Hospice movement in Hungary and experiences with hospital supportive teams

I. HOSPICE MOVEMENT IN HUNGARY

The first steps (1989-1993)

At the end of the 1980’s political changes granted more freedom for the establishment of non-governmental organisations and foundations. Two groups started up in the National Institute of Oncology, one dealing with the psycho-oncological care of patients with tumours, and the other, the National Association of Cancer Patients, protecting the interests of cancer patients. These groups started to work together for giving a complex, psychosomatic treatment for terminally ill patients and also organizing special courses for specialists and volunteers.

The Hungarian Hospice Foundation was founded in 1991 by two charismatic women: Dr. Alaine Polcz, a psychologist dealing with dying children for 40 years, and Dr. Katalin Muszbek, a psychiatrist, leader of the psycho-oncological hospital team. After collecting international experience about the hospice movement and philosophy and also having connections with liberal, democratic political personalities, for instance with Mr. President Göncz and American philanthropist Mr. George Soros. The first hospice organisation was supported by the Hungarian Soros Foundation.

The hospice movement was completely new for the public. Thus, in the first years the primary task of the Foundation was to advertise the forms of caring for dying people. Representatives of the Ministry of Social Welfare, social security, and local governments together with the directors of hospitals, showed great sympathy and willingness to co-operate. Everybody agreed on the necessity to introduce palliative care, but no one dared to take the first steps. They explored its concept and entered into debates on ethical and legal principles. Meanwhile, a model-team started to work in the National Institute of Oncology. A few doctors, nurses, physiotherapists and volunteers had learned the message of hospice-spirituality abroad and they launched an experiment in Budapest to provide for the home care of dying patients. In the first year, the care teams cared for 65 terminally ill cancer patients and their relatives. The Hungarian Hospice Foundation was a model for development of different hospice teams in Hungary.

In 1993, the Semmelweis University of Medicine started an extension training of 24 hours titled "Ethical and psychological problems of death and dying. For the dignity of the dying and death". There was a regular attendance of 100-120 participants at the lectures and in 1994, a further series of lectures was launched.

The hospice organizers were looking for different contacts with Ministry, Parliament, social insurance companies, because the care could not be developed further without regular support. The basic principles of palliative care were described for policy makers about improving the quality of life of patients, interdisciplinary team, free of charge service and special education.

The Ethical College of the Hungarian Chamber of Physicians approved the concept of terminal palliative medicine in 1993: 'Terminal palliative medicine is not identical with passive euthanasia. It is a particular field of medical activity. It aims to relieve the physical and mental suffering of patients regarded as incurable according to the current medical science. After due consideration, a physician can apply appropriate treatment and to set aside treatments considered as useless.' (Hegedus, 2000)

The beginning of process of integration into the healthcare system

The necessity to integrate hospice into the healthcare system was stated in the Bulletin of Social Welfare in December 1993, and led to a considerable increase in the number of organisations establishing hospice palliative units or home care teams. The Soros Foundation, local governments, and the Ministry of Social Welfare offered grants to support the establishment and operation of new units.

In 1995, 19 hospice/palliative organisations established a national association. With the aim of protecting the interests of hospice organisations, the Hungarian Hospice Association decided to take a strong line against any organisations and individuals who use and apply the hospice name and activity in a way which is not in line with the principles of hospice. In addition, the member organisations agreed that those who wish to be engaged in hospice work must first complete a basic course and then participate in continuous education. A national education program of palliative care was organized (40 hours basic courses and 40 hours advanced courses for different specialists), accredited by the Ministry of Health. More than 2660 people participated in the courses, nine textbooks, series of publications and the Kharon Thanatological Revue have been published until recently. Palliative care curriculum, guidelines and standards (e.g. WHO-standards) have been also translated.

The Association completed a national survey about the situation of the hospice movement in Hungary, the results of which were published in several forms and the Association forwarded the experiences to the Ministry and the National Health Insurance Fund. The Association organised meetings where hospice workers could exchange experiences. Four national congresses were held beginning in 1997 (in Miskolc, Gyula, Szombathely and Budapest.) The 10th anniversary of the Hungarian hospice movement was organized in 2001 the Ministry of Health, with the representatives of Ministry.

During the preparation of the new Health Care Act a three-member committee was created for dealing with problems of dying patients. The short version of the document of this Committee came to be included as the principles of hospice care in the Health Care Act in 1997:

1. Caring for the dying patients (hereinafter: hospice care) is aimed at the psychical and mental care and nursing of persons suffering from terminal illnesses, including improving their quality of life, relieving suffering and protecting their human dignity until death.
2. In order to achieve the aims specified in paragraph (1) patients are entitled to have their pain controlled, physical and mental sufferings ceased and they have the right to have with them their relatives and other persons in close emotional relationship.
3. Where possible, hospice care should be offered in the home of the patient, in the family circle.
4. Hospice care includes support for the dying patient’s relatives, and the offer of spiritual support during the period of the illness and in the bereavement period.

(Article 99)

National Professional Guidelines of the hospice/palliative care was elaborated by hospice and health care specialists and published by the Association in 2000. The Guidelines – accepted by the Ministry of Health – was sent to all hospitals in Hungary.

The content of Guidelines is the following:

1. Concept of palliative care
2. Legal background, regulation of care
3. Organisational forms
4. Interdisciplinarity. Tasks and responsibility of team members
5. Representing the patient’s interest
6. Accessibility of palliative care
7. Palliative care of children
8. The process of care. Therapies
9. Documentation

10.Cost analysis
11. Quality standards
12.Education, trainings
13. Research
(The second edition of Guidelines will be translated to English in 2002.)

The present situation. Successes and failures

At the end of 2001, Hungary had 4 hospice palliative (inpatient) units with 56 beds, 13 hospice home care teams, two day care centres and 2 hospice mobile supportive teams. There are also hospice/palliative teams in five nursing homes. Hospice organisations have accompanied the death of altogether 8780 patients since their establishment (1600 in 2001).

Table 1. Hospice palliative units

Name:	Date of establishment:	Number of beds:
Gyula, Pándy K. Hospital Hospice Department	1994	20
Budapest, Szt. László Hospital Hospice Department	1995	10
Miskolc, Semmelweis Hospital Erzsébet Hospice Home	1995	20
Budapest, Bethesda Hospital for Children Oncology and Hospice Department	1995	6

Table 2. Hospice palliative teams in nursing homes

Name:	Date of establishment:	Number of hospice beds:
Sóstó, Nursing Home	1997	5
Nyírtelek, Nurssing Association	1998	2
Pécs, Nursing Home	1998	-
Szederkény, Nursing Home	1999	-
Tatabánya, Nursing Home	1999	-

Table 3 Hospice home care

Name:	Date of establishment:
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, Hospice 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

There are two hospice supportive mobile teams in Budapest: in the Jewish Charity Hospital and in the St. Imre Hospital (founded in 2001). Day care centres are in Budapest (St. Margit Hospital) and in Miskolc (Erzsébet Hospice).

Table 4 Hospice staff in Hungary, 2001
29 physicians
191 nurses
26 physiotherapists
14 psychologists and mental health experts
81 volunteers
17 priests
15 social workers
9 dietitians
16 administrators, co-ordinators
5 occupational therapists
5 bereavement counsellor

Hospice inpatient units are financed as part of hospital budgets (as chronic departments). The home care teams are supported by the National Health Insurance Fund in compliance with the regulations for special home care. A ministerial decree about financial support of home care services was published in 1996. This document created the conditions for development of home care services. Now more than 300 home care services have been working in Hungary, 13 of which are hospice home care teams. Unfortunately, just nurses' and physiotherapists' services are paid in this system. The hospice organisations can survive only with help of the grants and donations. Some major grants/donations have been associated with hospice development:

- Hungarian Soros Foundation: for all hospice organisations, for different purpose (development of services, education, publishing of book and paper, study tours, travel grants, congresses, etc.)
- Phare (European grants for Eastern European Countries) for development of services, education program, publishing of books;
- Open Society Institute (2000-2002) in Death in America project – for education, study tours, travel grants.

Every Hungarian citizen has also right to offer 1% of his annual tax to a non-profit organisation and an other 1 % to a religious organisation of given kind. This may be done in the system of annual tax returns. A number of hospice organisations can get support in this way.

What are the successes in the Hungarian hospice movement after 11 years?

1. Law about the hospice/palliative care in the Health Care Act
2. Good national organisational system of hospice/palliative services (Hungarian Hospice-Palliative Association)
3. 27 hospice teams working in Hungary
4. Excellent postgraduate training system for nurses (The one-year education programme of the Skilled Hospice Nurse and Coordinator (by decree of the Ministry of Health, 6/2001) has been started in March 2002).
5. A lot of textbooks and teaching materials available in Hungarian

What are the failures?

1. Not enough financial support from National Health Insurance Fund. Lack of ministerial decree regulating the financial support of the hospice/palliative care.

3. Lack of the palliative care topics in the medical curriculum
4. Lack of hospice inpatient units in clinics of medical schools for development of research and education of pain and symptom management
5. Few volunteers

One of the most important things is changing the attitude of health care professionals toward death and dying. In a questionnaire survey conducted by the Institute of Behavioural Sciences of the Semmelweis University of Medicine, we asked 182 nurses, 288 medical students and 124 physicians about their attitude towards death and dying. The results of our examination are totally in line with the data and conclusions of several foreign researches. During the 4600-hour nurse education there are 33 hours dealing with the problems concerned while there are 34 hours in the 7000-hour medical curriculum. 40.8% of participants of our survey has never talked to a dying person about questions beyond professional ones. Approximately 40% of participants couldn’t choose the characterization of hospice care even among possible answers which seemed to be easily excluded. (Hegedus, Pilling, Bognár, Kolosai, 2001, 2002)

These results demonstrate that it is crucially important to change public attitudes and views, and to integrate the scientific achievements of palliative care into the educational curricula.

II. EXPERIENCES WITH A HOSPITAL SUPPORTIVE TEAM

In 2000, the Hungarian Jewish Social Support Foundation (HJSSF) applied and won a grant from the Nazi Persecutee Relief Fund of the Government of Luxembourg to set up a hospice centre in Budapest. The Luxembourg grant – supplemented with the donation from the American Jewish Joint Distribution Committee – greatly improves the quality of life of the terminally ill patients. In addition to the already operating forms of hospice care – palliative units and home care services – we decided to form a hospital supportive mobile team for the patients of the Jewish Charity Hospital.

The mobile team is a preferable and cost-effective solution. Patients get care in their usual environment and the practice does not require setting up a separate ward or unit. At the same time the supportive care – offered by a specially trained staff – can generate positive changes of attitude in the traditional health care system.

Within the Hungarian Jewish community there are high numbers of elderly people, all Holocaust survivors, often ill and living alone. Nearing the end of their lives that have beev afflicted with disasters and humiliation, they would have had to face their deaths all-alone. HJSSF felt obliged to provide the benefits of hospice care parallel to already-existing home nursing and home care programs. The service became reality in January 2001. The HJSSF mobile hospice team was set up in coordination with the Charity Hospital of the Federation of Hungarian Jewish Communities in Hungary.

About the Charity Hospital's hospice program

The patients of the Charity Hospital are mostly elderly people. During the past year, 257 of the hospital’s 1141 patients unfortunately died. The majority of the deceased patients suffered tumour-related illnesses. At the same time, a home care team at HJSSF cared for 100 terminally-ill patients. In early 2001, HJSSF representatives along with hospice experts and the hospital staff drafted a list of objectives for a mobile hospice unit that would benefit both hospital inpatients and home care patients. They are as follows:

Aims of the mobile team

- To provide holistic support and health care to terminally-ill patients, first of all to patients who suffer tumour-diseases, as well as emotional support to the family members through an interdisciplinary team.
- Offer consultation and advice to staff at the hospital and nursing home.
- Mediation in the spirit of hospice with the goal of shaping future medicine.

Requirements of the operation

- Each mobile hospice team member should receive special trainings in the area of hospice/palliative care.
- Team members should meet once a week for discussion on patient cases.
- Setting up a properly equipped office for the unit inside the hospital.
- Provide documentation of each patient's care, accessible in print and computer files.
- Admission of patients happens in consensus with the leadership and the staff of the hospital and the mobile team.

Current members of the team are:

One hospice adviser, head of the service (part-time), one consulting physician (part-time), three nurses (2 full-time, 1 part time), one psychologist (part-time), one physiotherapist (part time), two social workers (part-time), one rabbi, three volunteers.

Members of the hospice team participated in a 40-hour basic training course on hospice, which was organized by the Ministry of Health and by the Hungarian Hospice-Palliative Association. This initial learning phase was followed by another 40 hours of advanced course work and a study tour to the Erzsébet Hospice in the City of Miskolc in eastern Hungary.

The hospice team worked out a patient registration sheet and a nursing care sheet. The doctor requesting hospice care fills out the patient registration sheet and indicates the nature of care expected (psychological, social, spiritual, etc.). Hospice team members must properly mark on the nursing form their activities performed in relation to the patient. Subsequently, admission and care are discussed on weekly team consultations. The consulting doctor has a long experience in the hospital; it is his task to discuss hospice care with the medical staff of the Charity Hospital.

The hospice service began operating in early March of 2001. Until the end of January 2002 it performed care for 98 seriously and terminally ill patients – providing physical, psychological, social and spiritual support to the inmates. Medical and nursing care was rendered to 42 patients on 1257 occasions. Social care was given to 74 patients on 307 occasions. Psychological and mental health care was provided to 47 patients on 245 occasions. Of the 98 hospice patients 35 suffered from a tumour-related disease. During the operation period, 24 of our patients unfortunately died while others left the program and were subsequently cared for by a nursing home or were transferred to another institution. Currently, 18 people are under our care.

In 2001, an estimated 5 million Hungarian Forints (17544 USD) of the hospice program budget was spent on purchasing various equipment for improving the comfort of hospital patients.

TABLE 1: STATISTICS OUTLINING OPERATION OF THE HOSPICE TEAM, MARCH 2001 – JANUARY 2002

1. Nursing activity

to 42 patients at 1257 occasions

Types of care: somatic and mental care

Somatic care: medication to ease pain (as prescribed by hospice doctor), treatment of ulcers, photo treatments by Bioptron lamp, blood pressure checks, monitoring pulse and blood glucose levels. Regular mouth hygiene, nail cutting, massage, callisthenics, bladder control, regular diaper-changing.

Spiritual care: psychological support by listening and helping to cope with bereavement.

2. Social work

to 74 patients on 307 occasions

Social work tasks included: deal with legal issues and restitution claim cases, manage the correspondence and the banking errands; organizing home nursing or home care service; order meals-on-wheels service; contact relatives, mediate services; apply for financial aid; supply items such as a tape recorder and earphones, psychic support; occupational therapy for patients.

3. Psychological and mental health care

to 47 patients at 245 occasions

Tasks performed included: active listening, help the patient reviewing and evaluating his/her life, advisement on current problems, coping with depression, anxiety and paranoia, discussion of spiritual issues, consultations with family members, help with various hobbies such as writing and reading.

4. Community Tasks (participation by all hospice team members):

looking for financial resources; organizing programs to patients; accompanying patients to programs; taking them for walks; training volunteers and inviting various lecturers to give talks.

Experiences

Based upon the experiences of the hospice activity in the Charity Hospital, the team arrived at the following conclusions:

It is hard to draw a dividing line between terminally ill cancer patients and other patients. Whether one'a status is attributed to a tumour-related illness or to depression, immobility or other serious emotional problems, each one needs the same kind of complex care. Our other remark is that highly developed diplomatic skills are necessary to do the implementation of a new team into an already existing hospital system. Competencies will have to be preserved and the new team cannot burst in and "enter unannounced". Empathy and tact are necessary when establishing relationship with hospital staff.

Luckily, the patients and their relatives welcomed our mobile hospice team. Hospital nurses often consulted us on how to treat or handle certain patients. One of our success stories is about a blind and paralysed 83-year-old man, who had been at the hospital for years. Prior to our intervention, this man rarely communicated and was considered out of touch with the environment. Today he sits in a wheelchair and even participates in Tuesday afternoon lecture sessions or other programs. With our help he spends time reading and sitting in the hospital garden. The great improvement happened without any changes in his medication, as a sole effect of the hospice care.

Another valuable service our team offers is listening attentively to the patients. Our night shift often spends hours at the bedside of the dying patients, offering companion to listen to their life stories, to share their sorrow, anxieties and uncertainties, to evaluate their lives.

Above all, our most positive experience has been the exceptional teamwork that emerged between members of our interdisciplinary team – the efforts of all members of the team are equally esteemed and respected.

Our plans in the future

We hope to establish closer ties with the home care team of the HJSSF. Already, our psychologist has been offering assistance to patients and staff. Several home care staff members have also attended a training course on hospice.

Additionally, we continue to organize a variety of programs for hospital patients, including concerts, presentations and video projections. A goal of ours is to eventually open a day care centre for patients and their relatives, which would offer physical and psychological care and employ patients nursed there.

Our mobile hospice unit is fully funded through the end of 2002. For its survival we are highly dependent on funding from those who consider our work and services to be as important as we do. An important effort of our team is to gain the financial support of the Hungary's National Insurance Fund.

Recommendations for policy change[*]

The Hungarian hospice services need regular financial support from the National Health Insurance Fund for all organisational forms of hospice care. We made two surveys to assess the necessary time for patient care where the activity (per patient per day) of the social worker, physiotherapist, psychologist/mental health specialist, chaplain and co-ordinator were studied and proved to be essential. After the calculations, in the hospice inpatient centres the aggregated cost is 8500 HUF per day, which is equal to the daily basic chronic nursing cost modified with a 2.5 multiplier according to the valid financial regulations. Daily costs can be significantly decreased by extending home care services and hospital supportive (mobile) teams. The task is to achieve that the activity done by professionals providing mental, social and spiritual care also get finance.

All medical universities – with government support – should establish a faculty or institution to teach palliative medicine and to research on pain and symptom management. Similarly, it is necessary to develop model departments and services of palliative therapy to provide basis for practical gradual and postgraduate courses. (Fortunately we have adequate pharmaceuticals available.) Government support for public education should recognized and a promotion of change in "public views and attitudes" campaign should developed and implemented.

It would be very important to promote volunteerism with campaigns, to improve the cultural acceptance of volunteerism. Voluntary associations need financial support to provide the structure for the introduction of voluntary helpers in hospitals. They are also essential for the provision of voluntary help at home.

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[*] see: Palliative Care of Terminally Ill Cancer Patients Professional guidelines *2nd improved and extended edition*. Hungarian Hospice-Palliative Association, 2002.