Development of Palliative Care in Armenia

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Abstract

In the last seven years, considerable progress has been made in palliative care (PC) in Armenia, but many problems remain unresolved. Policies developed include completion of a national needs assessment, a recognized working group on PC formed, national standards approved, a concept paper on PC approved, resolutions on PC as a specialized service approved, PC became a subspecialty in medicine, PC qualifications developed, and a social assistance package approved. In addition, the Government of Armenia lately approved the National Strategy on Palliative Care for Adults and 2017–2019 Action Plan. Oral morphine was added to the list of essential medicines but remains unavailable in Armenia, and many highly restrictive regulations remain in force. Progress in basic training in PC for physicians and nurses has been made, and two nursing schools now require it for all students. A “Pain Control and Palliative Care Association” began in 2003, and for two years, four pilot PC programs successfully operated with Global Fund resources. However, now only one service provider is operating. The public has begun to learn about PC, but funding remains a challenge.

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Key Words
Armenia, palliative care, opioid, human rights, pain, Global Fund

Background

Armenia is located in the Southern Caucasus and is the smallest of the former Soviet Republics. It borders Georgia on the north, Azerbaijan on the east, Iran on the south, and Turkey on the west. It has a total area of 27,943 sq. km. The population has declined, mostly through migration, from 3.5 million in 1992 to 2,969,000 inhabitants. The Republic of Armenia (RA) is divided into 10 provinces and one city. The largest city is Yerevan, the capital of Armenia. The birth rate is 13.61/1000; infant mortality rate is 13.51/1000; and life expectancy is 74.371.1

After the collapse of the Soviet Union, Armenia inherited a centralized health care system with free medical care for the entire population and access to a comprehensive range of primary, secondary, and tertiary services funded from the general government revenues. Since then, Armenia has undertaken extensive health care reforms to decentralize the health care system, to make it more efficient, and to implement new approaches to health care financing, including privatization. One of the core elements of the reform was changing the primary care system and the introduction of the family doctor. In spite of the health reform work, Armenia still has a highly centralized health care system in which the central government makes most decisions on the allocation of resources.

Primary health care is typically provided by a network of first-contact outpatient facilities involving urban polyclinics, health centers, and rural ambulatory facilities, depending on the size of the population in a particular community.

Secondary health care is traditionally provided in a range of institutions including freestanding municipal and regional multiuse hospitals; integrated multiuse hospital networks with ambulatory care provision; health centers with inpatient beds; maternity homes; and specialized units for inpatient and outpatient care.

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Tertiary, highly specialized care is provided through specialized single-purpose health care structures, mainly concentrated in the capital city of Yerevan and with a major focus on complex technologies. As of 2014 national data, there are 130 hospitals and 509 primary health care institutions operating in Armenia with a total number of physicians 12,896 and total number of nurses 18,053.2

The public health system is focused primarily on the control of communicable diseases (NCDs). Rehabilitation, long-term, and palliative care (PC) are not as well developed as other parts of the health system which affects the system’s overall efficiency. Most long-term care is provided within the family, and there are few resources available for informal caregivers. Home-based services have not been introduced in the country, which leads to the unnecessary admission of chronic patients and over capacity of hospital beds.2 The state supports social services for the poor and people with disabilities and provides assistance with general domestic tasks, including cleaning, cooking, bathing, and maintaining hygiene.

In Armenia, knowledge about NCDs and cancer is limited, leading to frequent misdiagnosis and the late referral of patients. Armenia does not have a national cancer registry and data on cancer mortality varies. According to the national data that do exist, 2 total deaths in Armenia in 2014 were 27,714, including 598 pediatric deaths (1–19 years old). NCDs are estimated to account for 92% of total deaths. The number of new cancer cases grows by 3%–4% per annum. Armenia had 7593 new cancer diagnoses in 2010, whereas the number grew to 8365 in 2014. In 2014, there were 188 cancer deaths per 100,000 men and women registered in Armenia.

According to the 2014 World Health Organization report on NCDs,3 Armenia’s cardiovascular diseases constitute 54%; cancers: 22%; communicable, maternal, prenatal, and nutritional conditions: 4%; injuries: 4%; diabetes: 3%; chronic respiratory diseases: 5%, and other NCDs: 8%. The probability of dying between ages 30 and 70 years from the four main NCDs is 30%.

The first PC organization in Armenia was the “Pain Control and Palliative Care Association” (PC&PC),4 which was established in 2003 and currently has 116 members, mainly the leading specialists of the National Center of Oncology and other polyclinics (Table 1). The PC&PC is a member of the International Association for Hospice and Palliative Care and the Worldwide Hospice Palliative Care Alliance.

In 2008, the president of PC&PC participated in the Open Society Foundations International Palliative Care Initiative’s International Pain Policy Fellowship project to analyze the legal and regulatory frameworks in Armenia regarding the access and availability of opioid analgesics for pain management for patients with life-limiting illness. The research results were further used for assessment of needs in PC in Armenia.

Policy

In Resolution N276-N of RA on March 27, 2008, PC was included in the list of specialized medical aid and services5 but exclusively for adults. It is necessary to include it also in the list of health care services provided for children.

In 2010, at the request and in cooperation with the Ministry of Health (MoH), Open Society Foundations—Armenia (OSFA) and International Palliative Care Initiative (IPCI) supported a PC needs assessment.6 The assessment was completed by Stephen Connor, IPCI consultant with the assistance of the Palliative Care Task Force, to advise the MoH on the implementation of PC.

The assessment estimated that approximately 3600 patients per day, 18,000 annually, including 5500 cancer patients, need PC.7 Data show that about 46% of patients are diagnosed at Stage 3 or 4, when treatment is ineffective and PC is needed. In addition, at least twice as many family members require PC support. The same study estimated that up to 60 palliative homecare teams, including 24 for Yerevan, 600 nurses, 120 physicians, and 300 other clinical support staff would be required in order to provide home-based and inpatient care both for urban and rural areas. The assessment highlighted several aspects of PC to address, including education and access to essential PC medications. The lack of policy guidance from the Armenian government was identified as the main obstacle to national PC development and implementation.

In 2011, by Resolution N1936 of RA the requirements for technical and professional qualifications, as well as the terms and conditions for PC units and mobile services were defined.8 In 2012, the MoH formed a task force to develop national policies, legal mechanisms, and capacity for integrating PC into the general health care system.

In 2012, the Government approved the decision “On Establishing the Concept of Palliative Care and Action Plan for its Implementation.”9 The policy document assessed the current state of the health system, in terms of introducing PC, and emphasized the need for developing a long-term sustainable national strategy for PC for 2017–2019.

In 2013, by Order of the MoH N17-N, the list of 12 drugs for PC was approved, including oral morphine.

In 2014, Armenia signed the World Health Assembly Resolution, “Strengthening of PC as a component of comprehensive care throughout the life course,” calling the provision of PC an “ethical responsibility of health systems” and urging United Nations member states to integrate PC into their health care systems.10
In 2014, the MoH approved three policy documents outlining the: 1) structure and organization of PC services and professional qualifications for doctors and nurses in PC,\(^{10}\) 2) standards for palliative medical care and services,\(^{11}\) and 3) clinical guidelines for pain management.\(^{12}\)

In the same year by the Resolution N952-N of RA, palliative medicine was listed among specialties of
medical, dental, pharmacological, and public health sector of RA but only for adults. It is necessary to have a pediatric PC specialty.

In 2014, provisions on PC were also enshrined by RA Law HO-231-N on “Social Assistance” in the Part 2 of the Article 13 “Care and Provision” that PC is delivered to a person with a disease in the last months, days of the terminal stage, and to his family members if needed.13

In 2016, pediatric PC was articulated at a high policy level. A needs assessment was conducted by the Armenian Pediatric Association and revealed enormous gaps in the care of children with life-limiting illnesses and recommended the inclusion of pediatric PC in the national PC strategy. The number of children identified by prevalence data in the assessment with PC needs is 3326. Presently, there is a lack of specialists and no regular trainings in pediatric PC. PC elements are provided in some medical facilities and orphanages by doctors, special educators, therapists, psychologists, social workers, and educators.

In 2016, the National Concept of Pediatric Palliative Medical Care and Services was developed and included into the National Strategy on Improving Child and Adolescent Health.

Eventually in 2017, the Government of Armenia approved the National Strategy on Palliative Care for Adults and 2017–2019 Action Plan. The document addresses all major areas of PC policy: education, medicines availability, and implementation of PC services. However, it does not include pediatric PC.

The development and adoption of the aforementioned documents were important, but without drug control reform making essential PC medicines available, namely oral morphine, the delivery of PC is impossible. Currently, oral morphine is not registered in Armenia, therefore cannot be administered. The MoH with the support of OSFA and with engagement of wide range of experts and civil society organizations elaborated amendments to the Law on Narcotic Drugs to ensure access to adequate pain relief. However, these amendments have not yet been adopted. Existing drug regulations remain restrictive and even the prescribing of injectable opioids is complex time-consuming.14 PC was included in the National TB Strategy.

**Education and Training**

The first PC training center was established in 2011 by PC&PCC with the support of OSFA and IPCI at the National Oncology Hospital in Yerevan. The center trains physicians and provides inpatient and outpatient PC services to cancer patients. One hundred sixteen physicians have attended courses on “Educating Physicians in End of Life Care—Oncology” from the U.S. National Cancer Institute. In total, about 450 patients have received PC services (186 inpatient services and 264 home-based services).

In 2011, OSFA collaborated with IPCI and the Global Fund to Fight AIDS, Tuberculosis and Malaria and conducted Educating Physicians in End of Life Care—Oncology training for 60 physicians and the American Association of Colleges of Nursing “End of Life Nursing Education Consortium” for nurses.

In 2012, the End of Life Nursing Education Consortium curriculum was piloted in four Armenian nursing colleges with two of them, Erebuni College and Yerevan State University Basic College integrating PC into their basic nursing programs.

In 2014, by the Decree of the MoH, PC was included into the list of medical subspecialties providing the legal basis for introducing PC for health professionals.

In 2015, the Yerevan State Medical University (YSMU) developed a 60-hour mandatory basic PC course for family medicine residents and 16 students to the course in 2016. The university has also developed a 1295-hour fellowship course (400-hour classroom and 895-hour bedside training) for continuing medical education students. The course will be taught in 2017 and will allow physicians specialized in PC to prescribe opioids.

In 2016, YSMU Department of Clinical Psychology developed a course on PC, and the Armenian Pediatric Association is developing a course on pediatric PC for practicing physicians and medical students.

**Services**

In 2011, the Global Fund funded four PC pilots: National Oncological Center named after Fanarjyan, YSMU named after Mkhitar Heratsi, Ararat Medical Centre and Vanadzor Hospital named after L. Arebyan. Two of the pilots were located in Yerevan, and the other two were located in Ararat City and Vanadzor City. The main objective of the Global Fund project was to establish PC programs that could be replicated throughout the public health care system. The project was not limited to HIV/AIDS or tuberculosis patients alone; patients with cancer also received PC. The project leadership believed that creating the PC infrastructure would ultimately be of benefit to all patients with serious illness. Even though the pilot services proved to be successful, the Global Fund support ended in 2014 and three of the services were forced to close. Even though the pilot services proved to be successful, the Global Fund support ended in 2014 and three of the services were forced to close and only one continues to provide PC services.

Since 2013, “Legal Clinic” was created by the Real World Real People NGO to provide legal aid to patients who do not receive adequate pain relief. The organization has been documenting and addressing systematic institutional violations of the human rights
of people who need PC and pain relief. The documented cases indicate that none of the patients applied for legal aid have ever been prescribed adequate medication to minimize the pain.

In 2016, 15 cases of violations have been documented and addressed by the organization. The cases are available to the broad community of stakeholders on the website (www.hrarmenia.info), which had been developed within the framework of the legal clinic project.

**Public Awareness**

Since 2012, a three-year “Life without Pain” public awareness campaign was launched by pain and PC leaders, human rights and legal activists, as well as caregivers, with a call to the government to address human rights violations and to ensure access to oral morphine. Articles, TV and radio talk shows, posters, patient’s stories, and documentary films were developed; meetings and discussions and street actions were organized during the campaign to educate and mobilize the population around the issue of pain relief, namely access to oral morphine. The organizers raised awareness of the population about the need in PC and pain relief. The campaign mobilized thousands of people via social media, face-to-face discussions, and meetings around the issue of pain relief.

**Drug Availability/Access to Opioids**

Cancer patients are not receiving adequate pain relief. Based on the Armenian Human Rights Watch report from 2012, Armenia consumed an average of 1.1 kg of morphine per year. This is sufficient to adequately treat moderate-to-severe pain in about 180 patients with terminal cancer or AIDS, which is about 3% of those estimated to require such treatment. Data collected by Human Rights Watch from nine polyclinics showed that only 47 of 594 patients who died of cancer in 2011 received adequate pain relief before they died.

The major obstacle to adequate pain relief remains overly restrictive regulations governing opioids. Pain treatment in Armenia deviates fundamentally from WHO standards where oral morphine is the medicine of choice for the treatment of severe chronic cancer pain because it is not available. The only strong opioid analgesic available in Armenia is 10-mg ampoules of intramuscular morphine. Currently, only oncologists are allowed to prescribe injectable opioid medications for patients in hospital or at home. Unfortunately, many oncologists have not been trained in pain assessment or the medical use of opioids for pain relief and too often perceive morphine as a dangerous drug. Police control over the prescription and dispensing process is rigid and generates a sense of trepidation among oncologists and pharmacists. Patients remain afraid to use opioids for fear of addiction, oncologists are afraid to prescribe for fear of creating addicts and being arrested by the police, and pharmacists are afraid to stock opioids for fear of theft.

**Challenges**

The government continues to limit the development of PC by:

- failing to reform drug policy legislation and regulations which impede access to oral opioids for pain relief;
- failing to integrate PC throughout the health care system;
- failing to develop PC services in hospitals and for patients at home; and
- failing to finance PC service provision.

**Future Work**

The OSFA and its partners will continue to advocate for enforcement of the approved national PC strategies for adults and children and relevant action plans; drug reform to make oral opioid medications available, especially oral morphine, for patients at home and in hospital; introducing PC services throughout the public health care system.

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