

Helping people at the end of their lives - Hospice and Palliative Care in Europe



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Hungary

by Marcel Globisch

1. General conditions

1.1 Demographics

In Hungary a *aging process* of society can be observed, though it nevertheless progresses markedly slower there than in Western Europe and also in comparison with some countries of Eastern Europe.

- In the year 1950 the population count of Hungary numbered 9.3 million. In 2000 10.0 million people lived in Hungary. By 2050 the population is estimated to have fallen to around 7.6 million¹.
- The average life expectancy has risen from 63.6 years (1950-1955) to 71.9 (between 2000-2005) years. By 2050 another rise is expected to bring the average age to 79.3 years². The comparatively low life expectancy can be ascribed above all to Hungary having the highest cancer rates Europe-wide³.
- In 1950, people aged 65 years or older constituted 7.3 % of the population. In 2000 it

¹ Population Division of the Department of Economic and Social Affairs of the United Nations Secretariat. *World Population Prospects: The 2002 Revision and World Urbanization Prospects: The 2001 Revision*.

Official homepage of the United Nations: <http://esa.un.org/unpp>

² *ibid.*

³ Imre Rodler / Gabor Zajikás: Hungarian Cancer Mortality and Food Availability Data in the Last Four Decades of the 20th Century. In: *Annals of Nutrition & Metabolism*. Vol.46 No. 2. 2002, p. 49-56.

was already 14.6 % and is projected to grow to 28.8 % by 2050⁴.

- Similarly, people aged 80 years or older constituted 0.8 % of the population in 1950. That percentage grew in 2000 to 2.5 and is estimated to grow to 7.6 by 2050⁵.
- In 1950, the working-age population (15-64 years) made up 67.6 % of the entire population. In 2000 that percentage had minimally risen to 68.4 %. For the future a rapid decrease to 57.2 % in the year 2050 is expected⁶.
- In 2003, 132.833 people died in Hungary; 33.537 of these died of cancer. In the same year 2.203 patients received care by Palliative Care institutions⁷.

1.2. Health Care System

During communist times health care was the responsibility of the state and was administered through hierarchical model that was highly centralized. Following a reformation in 1993, the Hungarian healthcare system today is principally a comprehensive, compulsory, employment-based national health insurance scheme that provides near universal coverage both in terms of treatments and in terms of population, with nearly all citizens receiving care whether or not they contribute.

The management and supervision was delegated to a self-governed committee. The compensation of the providers falls within the responsibility of the National Fund and is mainly oriented at contribution. Excepting additional payment for medication the medical care is free⁸.

Compared to the western European population the Hungarian population is in poor physical condition, the quota of deaths by cancer (342,5 per 100.000) is the highest in relation to other countries of Eastern Europe or Central Asia⁹. In 2002 the permission of general medicine surgeries was agreed on within the scope of a ten-year program for the reformation of the health system. With the enacting of a new law in 2003 the way was cleared for a large-scale privatisation of the health system (including the hospitals). Special care is given to the

4 ibid.

5 ibid.

6 ibid.

7 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

8 cp.: Eva Orosz/ Andrew Burns: Organisation for Economic Co-operation and Development. The Health Care System in Hungary. Economics Department Working Papers No. 241. The text can be accessed on the internet: [http://www.oilis.oecd.org/oilis/2000doc.nsf/4f7adc214b91a685c12569fa005d0ee7/c125685b0057c558c12568cf00330dd9/\\$FILE/00076478.PDF](http://www.oilis.oecd.org/oilis/2000doc.nsf/4f7adc214b91a685c12569fa005d0ee7/c125685b0057c558c12568cf00330dd9/$FILE/00076478.PDF)

9 David Clark/ Michael Wright: Transitions in end of life care. Hospice and related developments in Eastern Europe and Central Asia. Buckingham 2003, p.60.

foundation of institutions for home and outpatient care as well as the advancement of private health insurances and nursing institutions as an alternative to the current inefficient health system, which is characterized by too many hospitals.¹⁰ According to the OECD, for the year 2000, Hungary maintained 6,5 hospital beds per 1000 inhabitants. With that Hungary together with Germany and the Czech Republic leads the world count.¹¹ Astonishing though is the comparatively low number of employees in the hospital sector, the number of full-time workers employed per bed. In Hungary this figure lies visibly below the UN-average (0,8 to 2,0).

One may not understand the Eastern European health care system without confronting a phenomenon called tipping. The informal payment of medical and care services were tolerated in Hungary at the time of Communism and still remains an integral part of the health system, as statistics of the *European Observatory on Health Care Systems* prove. In 1997 the share of costs the patients had to pay amounted to 17,4%.¹² So-called informal payments to doctors and nurses constitute 8% of that.¹³ This practice has existed since the early years of Communism when the salaries of physicians were held at an artificially low level. The practice that has penetrated into all aspects of patient-physician relationship is still present. It discriminates between rich and poor and divides physicians beyond the possibility of reconciliation. Thus, the medical profession is divided, the patients are uncertain whom to pay, when and how much, and are exposed to the mercy of the system. The legal status of tipping is controversial. Although tipping as a form of bribery is an illegal and punishable act, it is a common knowledge that a tip given after medical treatment is a sign of gratitude and not against the actual law.¹⁴ The practice of "gifts" is so common in Hungary that many Hungarians regard it as a national tradition rather than a case of severe bribery.¹⁵ Hospice workers refuse these "gifts" as they argue that financial reasons should play no part in the treatment of patients. This paradigm of equality of patients and the renunciation of illicit money tends to cause conflicts with the workers in Hungarian hospitals who wish to retain the old structures¹⁶.

10 cp.: Complete monitoring report of the preparation of Hungary for the membership within the EU, p.10. In: http://www.mfa.gov.hu/NR/rdonlyres/38C506FC-02D5-417F-B62B-5CD6101ED9C2/0/cmr_hu_final_de.pdf

11 Bundeszentrale für politische Bildung: http://www.bpb.de/popup_druckversion.html?guid=MPPBS3

12 European Observatory on Health Care Systems: Healthcare systems in transition - Hungary. Copenhagen 1999, 25. In: <http://www.who.dk/document/e68317.pdf>

13 *ibid.*

14 Imre Szebik: Masked ball: ethics, laws and financial contradictions in Hungarian health care. In: *Science and Engineering Ethics*. Vol. 9. Issue 1. 2003, p. 109-24.

15 Complete monitoring report of the preparation of Hungary for the membership within the EU.p.17. In: http://www.mfa.gov.hu/NR/rdonlyres/38C506FC-02D5-417F-B62B-5CD6101ED9C2/0/cmr_hu_final_de.pdf

16 Interview with Barbara Kallo on August 12th 2004 in Budapest. Interview with Dr. Csaba Simkó and Kamilla Bánkúti on August 14th 2003 in Miskolc.

2. Hospice and palliative care in Hungary

2.1 History

Dr. Alaine Polcz, a psychologist who has been working with dying children for 40 years, and Dr. Katalin Muszbek, psychiatrist and head of a psycho-oncological hospital team, established the Hungarian Hospice Foundation in 1991.¹⁷

In the first instance, international contacts were established to become acquainted with the hospice idea. The *Hungarian Soros Foundation* supported the first hospice initiative.¹⁸

The concept of hospice was completely unknown in the public, the approach to death and dying a taboo¹⁹. Consequently the *Hungarian Hospice Foundation's* main concern was to bring this new form of care for the dying into the public and to enlist relevant social instances for support. A first project was launched in the *National Institute of Oncology*. A number of doctors, physiotherapists and volunteers had worked in foreign hospices. They started the first home care hospice team in Budapest, which attended to 65 mortally sick cancer patients and their families in its first year. The *Hungarian Hospice Foundation* became an example for further hospice teams which were formed in Hungary during the following years²⁰.

In 1993 the *Semmelweis University of Medicine* organised a 24-hour course with the title "Ethical and psychological problems of death and dying. For the dignity of the dying and death". 100 - 120 participants regularly attended this course, and in 1994 further lectures on the same topic were offered.²¹

In a declaration of the Ministry of Health and Social Welfare in December 1993 the necessity of the integration of hospice work and Palliative Care into the health system was stated. This led to a considerable rise in the number of organisations founding hospice and palliative units as well as home care teams. The *Hungarian Soros Foundation*, the communities and the Ministry of Social Welfare supported these services with grants.

In 1995 the 19 Hospice- and Palliative organisations formed the Hungarian Hospice-Palliative Association to state their interests and legally protect the name hospice from misuse²². The members also agreed that people who wish to engage themselves in hospice work have to pass

17 Interview with Dr. Katalin Muszbek on August 12th 2004 in Budapest.

18 Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002.

19 Interview with Dr. Katalin Muszbek on August 12th 2004 in Budapest.

20 Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002.

21 *ibid.*

22 David Clark/Michael Wright: Transitions in the end of life care. Hospice and related developments in Eastern Europe and Central Asia. Buckingham 2003, p.65.

a basic course spanning 40 hours before taking up their vocation. Additionally their continued participation in educational arrangements became obligatory.²³

Today the umbrella organisation, the Hungarian Hospice-Palliative Association, arranges regular meetings where the hospice workers can exchange ideas. Since early 1997 annual national hospice congresses are held. The 10th anniversary of the Hungarian hospice movement in 2001 was organised²⁴ by the *Ministry of Health*, and the *Hungarian Hospice Foundation* was chosen NGO (non-governmental organisation) for the year 2002.²⁵ Both facts are further indicators for the growing acceptance of the hospice concept and its representatives in the Hungarian society.

2.2. Hospice and palliative care provision

In April 2004 Hungary had 5 inpatient Hospice and Palliative Care units with 77 beds. Additionally, 2 day care centres, 5 hospital teams, 4 hospice teams in nursing homes and 15 hospice home care teams exist. Since their foundation in 1991 these hospice services have cared for 12.913 patients in all, for 2203 of these in the year 2003.²⁶ Compared to the year 2001 more than 600 additional patients were cared for, which accounts for a rise of 27.4%²⁷. 89% of these patients suffered from cancer. The average duration of medical attention is 29.4 days²⁸. The statistic mainly refers to forms of organisation, which provide hospice- or palliative care services. Regrettably there is no separate listing of the different types of organisations available. In 2004 the following personnel were working in Hungarian hospices: 33 physicians, 184 nurses, 27 physiotherapists, 20 psychologists and mental health experts, 19 priests, 15 social workers, 9 dieticians, 17 administrators/co-coordinators, 6 occupational therapists, 7 bereavement counsellor, 1 Bach flower therapist, 2 masseur and 121 volunteers.²⁹ The inpatient units are located within hospitals as chronic departments, yet they operate in separate buildings, as in the case of the *Semmelweis Hospital* and the *Szt. László Hospital*. While the hospice in Miskolc is lead by a doctor³⁰, the hospice attached to the *Szt. László*

23 Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002

24 ibid.

25 <http://www.hospicehaz.hu/eng/rolunk-alap.html>

26 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

27 comp.: Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002

28 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

29 ibid.

30 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

Hospital is under the direction of a head nurse. Doctors from other hospital departments take over the medical care but are not continually present within the hospice.³¹ Unfortunately Hungary's only paediatric hospice unit in *Bethesda Children's Hospice* was closed in February 2004 due to the reorganization of paediatric oncology units in Budapest in February.³²

Table 1. **Inpatient Hospice and palliative care units**

Name:	Founded in:	No. of beds
Gyula, Pándy K. Hospital Hospice Department Budapest, Szt. László Hospital Hospice Department	1994	20
Miskolc, Semmelweis Hospital Erzsébet Hospice Home	1995	10
Debrecen, St. Erzsébet Hospice	1995	20
	2003	12
Pécs, Merciful Hospice	2004	15

Hospice care in the nursing homes is only at its beginning. At present 4 homes exist where patients are cared for by hospice care teams. In Hajdúböszörmény 15 hospice beds are integrated, whereas the nursing homes in Sóstó and Tatabánya care for 5 hospice patients each, 4 further hospice beds are located in the nursing home in Pécs.³³

There are also *hospital teams* whose main duty it is to provide medical advice for terminally sick cancer patients in basic medical care, in hospitals and nursing homes³⁴. Currently 5 such teams work in the following institutions: *Jewish Charity Hospital*, Budapest; *"Life for years" Foundation*, Dombóvár; *Satisfaction Hospice Foundation*, Budapest; *Hungarian Hospice Foundation*, Budapest; *Baranya County Hospital*, Pécs. Day care facilities exist in *St. Margit Hospital* in Budapest as well as in the *Erzsébet Hospice* in Miskolc.³⁵

According to the Guidelines of the *Hungarian Hospice-Palliative Association*, home care hospice teams are expected to provide the patients with similar palliative care treatment as in hospital departments. The guarantee of a 24-hour care is desirable.³⁶ While the home care teams are responsible for the basic nursing care and physiotherapeutic treatment the multi-

31 Interview with Zsóka Kelemen on August 13th in Budapest.

32 Email from Dr. Andrea Bekesi, 15 October 2004.

33 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

34 Katalin Hegedus / Ildiko Szy (Hg.): Hungarian Hospice Foundation/ Semmelweis University: Palliative Care of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Budapest 2002, p.10.

35 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

36 Katalin Hegedus / Ildiko Szy (Hg.): Hungarian Hospice Foundation/ Semmelweis University: Palliative Care of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Budapest 2002, p. 10.

disciplinary teams solely attend to dying patients. The staff members have passed a hospice course and co-operate with other hospice services.³⁷

Table 2. **Hospice home care teams**

Name:	Founded in:
Hungarian Hospice Foundation (Budapest)	1991
Hospice Foundation of Szombathely	1992
Satisfaction Hospice Foundation (Budapest)	1993
Miskolc, Erzsébet Hospice Foundation	1994
Debrecen, Spital Hospice	1994
Kecskemét, "Embracing Hands" Foundation	1995
Székesfehérvár, Help Bt	1995
Nagymaros, Pax Corporis Foundation	1995
Pécs, Social Net Association	1996
Óbuda-Békásmegyer Home Care Service	1998
Nyírtelek, Nursing Association	1998
Ruzsa, Bánfi Home Care Service	1999
Kaposvár, Nevitt Cindy Home Care Service	1999
Szeged, Hospice Foundation	2002
Pécs-Baranya Hospice Foundation	2004

2.3. Legal regulations and funding

Inpatient units are financed according to the hospital budget as chronic departments. In correspondence with the regulation of *special home care* the home care hospice teams receive support by the compulsory sickness insurance. A decree, which decides the financing of home care, was accordingly passed in 1996. This regulation provided the basis for the development of home care services. 300 home care services operate currently, among them 15 hospice teams. This account system covers only the functions of nurses and physiotherapists.³⁸ Therefore the hospice services are only able to survive with the help of funds and donations. Various organisations have engaged themselves in the hospice and palliative care system, among them the *Hungarian Soros Foundation*, *Phare (European grants for Eastern European Countries)* and the *Open Society Institute*.³⁹

As part of the new *Health Care Act*, a new paragraph (article 99) was decreed in 1997, which legally defines the principles of *hospice care*.⁴⁰

1. The care for dying patients (hereafter *hospice care*) is aimed at the psychical and mental care and the nursing of persons suffering from terminal illnesses. The aim of hospice care is the improvement of their quality of life, the reduction of pain and the protection of their dignity until the end.
2. In order to achieve the aims formulated in paragraph 1 the "patients are entitled to have their pain controlled,

³⁷ Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

³⁸ Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002

³⁹ *ibid.*

⁴⁰ *ibid.*

physical and mental sufferings ceased and they have the right to have with them their relatives and other persons in close emotional relationship"

3. Whenever possible, *hospice care* should be granted within the home of the patient and within the familiar environment.
4. *Hospice care* includes the psychosocial support of the family of the dying patient during the period of illness and after the patient's death.

National guidelines for *hospice-* and *palliative care* were developed by hospice and health experts and have initially been published in 2000 and 2002 by the *Hungarian Hospice-Palliative Association*. These guidelines – approved of by the Health Department - were sent to all Hungarian hospitals.⁴¹

On April 29th of this year, clear legal structures and financing guidelines for *hospice care* were decided on by the National Health Insurance and the Health Department. Hospice care therefore is an integral part of the health system. In September 2004, a 2-year model program started in the course of which the National Health Insurance will pay altogether 300 million Hungarian Forint to 21 home care services and 9 inpatient hospital departments which offer hospice care for patients and their families.⁴² A lot of the existing inpatient and home hospice services applied, and also some "normal" hospital departments and home care services, who suited the application's requirements, for example they had some nurses trained in hospice care or the service had a quality control system. Some of the other old hospices did not apply, but they continue their hospice work on the basis of other supports. The application was very difficult for some services, because of the requirements. As a result, in addition to the existing Gyula, Miskolc and Pécs hospice inpatient centres, some other hospital got financial supports, that were not hospices before. Amongst those are Baranya County Hospital, Heves County Hospital, Komárom County Hospital, Zala County Hospital, and in Budapest, the MÁV Hospital. Some of the "new hospices" have not started their hospice work yet but will do so during this autumn. **The hospice beds that will be established in those hospices are not counted yet, thus the number of hospice beds in Hungary will considerably climb to 123 beds within the next few months.** It is the same situation with the home care hospices, there are some new services supported by the NHIF. By taking this measure it is hoped to increase the number of people who have access to hospice care. A congress combinedly held by the *Hungarian Hospice Foundation*, the National Health Insurance and the *Open Society Institute* took place in April with the aim to map out the financing and a national strategy for hospice work. The conference advised to have 70% of the arising costs for at least half the people

41 Katalin Hegedus / Ildiko Szy (Hg.): Hungarian Hospice Foundation/ Semmelweis University: Palliative Care of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Budapest 2002.

42 Email from Dr. Katalin Hegedus, 16 October 2004.

needing hospice care covered by the national social insurance until 2009.⁴³

The Hungarian tax system contains a paragraph allowing citizens to assign 1% of their salary to the support of social organisations, churches and foundations, which increasingly benefits hospice institutions. Through advertising campaigns covering all media social organisations attempt to reach the largest possible number of people. The *Hungarian Hospice Foundation* has taken advantage of this fact. The institution in Budapest is an outpatient hospice service and in the near future will open the first independent inpatient hospice as well as a day care hospice. On the level of fundraising the *Hungarian Hospice Foundation* is already an exceptional case and can call the largest advertising campaign in the Hungarian health system its own, a campaign by now known beyond the Hungarian border.⁴⁴ Dr. Katalin Muszbek, head of the institution, reports severe difficulties in the past in acquiring donations to the hospice service.⁴⁵ This was changed by the personal experience of the famous Hungarian actor Kata Dobó. During her last days the *Hungarian Hospice Foundation* had cared for Kata Dobó's grandmother, who suffered from cancer disease. The positive personal experience with the hospice service prompted Dobó to become involved with the organisation. With help from the widely known advertising agency McCann-Erickson Budapest the *Hungarian Hospice Foundation* launched a large scale TV campaign. Dobó and two other famous personalities advertised for donations to the hospice. The well-produced spots were broadcast at prime time and had pioneering effect. Donations have increased many times since the first serial – at the moment the second serial is broadcast. As *Programme Manager* Melinda Szöllösi reports questionnaires prove that since the TV campaign the familiarity with and acceptance of hospice services have increased enormously.⁴⁶

2.4. Organisations

The *Magyar Hospice-Palliatív Egyesület (Hungarian Hospice-Palliative Association)*⁴⁷, as the national "umbrella" association, was founded in 1995 and represents the interests of 28 Hungarian hospice- and palliative institutions in, for example, negotiations with the Hungarian health Department. The Association initiated and coordinated of elaboration of the legal background of the Hungarian hospice-palliative care: Hospice and patient's right chapters of the Health care act (1997) and the National Guidelines (2002).

43 comp.: Official homepage of the Hungarian Hospice Foundation: <http://www.hospicehaz.hu/eng/rolunk-hir.html>

44 Interview with Dr. Katalin Muszbek. In: Pol.it. The Italian on line psychiatric magazine. <http://www.pol-it.org/ital/psico-oncologia/katalineng.htm>

45 Interview with Dr. Katalin Muszbek on August 12th 2003 in Budapest.

46 Interview with Melinda Szöllösi on August 12th 2003 in Budapest.

47 For further information see: <http://www.hospicehaz.hu/eng/rolunk-hir.html>

The Association started an offensive and successful media campaign with human rights and patients rights organisations in March 2003 to initiate a parliamentary examination in this field. Four questions were addressed officially to the Parliament to examine:

1. Are there enough available modern treatments, medicines and trained specialists in the institutions caring for dying patients?
2. Is there enough psychical care and information for terminal patients?
3. Are there enough palliative care services?
4. Is there a good-quality care in the chronic departments and institutions?

After one year of this initiative and Parliament examination process the Ministry of Health accepted the Minimum Standards (2004) and the Health Care Insurance Fund started to finance the palliative care in Hungary.⁴⁸

Since 1999 this organisation has been a member of the *European Association of Palliative Care* and is supported by the *Open Society Institute* in New York.⁴⁹

2.5. Professionals

A national training program for *Palliative Care*, organized by the Hungarian Hospice-Palliative Association, was accredited by the Health Department and includes a basic course spanning 40 hours as well as an advanced course of the same duration. Since 1994 more than 3000 people have participated in these courses.⁵⁰ Nine textbooks, a number of specialised literature and the *Kharon Thanatological Revue* were published. Curricula, guidelines and standards for palliative care (for example WHO- standards) have been translated into Hungarian.

Additionally a one-year post-graduate educational program for nurses (possibilities of graduation: trained hospice nurse, coordinator) exists, which, following a law decreed in June 2001 by the Ministry of Health, began in March 2002.⁵¹

While the nurses' readiness concerning hospice- and palliative care seems rather distinct and corresponding courses are quite frequented, the attitude of the doctors is marked by reserve, ignorance and fears. What both professions often have in common is a lack in knowledge about hospice care, as proved by research conducted by the Institute of Behavioural Sciences at the *Semmelweis University of Medicine*. 182 nurses, 288 students of medicine and 124

48 Email from Dr. Katalin Hegedus, 16 October 2004.

49 David Clark/ Michael Wright: Transitions in end of life care. Hospice and related developments in Eastern Europe and Central Asia. Buckingham 2003, p.65

50 Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

51 Katalin Hegedus: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium - Hospice and Palliative Care. 21.03.2002

doctors were questioned about their attitude towards and knowledge about death and dying. The results go along with comparative questionnaires conducted in other countries.⁵² 40,8% of the interviewees have never during their practice or training spoken to a dying patient about other things than purely medical concerns. About 40% of the interviewees did not know what to do with the term *hospice care* though they were given opportunities, which should have made finding an answer easier for them.⁵³ The reasons for this ignorance are obvious: in the course of the training for nurses spanning a whole 4600 hours only 33 hours were devoted to the treatment of the topics death and dying, for the medical students the time amounted to 34 hours by a total of 7000 hours.

A statement by Dr. Katalin Muszbek summarises the importance of education and advanced training for the professionals in the area of hospice- and palliative care:

Being fit for work in hospice care means having acquired its philosophy, being ready to work in a team and take part in extension trainings [...] Continuitive education and the mental care of our staff is highly important, since burnout is a constant danger our colleagues have to face. Extension trainings and professional programmes help keep their knowledge and skills fresh and applicable, they help maintain high professional quality as well as reinforce their original motivation and a sense of competence.⁵⁴

2.6. Volunteers

Currently only 121 volunteers work in the Hungarian hospice- and palliative system⁵⁵, compared to the international figure a strikingly small number. Up to now the reasons for this have not been researched. There are two possible main reasons for the lack of voluntary engagement: for one, Hungary's socialistic past where voluntary structures were not supported and consequently hardly existed. For another, the misuse of donation money by so-called charity organisations in post-socialistic Hungary proves to be a hindrance for those organisations who wish to work on an voluntary basis. The *voluntary* office therefore is seldom regarded or perceived as an *honour*.⁵⁶ In the institutions we visited especially religious people engaged themselves in voluntary hospice work.⁵⁷

In the guidelines *Palliative Care of Terminally Ill Cancer Patients*, the work of the volunteers is defined in a separate chapter.⁵⁸ The selection of volunteers is supposed to begin with a

⁵² Katalin Hegedus and others: Attitude of Nurses and Medical Students toward Death and Dying. Poster for the 7th Congress of the European Association for Palliative care. Palermo. Italy 2001.

⁵³ *ibid.*

⁵⁴ Interview mit Dr. Katalin Muszbek. In: Pol.it. The Italian on line psychiatric magazine. <http://www.pol-it.org/ital/psico-oncologia/katalineng.htm>

⁵⁵ Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

⁵⁶ Interview with Barbara Kallo on August 12th 2004 in Budapest.

⁵⁷ Interview with Dr. Katalin Hegedus and Annamaria Köszegi on August 11th 2003 in Budapest. Interview with János Magyar on August 14th 2003 in Miskolc.

⁵⁸ Katalin Hegedus / Ildiko Szy (Hg.): Hungarian Hospice Foundation/ Semmelweis University: Palliative Care

personal conversation. After completion of a not further defined *hospice training* the voluntary is supposed to be introduced to the hospital work. After a three-month stay in the hospice section of the hospital assignment to the home care service is considered. The volunteers are supposed to support the patients, their relatives and the institution. They are assigned a vital role in the hospice work:

Voluntary work is a significant contribution from an economical point of view. Voluntary work is a key-issue expressing civil commitment, trust, mutuality and solidarity among people.⁵⁹

2.7 Example⁶⁰

Erzsébet (Elisabeth) Hospice Foundation in Miskolc

Organisation and funding

In 1994 the *Erzsébet (Elisabeth) Hospice Foundation* in Miskolc began to care for mortally sick patients. In 2002 151 patients were cared for in their own homes.⁶¹ The foundation also supports the *Erzsébet Hospice*, which is integrated into the *Semmelweis Hospital* in Miskolc and cares for about 320-350 patients each year.⁶² With financial help by a foundation of the Netherlands the number of beds in the inpatient hospice increased to 20 and a possibility of a day care hospice established. Unfortunately the day care apartment is not running at the moment. Currently more than 400 mortally sick cancer patients are being cared for per year – in Hungary's third largest city housing about 180.000 inhabitants. This number amounts to 60% of the terminally ill cancer patients concerned.⁶³

The *Training and Ressource Centre for Palliative Care* is an important part of the *Erzsébet Hospice Foundation*. More than 1.500 professional workers have been trained there, among them doctors, nurses, social workers, psychology students, so-called *mental hygiene students* as well as clergy. Other hospice institutions, like the *Jewish Charity Hospital hospice mobile team* in Budapest also send their members to Miskolc for their training.⁶⁴ In 2000 the achievements of the training centre were honoured by the *Open Society Institute* and the title “Educational and Training Centre” conferred. The main part of the home care hospice team's

of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Budapest 2002, p.10.

59 *ibid.*, p. 62.

60 Additional detailed examples of hospice services in Hungary can be found in:

David Clark/ Michael Wright: Transitions in end of life care. Hospice and related developments in Eastern Europe and Central Asia. Buckingham 2003, p. 195-214.

61 Statistics of the Erzsebet Hospice. Miskolc 2003, p. 24. Unpublished document.

62 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

63 www.eapceast.org/upload/Elizabeth%20Hospice%20Hungary.doc

64 Interview with Dr. Katalin Hegedus on August 11th 2003 in Budapest

work is still financed by donations, funds and charity performances. The acquisition of donation money proves to be difficult since a tradition of donations does not exist and the people in and around Miskolc have their own financial problems to cope with.⁶⁵ Up to February 2004 the health insurance companies thought the home care in Miskolc sufficiently extended and they hold that other medical services already do the same work as the hospice service, so they refused to pay for the outpatient hospice teams.⁶⁶ Now the hospice home care service also gets money from the health insurance for the nursing activities in Miskolc. Dr Csaba Simkó: “Furthermore there is a new nationwide trend in the financing of hospices in Hungary nowadays. In this new system money will be paid not only for the nursing care but also for the physician’s, physiotherapist’s and dietician’s visits also.”⁶⁷

The care for one patient within the inpatient hospice is estimated at 7400 Hungarian Forint per day. So far the Health insurance paid 3400 Forint, the remainder was provided by the hospital. This way the hospital lost 30 million Forint (about 100.000 Euro) by financing the hospice unit.⁶⁸ In the new financing system the hospital will get 1,8 x 3900 Forint for a hospice bed per day. It will cover 75% of the costs.⁶⁹ The average stay within inpatient care is about 18 days.

The professional team of the inpatient hospice

The hospice employs 2 doctors, 15 nurses, 1 physiotherapist (part-time) and 1 voluntary coordinator who is a trained nurse as well. A protestant pastor works part-time in the hospice, a catholic priest comes at least twice a week. The greater part of the workers has received their training in the training centre of the *Erzsébet Hospice Foundation*. The team is not supervised. Earlier attempts failed “because of the poor care of one psychologist. Neither is supervision desired by the workers.”⁷⁰

The voluntary team of the hospice

The 12 volunteers (11 women, 1 man) are chosen, trained and supervised by an voluntary coordinator. In choosing the voluntary workers attention is paid to the applicants not having suffered a death in their family in the last two years and that they themselves and no family member suffer a fatal sickness at the moment of their application. A minimum age of 18 years

65 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

66 *ibid.*

67 Email from Dr. Csaba Simkó, 17 October 2004.

68 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

69 Email from Dr. Csaba Simkó, 17 October 2004.

70 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

is also required.⁷¹ Before taking up work the voluntary has to pass a training program. Special emphasis is placed on the psychological training of the volunteers.⁷² For instance, the phases of the dying process are treated by Dr. Elisabeth Kübler-Ross. Further aspects of training include communication, basic care and physiotherapy. Towards the end of the course the volunteers are taken along to visit patients to get an impression of the daily work. The volunteers themselves decide on their field of activity. 30% of this consists of nursing care, which initially caused conflicts with the professional nursing team. By now though, the relationship is perceived as very good. One indication for this is the communal use of the changing room by professionals and volunteers alike, which is rather uncommon by Hungarian standards.⁷³ The voluntary workers confirm that, describing the relationship to the nurses in the hospice as “very good. Compared to the nurses in the hospital these nurses are glad for our support”⁷⁴. In addition to the improved relationship to the nurses Kamilla Bánkúti emphasizes the fact that in the hospice no “gifts” by the patients are accepted and all are treated as equal. She comes to the hospice for 3 to 6 hours once a week to attend to the patients. She “converses with patients”, takes them for walks, runs errands or helps distributing meals.⁷⁵ Like almost all volunteers in Miskolc she is very religious and is a member of the Roman Catholic church. In isolated cases voluntary coordinator János Magyar observes the risk of missionary ardour in religious volunteers. The training therefore clarifies that the initiative for prayer has to come exclusively from the patient and not from the voluntary. As in the case of the professionals there is no supervision, but once a month a meeting with the voluntary coordinator is being held.

Specific issues

In all the conducted interviews a marked delimitation from the habits in Hungarian hospitals can be observed. The handling of the deceased patients is very dignified and ritualized. "We try to treat the dying just as it would happen if they were at home".⁷⁶ After the patient's death his body remains in the bed for 2 to 4 hours. In front of the nurses' room and in the patient's room a candle is lit and flowers for decoration are placed. The bed of the deceased patient remains vacant for at least one day, sometimes for even 48 hours. This is regarded as a symbolic gesture of respect for the dead. Sometimes team members, especially the nurses, also attend the funeral.⁷⁷

71 Interview with János Magyar on August 14th 2003 in Miskolc.

72 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

73 Interview with János Magyar on August 14th 2003 in Miskolc.

74 Interview with Kamilla Bánkúti on August 14th 2003 in Miskolc.

75 *ibid.*

76 Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

77 Interview with Annamária Breznai on August 14th 2003 in Miskolc.

3. Summary and outlook

In the course of its ten year history the Hungarian hospice movement has been able to count a number of remarkable successes its own. Within the *Hungarian Hospice-Palliative Association* national hospice services are now organised and speak with one voice. A law for hospice- and palliative care has been established within the National Health Act. These shortly decided agreements with the compulsory sickness fund and the Ministry of Health are expected to guarantee the hospice services are able to operate on a financially secure basis in the future. After 13 years of lobbyism, publicity and educational work, numerous advertising campaigns and the organisation of charity events to spread the hospice philosophy hospice work now is no longer a movement but an integral part of the health system.

Hospice services can draw from nursing personnel trained in standardised national basic and advanced courses and possessing at least basic knowledge of Palliative Care. The post-graduate course founded in 2002 will soon produce disciplinary specialised hospice nurses. Textbooks and teaching aids for hospice- and palliative care are available in Hungarian.

While the hospice and palliative training for nurses is expanding, the medical section states a severe shortage of doctors with palliative knowledge. Palliative care content hardly exists within the medical curriculum, though - if only sporadically - , there is some interest in the matter within the medical profession, as an integrative model in Miskolc shows, which tries to impart palliative care knowledge to resident doctors.⁷⁸ The integration of hospice structures into the existing frame of the health system still remains underdeveloped. At present, there exist only two services in Hungary, which Katalin Hegedus defines as *complex services*.⁷⁹ This includes institutions which have established inpatient as well as outpatient and home care facilities and also operate as training and educational centres. The existing complex services *Hungarian Hospice Foundation* and *Erzsébet Hospice* will shortly be followed by a third such institution. Further educational work will be necessary to soften the stiffened structures of the current health system and to increase the still low acceptance of multi-disciplinary teams. Within the inner hospice structures this aim has obviously been reached. In the conducted interviews the interviewees repeatedly point out the conducive team structures and accentuate these as an asset towards other institutions.⁸⁰ The refusal of bribery and the explicit delimitation from the institution hospital is also mentioned in several interviews.⁸¹

⁷⁸ Interview with Dr. Csaba Simkó on August 14th 2003 in Miskolc.

⁷⁹ Katalin Hegedus: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004

⁸⁰ for example: Interview with Nóra Ferdinandy on August 12th 2003 in Budapest.

⁸¹ One of numerous examples is the interview with Edit Szigeti on August 12th 2003 Budapest.

Another deficit is the lack of inpatient hospice units in the medical faculties' clinical field where they would be necessary for the research and education in pain and symptom management. A few experts critically remark on the lack of suitable quality control and evaluation of hospice institutions. Dr. Andrea Bekesi, head doctor of the only children hospice in Hungary, relativises the importance of formal evaluations. For her it would be confirmation enough when the parents of deceased children return to express their thanks for the care their child received. In this way, they would give back much more than an evaluation certifying successful work. The indicator for successful work would be the continued contact with the family members and their positive reaction: "That's what I call success!"⁸²

Hungary's socialistic past has prevented a tradition of donations or voluntary offices to arise. Yet the current development gives cause for hope, as the successful advertising campaign of the *Hungarian Hospice Foundation* shows. Chances are good that especially the terminally sick cancer patients will continue to profit from the pioneering work done by exceptional personalities like Dr. Katalin Hegedus, Dr. Katalin Muszbek and Dr. Alaine Polcz.

4. Literature and sources:

Clark, David/ Wright, Michael: Transitions in end of life care. Hospice and related developments in Eastern Europe and Central Asia, Buckingham 2003.

Hegedus, Katalin: Legal and ethical elements of hospice-palliative services in Hungary. *Progress in Palliative Care* 8 (1) 2000, p. 17-20.

Hegedus, K., Pilling, J., Kolosai, N. and Bognár, T: Attitude of Nurses and Medical Students toward Death and Dying. Poster for the 7th Congress of the European Association for Palliative Care, Palermo, Italy, 2001.

Hegedus, Katalin: Hospice movement in Hungary and experiences with hospital supportive teams: V Symposium – Hospice and Palliative Care, 21.03.2002.

Hegedus, Katalin: VI. Hungarian Hospice-Palliative Congress. Hospice in Hungary 2004. Miskolc 23.04.2004.

Hegedus, Katalin/Szy, Ildiko (Ed.): Hungarian Hospice-Palliative Association: Palliative Care of Terminally Ill Cancer Patients. Professional guidelines. 2nd improved and extended edition. Budapest 2002.

Information brochure Jewish Social Support Foundation 2001-2002. Budapest 2002.

Rodler, Imre/ Zajkás, Gabor: Hungarian Cancer Mortality and Food Availability Data in the Last Four Decades of the 20th Century. In: *Annals of Nutrition & Metabolism*. Vol. 46. No. 2. 2002, p. 49-56.

Statistics of the Erzsébet Hospice. Miskolc 2003. Unpublished document.

Szebik, Imre : Masked ball: ethics, laws and financial contradictions in Hungarian health care. In: *Science and*

82 Interview with Dr. Andrea Bekesi on August 15th 2003 in Budapest.

Sources on the internet (in chronological order of the text)

Official Homepage of the United Nations: <http://esa.un.org/unpp>

Orosz, Eva / Burns, Andrew: Organisation for Economic Co-operation and Development. The Health Care System in Hungary. Economics Department Working Papers No. 241. Im Internet abrufbar unter:
[http://www.oecd.org/olis/2000doc.nsf/4f7adc214b91a685c12569fa005d0ee7/c125685b0057c558c12568cf00330dd9/\\$FILE/00076478.PDF](http://www.oecd.org/olis/2000doc.nsf/4f7adc214b91a685c12569fa005d0ee7/c125685b0057c558c12568cf00330dd9/$FILE/00076478.PDF)

Complete monitoring report of the preparation of Hungary for the membership within the EU.p.10. In:
http://www.mfa.gov.hu/NR/rdonlyres/38C506FC-02D5-417F-B62B-5CD6101ED9C2/0/cmr_hu_final_de.pdf

Bundeszentrale für politische Bildung: http://www.bpb.de/popup_druckversion.html?guid=MPPBS3

European Observatory on Health Care Systems: Healthcare systems in transition - Hungary. Copenhagen 1999.
In: <http://www.who.dk/document/e68317.pdf>

Official Homepage of the Hungarian Hospice Foundation : <http://www.hospicehaz.hu/>

Official Homepage of the Hungarian Hospice/Palliative Association <http://www.hospice.hu>

Interview with Katalin Muszbek. In: Pol.it. The Italian on line psychiatric magazine. <http://www.pol-it.org/ital/psico-oncologia/katalineng.htm>

[www.eapceast.org/upload/ Elizabeth%20Hospice%20Hungary.doc](http://www.eapceast.org/upload/Elizabeth%20Hospice%20Hungary.doc)

The interviews were conducted with (in chronological order)

Dr. Katalin Hegedus, Leader of the Hospice Programme of the Jewish Support Foundation, President of the Hungarian Hospice-Palliative Association and member of the Board of Directors of the EAPC, 11.08.2003 in Budapest.

Monika Veress, Nurse at Jewish Charity Hospital, 11.08.2003 in Budapest.

Annamária Kőszegi, Social worker at Jewish Charity Hospital, 11.08.2003 in Budapest.

Dr. Katalin Muszbek, Leader of the Hungarian Hospice Foundation, 12.08.2003 in Budapest.

Edit Szigeti, Head nurse of the Hungarian Hospice Foundation, 12.08.2003 in Budapest.

Barbara Kalló, Social worker of the Hungarian Hospice Foundation, 12.08.2003 in Budapest.

Melinda Szöllösi, Programme Manager of the Hungarian Hospice Foundation, 12.08.2003 in Budapest.

Nóra Ferdinandy, Physiotherapist of the Hungarian Hospice Foundation, 12.08.2003 in Budapest.

Zsóka Kelemen, Deputy head nurse at the Hospice of Szt. László Hospital, 13.08.2003 in Budapest.

Dr. Csaba Simkó, Medical director at the Erzsébet Hospice, 14.08.2003 in Miskolc.

János Magyar, Voluntary coordinator at the Erzsébet Hospice, 14.08.2003 in Miskolc.

Annamaria Breznai, Physiotherapist at the Erzsébet Hospice, 14.08.2003 in Miskolc.

Kamilla Bánkúti, Voluntary worker at the Erzsébet Hospice, 14.08.2003 in Miskolc.

Dr. Andrea Bekesi, Medical director of Bethesda Children's Hospice, 15.08.2003 in Budapest.

More information about the book and the project is available on the official website in German language (the English www-version is set to be launched in June 2005) at: <http://www.uni-giessen.de/hospizprojekt>

