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# The SWOT analysis of Hungarian hospice palliative care

## Abstract

**Background:** In this review, we analyse the current situation of the Hungarian hospice palliative system. The aim was to find out more about positive aspects of care provided as well as barriers that undermine the development of high quality care in a hospice palliative system in operation since 1991.

**Material and methods:** A SWOT analysis was utilized whereby we investigated internal factors such as Strengths and Weaknesses and external factors such as Opportunities and Threats that affect the system. Questionnaires were sent by the Hungarian Hospice-Palliative Association to the 69 active hospice services in Hungary as of the beginning of 2010, and 49 hospice services returned completed questionnaires.

**Results:** Strengths include a well-developed legal mandate, government support and financing, and multi-level professional training available at various sites. Primarily, the lack of a genuine multidisciplinary and the absent of physicians may be seen as barriers. Success may also be threatened by the lack of a comprehensive conceptualized health policy that is characteristic of Central-Eastern European political systems in general. Among the opportunities, it is worth mentioning the ongoing development of management activities, specifications related to professional criteria and competence, and the promise of future development of palliative care units within university clinics.

**Key words:** palliative care, hospice care, SWOT analysis, Hungary

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## Introduction


### Brief history of hospice in Hungary

The first hospice organization, the Hungarian Hospice Foundation was founded in 1991, after dissolution of the socialist state. The Soros Foundation, Open Society Institute supported and funded much of the development of hospice initiatives in the country. The Hungarian Hospice-Palliative Association, a national membership organization, was established in 1995 with all 19 hospice organizations that existed at that time. The initial efforts made by hospice and

palliative care professionals on their own accord combined with external funding from the Open Society Institute were likely influential in gaining the recognition of policymakers. A national palliative care training program began in 1995 that was accredited by the Ministry of Health. In 1997, hospice-palliative care was recognized by the new Health Care Act (§ 99) and within the National Guidelines that were expanded in 2002 (the National Guidelines were published as a ministerial decree in 2010) [1].

In 2003, a media campaign was initiated by palliative care organisations that called for a parliamentary

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investigation into the care of dying patients that would pay particular attention to issues of human rights and patients' rights. As a result a set of minimum standards was published in March 2004 [2] and the National Health Service started to finance hospice care in May 2004.

The Hungarian Hospice-Palliative Association (HHPA) has played a significant role in coordinating and organizing the Hungarian hospice movement since 1995. Specifically, the association was instrumental in establishing its legal basis; in educating leaders within the national education system; in publishing academic textbooks and standards; and in devising a plan to keep in touch with policymakers. HHPA lobbied for recommendations regarding the appropriate use of hospice to be included in the National Cancer Control Program (2005) [3] and the HHPA became a member of the National Health Council in 2006.

In 2007, the HHPA organized the 10th Congress of the European Association for Palliative Care in Budapest which was a conference that brought further attention to the efforts to expand hospice and palliative care in Hungary and Eastern Europe.

As of October 2010, the HHPA coordinates the activity of 80 national hospice organizations (11 hospice in-patient units, 64 hospice home care teams, 2 hospice type care in nursing homes, 3 hospital support team). A total of 1200 people either work or volunteer within these organizations. In Hungary the 'target group' of hospice care recipients is cancer patients in their terminal phase of illness whose life expectancy is less than 6 months. They make up approximately 90% of recipients. The total population of Hungary is 10 million and in 2009, the mortality rate in Hungary was 130.4 per 100,000 and 33.1 died due to cancer diagnoses. Of these, 4.8 people had received hospice care.

## Material and methods

An assessment of hospice in Hungary was undertaken with the help of a SWOT analysis. In SWOT analysis, we examined the internal factors of Strengths and Weaknesses within the institutional system of hospice and palliative care and the external factors of Opportunities and Threats to the system [4]. Data gathered for analysis was collected through a questionnaire administered by the Hungarian Hospice-Palliative Association. In January 2010, questionnaires were sent to 69 hospice services that were active with the Association at that time. Forty-nine hospice services returned completed questionnaires.

Along with general background demographic data (such as the year of foundation, services provided, number of beds or home care visits, number of service recipients, most frequent diagnoses, average lengths of stay, mortality rates), data regarding the composition of the staff and their training background, whether special educational courses were offered, use of various community resources to assist recipients, and perceptions of difficulties encountered by the organization were collected.

## Results

### Strengths

#### *Development of existing forms and capacity of care*

In 2009, a total of 69 health institutions and teams provided hospice care in Hungary:

- 11 hospice in-patient units (with 171 beds);
- 53 hospice home care teams;
- 2 hospice-type care in nursing homes, primarily serving older adults (with 15 beds);
- 3 hospice mobile team (hospital support team);

The total number of hospice beds in 2009 was altogether 186.

According to respondent organizations, the total number of patients receiving hospice care in 2009 was 4861. In-patient care units provided care for 1887 patients, home hospice services for 2974. Ninety-seven percent of hospice recipients had a cancer diagnosis and the average length of care was 40 days. Beds in in-patient units were utilized at a rate of 80% with an average waiting period for admission of 12 days. Seventy-four percent of those admitted to inpatient units died on that unit. The number of patients who died while waiting for hospice beds was 323 and indicates the insufficient number of available beds and thus the great need. Hospice home care services reported a mortality rate of 75%. The percentage of these deaths occurring at home was 38%. The most frequent cancer diagnoses were lung, colon, breast, prostate, and head/ neck tumors. The patients are relatively younger (mostly 61–71 years old) than in the previous years when the average age of patients was 75 years.

In Budapest, Miskolc, and Pécs hospice activities are complex. For example, the Budapest Hospice House (Hungarian Hospice Foundation) has an in-patient care unit and home care coordination centre, a pain management outpatient department and a day care centre. It is involved in psycho-oncology services and hot line services and organizes training

for professionals and bereavement groups in the community. The Erzsébet Hospice Home (Erzsébet Hospice Foundation) provides similar services in Miskolc. In Pécs the hospice care includes an in-patient care unit, home care, social services and a training centre. All hospice institutions and home care teams utilized a multidisciplinary approach to care.

### ***Legal mandates and financial system***

Article 99 of the Health Care Law (1997) provides the legal mandate and support for hospice care. Furthermore, hospice care is determined by the Minimum Standards (2004) and Professional guidelines (2002, 2010).

The Hungarian National Health Service started financing hospice care in 2004. According to a financial quota system devised by the National Health Insurance Fund, 90% of hospice recipients must be terminal cancer patients. Hospice home care can be prescribed by a general practitioner for an initial 50 day period which can be extended twice if certain conditions are met. State financing imposes strict quality control regulations and continuous supervision on the basis of minimum standards.

### ***Professional trainings***

In 2009, there were 34 different hospice training programs offered in Hungary and altogether 1038 people attended the courses (not only hospice workers). According to the minimum standards, health workers must attend at least 40 hours of hospice training before starting their hospice work. An average of 75% of the professional team members have been trained in various aspects of hospice care. It is important to note that in Hungary more than 250 nurses have a specialization as a "hospice specialized nurse and coordinator" and 200-250 medical students annually attend the 30hour Thanatology-Palliative Therapy course that is offered within the undergraduate curricula for medical students.

## **Weaknesses**

### ***Organisational and regional disparity***

While at the end of 2009 there were 69 hospice services operating in the country, as of October 2010, the number had grown to 80. This can be attributed to the influence of a new decree of the Ministry of Health that allows home care services to provide hospice services activities that can be reimbursed by the NHS. The difference between home care and hospice home services is that home care services exist for

rehabilitation of curable patients and hospice home care services provide care only for terminal patients.

Unfortunately, the development of in-patient hospice units was recently blocked by the National Health Service. This constitutes a great challenge since increasing the number of hospice beds is continually on the agenda and not being able to develop this aspect further would lead to great disproportion considering the rapid development of hospice home care. (It seems as though the preference is going toward home hospice.)

In addition to this organizational disparity is a geographic disparity. Hospice care covers almost 70–80% of the country, but is much more developed in the Western and more urban regions. So the 20–30% uncovered is primarily in the rural and remote regions of Hungary.

### ***Scope and Quality of Care***

The percentage distribution of hospice home care activities does not reflect the potential multidisciplinary and complexity of this form of care. Nursing care dominates; comprising 58% of all services provided, while other activities that are the essence of quality palliative care remain low. Specifically, nursing long-term pain management services made up 21%; physiotherapy 4%; physical therapy 1%; social activities 2%; dietary care 2%; mental health activities 3%; medication, palliative therapy provided by physician is 10%. The low rate of mental health care is most striking. For example, an experienced hospice home care team in Western Hungary provided hospice care in 3460 cases, but mental health services were provided in only 84 cases even though they have two part-time psychologists available. Providers frequently complain about poor financing as a reason for not providing a range of services, but the use of these complementary resources is indispensable for quality hospice care.

### ***Lack of awareness and education about palliative care and pain management among physicians***

Lack of recognition of the need for hospice care may be the most daunting. One of the providers in Budapest, who has been providing hospice home care since 2004, wrote the following:

"We receive few patients, despite of our efforts made targeting physicians for the benefit of those patients who are in need of our services (continuously providing information, contracting oncology institutions, announcements, etc.). Recently we

had 9 patients in our care for 2–3 days, who were transferred to us practically only in the phase of dying. We have difficulties in making GPs understand what hospice care is about. It is either that they don't realise the value of the help we can offer, or they lack adequate empathy and sympathy, or it does not occur to them that our work may be needed".

The need to change views is indicated also by the fact that in 2000 only 0.5% of the under-graduate medical training and 0.7% of nurse training focused on pain management, symptom treatment, psychological care, death and dying, bereavement, and their communicational and ethical aspects [5, 6]. Many changes have occurred since 2000 such as the introduction of thanatology /palliative therapy course in the medical training, development of education related to medical communication, including a hospice care module in the nursing education, however, there seems to have been little change in attitude and awareness of hospice care in Hungary. A majority of physicians still consider palliative care to be merely a component of nursing, whereas in many other European countries and the U.S., palliative medicine is a speciality for which physicians may be trained.

#### ***Most common problems of hospice organizations***

The respondent organisations reported problems that can be grouped around the following issues (we also indicate how often these were mentioned):

- inappropriate attitude of GPs, lack of knowledge, lack of information (16);
- inadequate financing (14);
- late arrival of patients into the system (11);
- few trained specialists, lack of human resources (physicians, psychologists, physiotherapists) (8);
- debates with the Health Insurance Services (documentation, reimbursement etc) (5);
- infrastructural problems, difficulties stemming from distance to city/hospital from patients'home (5).

#### **Opportunities**

##### ***Development of management activities***

Considering the resources necessary for the hospice organizations to operate successfully, it is important to note that the support from the National Health Service covers only 50–70% of the budgets of most hospice organizations. In order to provide quality hospice care, the institutions must find other resources to fund needed services. Of the 49 respondent organisations, 27 indicated that other sources were used to

supplement the contribution of the National Health Service or other social income, such as financing from the Social Ministry or local government. An increase in the development of fund-raising activities was seen compared to the previous years.

It is worth mentioning that 14 hospice organizations have at their disposal the 1% personal income tax (Hungarian taxpayers may indicate they wish to have 1% of their taxes paid donated to hospice care), and 11 hospice services successfully submitted proposals and were granted support from the National Civil Fund and other state grants. In addition, 19 organisations reported to have received donations, 16 had support from foundations, and 3 organisations enjoyed local government funds or grants.

##### ***Further specifying professional standards***

In 2009 and 2010, further development of Professional guidelines and Minimum standards was underway with particular emphasis on the specifying appropriate/optimal levels of service provision, professional composition of hospice teams, level of training/education and qualifications desirable for hospice work. The objective was to establish specific criteria that would be a standard for specialized hospice care across the country [7].

Professional recognition is needed in order to strengthen the medical side of palliative care. The primary goal of such an initiative would be to establish a palliative care unit in at least at one of the medical faculties/universities. Despite numerous international models and centres of excellence, the leadership of Hungarian universities have not yet recognized the importance and necessity of combining educational and research models in the field of palliative care.

##### ***Enhancing social attitude change, involving and engaging the civil sphere***

Regarding the promotion of change of attitude in society, two movements have gained strength. One of them is related to the World Hospice Day. In 2010, 28 venues hosted various programs (concerts, exhibitions, masses etc) with a focus on dying patients [8]. The other one is called the "Field of Dignity" program (within a larger Fields of Hope project) organized by the Hungarian Hospice Foundation. This program consists of events connected to the blooming golden daffodils at spring time and aims to raise the awareness and direct the attention of the public to people who may be suffering at the end of life. As is common in international practice, the program also involves school children.

**Threats*****Is it chronic care or hospice or home care?***

The greatest threat is the confusion among definitions of chronic care, general home care and hospice care. In the case of chronic in-patient and general home care nursing care is seen as dominant. In the case of in-patient hospice and home hospice care, the definition includes specialized, comprehensive, multidisciplinary care and so is not limited only to the provision of nursing services. The relatively rapid development of hospice care services within chronic and general home care organizations does not imply attitude change as even the managers of these service providers have difficulties distinguishing between the two forms of care.

***Lack of consistent and comprehensive health policy***

One main barrier to hospice care development is the lack of a comprehensive health policy. Fragmented governmental measures exist that are likely the result of continual political change. In Hungary, a complete change of the health ministries' governing body occurs every 1–2 years; thus making consistency in health policy improbable. Unfortunately, health policies to date have not given a high priority to the recognition and funding of hospice care (in 2009, hospice treatment was provided/funded for only 4800 patients).

**Conclusions**

With summarizing of SWOT analysis of hospice in Hungary (Table 1) our aim was to know more

about strengths as well as factors that may hinder the development of a high quality care in a hospice palliative system that has been in operation since 1991. Strengths include a well-developed legal mandate (laws, standards, minimum standard), government support and financing (although limited), and multi-level professional training available at various sites. Primarily, the lack of a genuine multidisciplinary and the absent of physicians may be seen as barriers. Success may also be threatened by the lack of a comprehensive conceptualized health policy that is characteristic of Central-Eastern European political systems in general. Among the opportunities, it is worth mentioning and emphasizing the ongoing development of management activities, specifications related to professional criteria and competence, and the promise of future development of palliative care units within university clinics.

Our present review can be regarded as a “snapshot” of the state of the hospice-palliative system in one Central-Eastern European former socialist country. Many elements may be similar to other countries in the region and may also inform palliative care experts in highly developed countries with more well-developed hospice and palliative care programs. All in all, we may conclude that despite of still being considered in its infancy, hospice care in Hungary has an important role. As Marie de Hennezel explains “Those who are privileged to accompany someone in life’s final moments know that they are entering the most intimate of times...” [9].

**Table 1. Summary of SWOT analysis of hospice in Hungary**

<b>Strengths</b>	<b>Weaknesses</b>
Development of existing forms and capacity of care	Organizational and regional disparity
Creation of legal background	Poor financing
Partially resolved financing	Problems of quality in care, lack of genuine multidisciplinary
Basic training with high number of attendants	Poor professional recognition
Professional trainings	Lack of appropriate knowledge of palliative care and pain management among physicians
Social recognition has improved	Palliative training for physicians are unsolved or partially solved
Significant international recognition	No palliative care unit within university clinics
<b>Opportunities</b>	<b>Threats</b>
Development of management activities	Confusion of chronic care, home care and hospice care
Specifying professional criteria and competence and relationships	Lack of a comprehensive health policy development concept
Enhancing social attitude change	
Involving and engaging the civil sphere	

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## References

1. Hegedüs K., Szy I. (ed.). Palliative Care of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Hungarian Hospice-Palliative Association, Budapest 2002. Available on: [http://www.hospice.hu/english/hospice\\_in\\_hu.php?almenu=8#szoveg](http://www.hospice.hu/english/hospice_in_hu.php?almenu=8#szoveg) (accessed on 25 October, 2010).
2. Hospice Minimum Standards. Ministerial Decree no. 15/2004. (III.8.). Available on: [http://www.hospice.hu/english/hospice\\_in\\_hu.php?almenu=2#szoveg](http://www.hospice.hu/english/hospice_in_hu.php?almenu=2#szoveg) (accessed on 25 October, 2010).
3. Palliative care in the National Cancer Control Program in Hungary. Available on: [http://www.hospice.hu/english/hospice\\_in\\_hu.php?almenu=4#szoveg](http://www.hospice.hu/english/hospice_in_hu.php?almenu=4#szoveg) (accessed on 28 October, 2010).
4. László G. Successes, failures and difficulties — SWOT analysis and evaluation of the national hospice system.) *Kharón Thanatológiai Szemle* 2008; 12 (3–4) (In Hungarian).
5. Hegedüs K., Pilling J., Kolosai N., Bognár T. Attitudes of nurses and medical students related to death and dying. *Lege Artis Medicinae* 2001; 11: 492–499 (in Hungarian).
6. Hegedüs K., Pilling J., Kolosai N., Bognár T., Békés V. Attitudes of physicians related to death and dying. *Orvosi Hetilap*. 2002; 143: 2385–2391 (in Hungarian).
7. Professional guidelines on hospice and palliative care of terminal adult and paediatric cancer patients. Ministerial decree. *Egészségügyi Közlöny* 2010; 60: 1458–1547 (in Hungarian).
8. Hungary — World Hospice and Palliative Care Day. Available on: <http://www.hospice.hu/english/hnews.php?kinyit=0#0> (accessed on 29 October 2010).
9. Hennezel M. *Intimate Death: How the dying teach us how to live*. Knopf Publishing Group, 1997. Available on: <http://www.spiritualityandpractice.com/books/excerpts.php?id=13266> (accessed on 29 October 2010).