concerns that patients and families face with serious illness. The legal aid groups work with patients and families and also educate lawyers about palliative care and palliative care providers about legal issues. There is a network of free legal aid professionals who have been trained in the provision of legal services to palliative care patients and their families. The legal aid providers have been informed about the issues related to patient access to opioids (as far as their ability to sign documents) and others. This network continues to operate and support families.

From 2014, the Department of National Prevention Mechanism of the Ombudsman Office in Ukraine has included hospices and palliative care wards on the list of the places of possible human rights abuses. Public monitors started visiting hospices and palliative care wards around Ukraine to identify human rights violations in the inpatient units.

Conclusions

Palliative care development is slowly taking place in Ukraine amidst the war with Russia and the ongoing economic challenges. Recommendations going forward include the following:

- Ensuring the adequate supply of oral morphine throughout the public health care system.
- Registering, procuring, and prescribing pediatric oral forms of morphine.
- Licensing all publicly funded urban and rural pharmacies to stock opioids and psychotropic medicines.
- Ensuring all palliative care medicines are on the Ukraine Essential Medicines List.
- Ensuring all palliative care medicines are free or subsidized or included in the reimbursement system.
- Making basic palliative care education mandatory for all health care professionals as a part of the primary health care reform launched in 2015.
- Providing advanced training for palliative care professionals.
- Increasing the number of home care, mobile teams, and inpatient units as a part of health care reforms and reduction in the hospital bed count.
- Developing and approving palliative care standards.
- Including palliative care on medical licensing examinations.
- Ensuring adequate funding for palliative care on both national and local levels and including these services into the minimal package of health services guaranteed by the government.
- Monitoring the quality of hospice and palliative care services.
- Monitoring human rights abuses related to accessing pain relief in closed settings (including geriatric, psychiatric adult, and pediatric facilities, irrespective of their subordination or ownership).
- Continuing public awareness activities about the benefits of palliative care.

Acknowledgments

Palliative care development in the Ukraine has taken place because of the support and leadership of the IRF and the International Palliative Care Initiative as well as the enormous commitment of numerous dedicated palliative care champions, governmental and nongovernmental organizations, donors, and human rights groups. The future development of palliative care will continue to depend on government commitment and collaboration with stakeholders.

References


