Hospice Palliative Care Development in Hungary

Agnes Csikos, MD, PhD, Csilla Busa, MA, and Katalin Muszbek, MD
Hungarian Hospice Palliative Association (A.C.), Pecs, Hungary; Department of Hospice-Palliative Care (A.C. and C.B.), Pecs University Medical School, Pecs, Hungary; Hungarian Hospice Foundation (K.M.), Budapest, Hungary

Abstract
During the past 25 years, many developmental steps have occurred in Hungary in palliative care. Further education and service development is needed to provide a quality palliative care for all the Hungarian people. Hungary has a universal health care system with a developed infrastructure. The first Hungarian hospice team started in 1991. At that time, the concept of hospice care was unknown. Symptom control and psychosocial support for the dying patient was inadequate. The regulatory framework was based on the 1997 Health Care Act which was followed by significant palliative care legislation including documents on the legal requirements for palliative care (2004). National guidelines were developed in 2002. Home and inpatient hospice care are reimbursed by the National Insurance Fund. Patients and families pay nothing. The multidisciplinary team provides care for patients and families and hospice home care is widely available across the country. Inpatient units are still lacking in Hungary. Strong opioids are readily available in the country and can be prescribed for cancer and noncancer patients. Palliative care is taught in medical and nursing undergraduate and postgraduate education. From 2014, physicians in Hungary can take a one-year course to qualify for a license in palliative medicine.

Key Words
Palliative, Hungary, Pecs, hospice

Background
Hungary is an East-Central European country with a population of 9.8 million. Cancer morbidity is increasing, and Hungary leads the Organization for Economic Cooperation and Development cancer death statistics. While oncology treatment for cancer patients is good, based on international standards, palliative care was not introduced into the care of terminally ill patients. The majority of patients died in hospitals alone, with poor symptom control, suffering from limited and paternalistic communication with health care professionals. The results of two recent national studies show that the majority of Hungarian adults prefer receiving end-of-life care in their own homes.

The Hungarian Hospice Foundation (HHF), the first hospice team in Hungary, was established in 1991 as a registered NGO. The concept of hospice and palliative care was completely unknown to the public, and the topic of death and dying was considered taboo. HHF’s first task was to inform the public and other health care professionals and government officials about palliative care through public forums and educational courses. In 2001, HHF became a Palliative Care Resource Training Center providing clinical training and technical assistance to governments, organizations, and health care professionals in Hungary and Eastern Europe who were interested in developing palliative care services. The foundation continues to provide inpatient care, home care, pain treatment, psychooncology and bereavement support, and day care programs for adults and children in Budapest and Debrecen.

The Hungarian Hospice Palliative Association (HHPA) was established in 1995 by the National Association of Cancer Patients and 19 hospice
organizations. Organizations and individuals who provided or wish to support palliative care were invited to become members. The HHPA has played a significant role in coordinating and organizing the Hungarian hospice movement, especially in establishing its legal foundation, the formation of the national education system, publishing guidelines and standards, and communicating and collaborating with decision-makers. Additionally, the HHPA provided insight based on international guidelines and the written summary of best practices and the experience of the member institutions, performing pioneering and outstanding work in the field of pediatric hospice care. At the end of the 1990s, some hospices provided a high level of care for dying patients, but public awareness regarding hospice care was limited. The HHF developed an extensive media campaign in 1999 to raise awareness about hospice care, to educate the society and to draw attention to palliative care. Due to this, campaign hospice awareness increased from 0% to 35% among Hungarian adults. In 2007, Hungary joined the international Fields of Hope program, a program designed to shape people’s approach to life and death and to direct attention to human dignity and to urge social responsibility. The Hungarian program focuses on engaging children through an annual event of planting daffodils to illustrate the cycle of life. The HHF also pioneered new ways of communicating about hospice palliative care through the Internet and on social media. All have contributed to the increasing hospice awareness to 51% in 2011.

Policy
In 1997, the Hungarian Health Act defined hospice and palliative care and declared palliative care a human right. The legal foundation was made to conform to the World Health Organization recommendations and European standards. The act dedicated an entire chapter to patient rights and a section to the definition of hospice treatment. National guidelines and standards for palliative care were established by the HHPA and accepted by the Ministry of Health in 2002. Following an investigation regarding the care of terminally patients, the Hungarian Parliament in 2003 radical changes began at a regulatory level to improve services and care for patients with terminal illnesses. One of the most important results was a Ministerial Decree for Minimum Standards for Hospice Palliative Care including defining what the care is and what the minimal educational and professional requirements should be. In 2004, the National Health Insurance Fund and the Open Society Institute’s International Palliative Care Initiative organized a Palliative Care Policy Development Conference to set up a National Strategic Plan for Palliative Care. Following this meeting, the Health Ministry launched the Ministerial Decree on the Hospice Minimum Requirements giving official licenses and detailing special reimbursements for hospice care providers. Existing and new services who met the minimum requirements were eligible to apply for the reimbursement. This greatly helped to extend hospice care throughout the country.

Hospice care has slowly been integrated into the Hungarian National Health System and became a part of the National Cancer Control Program in 2006. The HHPA has contributed to the development of quality pediatric hospice care as well. Leading experts of the HHPA and various representatives of the profession developed the minimum requirements of Pediatric Hospice Care, updated the Hospice Care Guidelines and included pediatric care. A draft proposal to include pediatric hospice in a regulation was also submitted to the Secretariat of State for Healthcare at the Ministry of Human Capacities in 2015. The proposal also included the development of reimbursement terms for institutional and pediatric home hospice care. The minimum requirements have been approved, but reimbursement for pediatric services has not yet started.

Volunteering in Hungary is not as well integrated into health and social care services as it is in other western European countries. However, over the last decade, more emphasis has been placed on its development by the Hungarian Health Ministry and education is now required for all volunteers in every service. It is an exemplary success and a good way to develop a new generation of hospice volunteering in Hungary.

Drug Availability/Access to Opioids
The new Drug Strategy of 2013—2020 was accepted by the Hungarian Parliament on October 7, 2013. Most long-acting, strong, and weak opioids are available in Hungary. Transdermal Fentanyl is the most frequently used opioid in the country, making up about 90% of all strong opioids. Strong opioids are prescribed mainly for cancer patients, but lower doses of strong opioids are also available for noncancer patients with severe pain. There is limited availability of short-acting strong opioids; only injectable morphine and tablets can be prescribed. There is no maximum daily dose for opioids for patients. The ultrashort-acting strong opioids are not available in Hungary. Access to strong analgesics in hospitals, as well as at inpatient and home hospice care, is assured. Opioids can be prescribed by all physicians who have their medical license and diploma in an emergency/acute care. They are allowed to prescribe opioids for 15 days for any patient with severe pain.
Only general practitioners (GPs) are allowed to prescribe opioids for patients who need them for longer than 15 days. However, some GPs do not have sufficient knowledge regarding the use and prescribing of opioid medications.13

**Clinical Service Availability**

The Hungarian National Health Insurance Fund started financing/reimbursing hospice care in 2004. Two forms of services have become integrated in the health system: home hospice care and inpatient hospice care. Health insurance also covers the care for the caregiver only in case of patients suffering from cancer, AIDS, autoimmune, and chronic neurological disease (amyotrophic lateral sclerosis and multiple sclerosis).

Home hospice services have been continuously expanded, and to date, hospice home care is widely available across the country. The multidisciplinary team offers hands-on care and also provides advice to GPs and community nurses. They can provide not only end-of-life care, but still the majority of patients would be referred for terminal care.

The number of hospice patients is increasing every year (Table 1). At present, 71 services provide hospice home care with multidisciplinary teams covering almost all locations in the country (Fig. 1).14,15 Inpatient hospice palliative services have been developing since 2004 and there are 215 hospice beds in the country. According to World Health Organization recommendations for a country with a population of nearly 10 million like Hungary, 500 beds are needed (Table 2) (Fig. 1).14,15 Unfortunately, beds are not evenly distributed across the country and are mainly concentrated in a few urban areas.15

Two inpatient hospices have been opened for children in Hungary since 2012. They provide not only end-of-life care but also respite care for families caring for children with long-term chronic progressive conditions. Home care services are also available for children in some locations in the country.15

Patients’ access to hospice palliative care is still limited due mainly to the uneven distribution of inpatient hospice services in the country. Patients with a cancer diagnosis are eligible for hospice services, but the availability of hospice palliative services for non-cancer patients remains limited. Hence 90% of hospice recipients are cancer patients.

**Table 1**

<table>
<thead>
<tr>
<th>Year</th>
<th>Number of Hospice Patients</th>
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</thead>
<tbody>
<tr>
<td>2001</td>
<td>1,669</td>
</tr>
<tr>
<td>2003</td>
<td>2,230</td>
</tr>
<tr>
<td>2004</td>
<td>2,060</td>
</tr>
<tr>
<td>2010</td>
<td>6,500</td>
</tr>
<tr>
<td>2015</td>
<td>8,970</td>
</tr>
</tbody>
</table>

**Table 2**

<table>
<thead>
<tr>
<th>Year</th>
<th>Inpatient Hospice Care Services</th>
<th>Number of Beds</th>
</tr>
</thead>
<tbody>
<tr>
<td>2001</td>
<td>4</td>
<td>56</td>
</tr>
<tr>
<td>2003</td>
<td>4</td>
<td>56</td>
</tr>
<tr>
<td>2004</td>
<td>10</td>
<td>133</td>
</tr>
<tr>
<td>2010</td>
<td>11</td>
<td>171</td>
</tr>
<tr>
<td>2015</td>
<td>16</td>
<td>215</td>
</tr>
</tbody>
</table>

Despite the professional educational programs and public awareness campaigns, patients and doctors still lack adequate information and knowledge about the availability and benefits of hospice palliative care resulting many times in late referrals of patients. This remains a significant barrier to the implementation of full palliative care.16,17

**Education and Training**

Fundamental changes must take place in doctors’ attitudes toward patients with terminal illnesses so they value what palliative care can offer. Education is the most promising way to change practice and attitudes.17

In 2010, the National Health Committee proposed to integrate palliative medicine into all undergraduate and postgraduate medical education; promote the hospice approach, and develop hospice palliative care services. In spite of this, palliative care is not included in the undergraduate medical education curricula throughout Hungary. However, some universities do and include courses on palliative care in their curriculum. An outstanding example is the University of Pécs and Semmelweis University in Budapest. Some other medical universities in Hungary also offer basic palliative care courses as electives. In postgraduate medical education, palliative care is included in the formal training. From 2014, all junior doctors receive a systematic and standardized 40-hour educational program on palliative care.

From 2014, physicians in Hungary can take a one-year specialized course to qualify for a license in palliative medicine. The program is built on basic clinical specialties such as internal medicine, surgery, family medicine, and other medical specialties, with special emphasis on pain management.
medicine, pediatrics, or oncology. The course includes both theoretical and practical sections and requires candidates to do clinical rotations in inpatient and home hospice programs. Participating physicians are trained in communications skills as well as pain and symptom management and bereavement. Physicians who pass the final exam are awarded a license to practice palliative medicine in Hungary. Until now, more than 100 physicians have taken and passed the licensing exam.

Nursing education offers very advanced training on palliative care in Hungary. An accredited training program on specialized hospice palliative care is available for qualified nurses. Forty hours of training are required for any health care workers wishing to qualify for a hospice palliative position.

The University of Pecs established the first, and so far the only, Hospice Palliative Care Department in the country in 2012. The department offers undergraduate palliative care education for medical and nursing students as well as postgraduate training programs for doctors and the multidisciplinary team. The department is also involved in national and international research.

Some services also take part in education and training. Pecs-Baranya Hospice Program implemented a project to improve access to care by providing health workers, nurses, physicians (GPs and other medical specialists), patients, and their relatives with relevant information about the importance of hospice palliative care in general and to improve services by taking the necessary preparatory measures for the future introduction of mobile palliative consultation teams as a new form of service in the Hungarian health system.

There are several hospices offering palliative care training opportunities including the Erzsebet Hospice Program, at Miskolc, which provides direct patient care, offers comprehensive theoretical and practical teaching courses for doctors, and is one of the leading educational centers in the country.

The Law Clinic, a project supported by the Open Society Foundations is an ongoing innovative educational program of the Pecs-Baranya Hospice Program in collaboration with the University of Pecs Medical and Law School. The aim of the project is to explore how legal provisions on the right to autonomy and self-determination, of patients in the case of terminal illness, work in practice, in the course of providing both medical and legal support to patients in connection with end-of-life decisions.

The HHPA is also heavily involved in education of multidisciplinary team members including volunteers and collaborates with medical universities in the country. The government approved the HHPA’s proposal on a national educational program for hospice volunteering based on a national consensus. As result, a supplemental Ministerial Decree was enacted on hospice volunteer work in Hungary.15

**Most Recent Achievement**
The Ministry of Health’s National Hospice Palliative Advisory Board was established in January 2016. Its role is to work collaboratively with other medical specialty boards on a strategy for the development and promotion of palliative care on the national level. Another aim of the advisory board is to clarify the vision and specific milestones to achieve better patient care in the hospice palliative care system in Hungary.

**Present Challenges**
The clinical service development of hospice palliative care has slowed during the past 10 years. While establishing hospice home care and spreading its availability was a great success, the capacity of hospice inpatient units has not increased.20,21

There are not enough medical doctors in the field of palliative care, and no comprehensive educational program was offered until last year to train doctors with basic and advanced knowledge and skills.

Only two forms of care (home and inpatient hospice services) are reimbursed by the National Health Insurance Fund. Palliative outpatient clinics and consult services (hospital mobile teams) in hospitals are not reimbursed and as a result not widely available in the country. Continuity of care cannot be assured.

**Recommendations for Further Development**

1. **Policy**—Change the eligibility criteria for hospice care to be able to provide care for more non-cancer patients. Define the minimum requirements/standards for Day Hospice Services as well for acute/active palliative care units. Assure and subsidize short-acting (immediate release) strong opioids (e.g., morphine, oxycodone, and fentanyl) in the country.

2. **Reimbursement**—Create a new reimbursement system for home hospice care services in which more than one visit per day can be reimbursed. Reimburse outpatient and inpatient consult services and develop a reimbursement system for the acute/active palliative care and Day Hospice. Reimburse hospice care services for children on a regular basis.

3. **Service development**—Increase the number of inpatient hospice palliative care beds in the country to 500, and establish at least one inpatient unit in every county with integrated outpatient and home care services. Expand outpatient and consult services and integrate them across the country to provide care based on the needs of
the patients and families. Develop hospice care services for children across the country.

4. Education—Palliative medicine should be mandatory subject for all medical students. Palliative Care Departments should be established in all medical universities in Hungary. Palliative Medicine should become a medical subspecialty. The involvement of volunteers should be increased in hospice palliative care services and volunteer training must be available. Hospice providers should be encouraged to train volunteers, and they should be integrated into the care of patients and families.

5. Public awareness and related activities—Continue to provide a positive image of hospice and palliative care for the community and professionals. Organize public awareness raising events to broaden public interest in palliative care, for example, charity concerts, solidarity walks, cultural, and sporting events, which could be linked to the World Hospice Day or held independently.

Disclosures and Acknowledgments

The authors thank Judit Schaffer, Hungarian Hospice Palliative Association, Dr. Gabor Benyo, National Hospice Palliative Advisory Board of the Ministry of Health, and Dr. Katalin Hegedus, Semmelweis University of Budapest for their contributions.

This research received no specific funding/grant from any funding agency in the public, commercial, or not-for-profit sectors.

References


Hungarian Hospice Palliative Care Development Timeline

1991: First hospice team developed at the Hungarian Hospice Foundation supported by the Soros Foundation
1995: Hungarian Hospice Palliative Association established
1997: Regulatory framework outlined
1997: Hungarian Health Act declared palliative care a human right and defined palliative care
1999: Hungarian Hospice Foundation media campaign raised public awareness
2001: Hungarian Hospice Foundation becomes Regional Resource Training Center
2002: National palliative care guidelines and standards accepted by MoH
2003: Regulatory changes to improve services took place
2004: Ministerial decree on hospice minimum requirements launched
2004: Hungarian National Health Insurance Fund started financing/reimbursing hospice care
2006: Hospice care integrated into National Health System
2006: Hospice became part of the National Cancer Control Program
2007: Hungary joined the Fields of Hospice program involving school children
2004: Legal requirements for palliative care established
2010: National Health Committee proposed integration of palliative care in undergraduate and postgraduate medical education
2012: University of Pecs established the first Hospice Palliative Care Department
2012: Two pediatric hospices have opened since 2012
2014: Junior doctors receive 40-hour education program in palliative medicine
2014: One-year course to qualify for license in palliative medicine developed
2015: Minimum requirements for pediatric hospice care approved
2016: National Hospice Palliative Advisory Board of the MoH established

MoH = Ministry of Health.