

# **A Situation Analysis of End-of-Life Care in Hungary and Opportunities for Enhancement**

Ph.D. theses

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Death is as much a part of life as birth and therefore deserves equal attention by the society.

## **Introduction**

In Hungary, but also internationally, two thirds of people died at home at the beginning of the 20 century. Today, two thirds of deaths occur in institutions. To care for the dying patient at home and to accompany/support them through death was the norm until the widespread reliance on the hospital/institutional system. The current generation has grown up during this time/period and largely has not experience what is the natural process of family members dying at home. In effect, home deaths with surrounding family has lost its cultural roots. As a result, in today's society we distance ourselves from the dying person, from death in general, even from the concept of our own mortality. The curing of a patient from and illness is considered a success as it should be, but if a patient declines, the disease progresses, and death occurs this is considered a failure despite the fact that everyone eventually dies. This feeling of failure causes frustration for doctors, and in part for this reason, they try to minimize or avoid the encounter and communication with patients having a poor prognosis. Doctors do not have sufficient knowledge of symptom control, and communication skills to be equipped to manage complex end-of-life care situations.

The philosophy of hospice care and palliative care more generally are relatively new in the profession in medicine. The hospice movement started in England in the 1960s by drawing attention to the care deficiencies of terminally ill cancer patients, their inadequate pain relief and the loneliness and other psychosocial aspects of dying.. The hospice was intended to address these problems by focusing on quality end-of-life care and the maintenance of human dignity until the very end of life. In Hungary, some twenty years later, the hospice philosophy started to grow. Thanks to Alaine Polcz and others and as a result of their hard work in pioneering the field, the Hungarian Hospice Foundation was founded in 1991. In the new Health Act of 1997, hospice care was recognized as the best/ most appropriate care for terminally ill patients. Hospice care has been reimbursed in Hungary since 2004 and has started to be integrated into the Hungarian health care system. This has contributed to greater access to hospice care throughout the country, although it remains inadequate.

When introducing any new form of service, it is of great importance to know the real need for that service. It is also important that the service be widely known. The lack

of physicians' knowledge of palliative care services and availability of hospice care poses an important barrier to access hospice care. No survey has been heretofore conducted in Hungary regarding what people (patients waiting for their doctors) want at the end of their lives, what their greatest fears are and their preferred place of death. There is no data in Hungary regarding family physicians' opinions and attitudes toward terminally ill patients care. What do they find difficult or challenging? What is their knowledge of hospice care? The current research project aims to study these questions. Two separate but thematically linked research questionnaires have been developed. The target group of the first of the two studies was patients waiting in the primary care office. The second targeted family physicians providing primary care. The physicians' survey was performed in the U.S. and Hungary on a similar sample of doctors.

## **Objectives**

- Review of the development of international and Hungarian national hospice-and palliative care as an introduction to the present situation of hospice care in Hungary and specifically in Baranya County.
- To understand more clearly patients' attitudes regarding end-of-life care, and regarding death and dying generally.
- To examine of family physicians' attitude regarding the care of terminally ill patients.
- Based on the research results, develop an outline of the needed components and specific steps to improve quality end-of-life care.

### **Pécs-Baranya Hospice Program**

The Pécs-Baranya hospice program was established in 2004 based on international and national experience and with professional support.

Objectives of Pécs-Baranya hospice program:

- To establish and develop hospice care in Baranya County,
- To provide hospice care in the patient's place of residence when appropriate,
- To support care givers and family members of terminally ill patients during the illness and beyond i.e., after the patients death during the period of bereavement,

- To introduce and disseminate the hospice philosophy in the region,
- To collaborate in developing a common approach with professional and civic organizations involved in the care of terminally ill,
- To leverage international knowledge and experience through cooperation with foreign hospice-palliative care organizations,
- To support research on the field of hospice and palliative care.

To date hospice care and support have been provided for more than 550 patients and families at 71 locations in Baranya county. The care of patients and their families is free to them and is delivered by an interdisciplinary team consisting of nurses, physicians, social workers, psychiatrists, chaplains, physiotherapists, dietitians and volunteers. The total number of employees is 29. Along with treating the symptoms open and honest communication is provided in accordance with the patient wishes. This allows patients and families to set realistic goals and preserve the dignity of the patient.

### **The collaboration between the Institute of Family Medicine at Pecs University Medical School and Pécs-Baranya Hospice program.**

The Institute of Family Medicine is one of the founding members of the Pecs Baranya Hospice program. The Institute embraced and supported the work of the hospice program from the beginning, and has pioneering role in the introduction of end-of life care topics in the academic curricula.

End-of-life care and palliative medicine related education programs in the curriculum of the Institute of Family Medicine:

- **"Medical communication skills"**, communicating bad news: theory and practice.
- **"Family Medicine"** the primary care aspects of end-of-life care as well as the introduction of hospice care.
- **"Hospice-Palliative Care"** is an elective subject. Topics discussed in detail: symptom management, psychological support, nursing care, children palliative care, the importance of teamwork and good communication skills.

In the **training of family medicine residents**, pain management and control of other distressing symptoms as well as communication with patient and family at the end-of-life are covered. In the Institute's **CME programs**, hospice and palliative care topics are also represented. In addition, an independent hospice-palliative care training program is accredited to family doctors and other clinical specialists.

# **Attitudes on death and dying: survey of patients visiting the primary care office**

## **Introduction**

The care and support of the terminally ill patients is not well developed in the Hungarian health care system. In caring for terminally ill patients two extreme approaches have emerged. One is "cure at any cost" i.e., focusing on curative therapy until the last day of the patient's life even when it is clear that such treatment will not prevent death from the disease. The other is the "total surrender" i.e., giving up on curative therapy and sending the patient home without any real support. Sometimes as the disease progresses, patients engage hospitals and other institutions, but they often spend the last stage/period of their lives filled with unbearable pain and fears. The health care system tends to fail the terminally ill in that often institutions are not willing to accept the dying patient. Hospice-palliative care offers a solution between overly aggressive ineffective treatment and total surrender approach. Palliative care focuses on patients' symptoms, on maintaining the dignity of patients and on the prevention of suffering. As the disease progresses, honest and open communication is needed to insure that hospice care is introduced at the appropriate time. However, in practice, death and dying are still taboo topics. Consequently, dying patients often do not receive adequate information regarding their real condition and are unable to share their fears and doubts. What are these fears? What do Hungarian people want at the end of their lives? Where do they wish to die? How much and truthful information do they desire? Our research was intended to explore Hungarian patients' attitudes on death and dying, to understand their fears and their need for honest information near the end of their lives.

## **Methods**

A research team composed of physicians, a sociologist, a bioethicist designed the questionnaire. It consisted of 27 questions, developed by the research team based on literature recommendations. The cross-sectional research method was used. Twenty-nine adult family practices were included into the research. The respondents were patients waiting to see their primary care physician. Participation in the survey was voluntary. Staff nurses distributed and collected the questionnaires. The scientific inquiry was done with the approval of the Regional Research Ethics Committee of

Pecs University Medical School. The descriptive and bivariate analyses were conducted using the Statistical Package for the Social Sciences (SPSS) program.

## **Results**

The total of 845 people completed the questionnaire. More than two thirds (68%) of the respondents were women. The mean age was 53 years.

More than half of the respondents indicated that they would like to die in their home, and less than one in five (18%) would choose to die in a hospital. The patient's level of education and their religiosity influenced the responses. The more educated the individual, the more he/she tended to choose his/her home as a place to die, and with less education institutional death is more preferred. Those who considered themselves religious were more likely to choose home as their place of dying as compared to the more non-religious.

Fifty five percent of the respondents most fear losing their autonomy and independence. Fear of pain was expressed by 38%, and only 7% reported their fear of loneliness. Interestingly, older patients tended to be more afraid of losing their autonomy, and less afraid of pain; the older the patient (between 61-70 years), the more concerned about the loss of autonomy (62%) and less afraid of pain (34%). The younger (<30 years) respondents' biggest fear was pain (50%). Education also influences fears during a fatal disease. The more education someone has, the more they fear losing their autonomy more than fearing pain and loneliness.

In case of terminal illness, 69% of the respondents consider it very important to receive care in their own home. A large majority of the respondents (70%) indicated that, among their family and friends, there "would certainly be someone" who would help provide care for them in case of serious illness. One fifth of respondents (20%) reported that there "might be someone" to care for them. These kinds of feelings are influenced by age, health status, and family make-up. Older patients were less likely to believe that someone would be available to care for them. Those who suffered from chronic illness were somewhat less likely to believe that "certainly" or "maybe" there would be someone to help (86%), than those who had no chronic illness (94%). Those living alone were least confident that help would be available in case of serious illness with 27% of this group responding "maybe" or "certainly not" to this question. This skepticism regarding assistance was rarely seen among those who live with spouse or family where only 4% responded similarly.

Visits by family members were considered very important to 84% of the respondents. Overall, respondents expressed their wish for full, honest information. According to 93% of respondents, truth-telling is very important in the event of terminal illness. More educated and younger individuals held openness in communication in higher regard.

## **Discussion**

Our research shows that the majority of the studied Hungarian population would prefer to die at home. Higher percentage of people with more education would prefer to die at home compare to those with less education. This observation may be explained by the fact that those with more education have a greater sense of self-efficacy and better financial circumstances and therefore want more control over their own dying. Religious people would rather die in the intimacy of their own home compared to the more non-religious. Their faith may help them accept the nearness of death, and they wish for privacy and closeness of family members.

Our results suggest that the fears of loss of autonomy or of pain were often ranked as the "greatest fear" in case of a terminal illness. This finding might reflect the existing deficiencies of the health care system regarding terminal care. The large proportion reporting a fear of pain suggests that insufficient pain relief in the health care system is a very serious problem. Despite the fact that our knowledge of pain management is more detailed and prescription of potent opioid analgesics is easier than in the past, still only 50% of severe pain is adequately controlled. Appropriate symptom control not only alleviates current suffering, but future physical and non-physical symptoms can be minimized.

More than two thirds of the respondents even in case of a terminal condition would prefer to receive the proper care at home. To make this possible, it is essential to further develop home care services for the terminally ill patients.

The trend was clear that increasing age and the narrowing of the social network of contacts affects the feeling of care "security". It is understandable that increasing proportion of older age groups believed that there would probably or definitely not be someone available to care for them. The presence of family and the household composition are also major influencing factors in the belief that there would be someone to care in a case of serious illness. Not surprisingly, the biggest uncertainty in this regard was among those living alone. This draws attention to the fact that home

care of people living alone is even more complex in that more assistance is needed in order to remain at home in the face of serious illness. It is worth noting that care "security" of people living with severe disease was less compared to the healthy individuals. It is possible that patients living with severe disease have personal experience, and they have observed that the supposed "care givers" in practice don't provide help to the extent that they expected. Respondents ranked family visits as being of great importance in case of serious illness. In practice, when the patient's condition deteriorates, they often reach a point when they no longer wish to receive visitors, but for earlier periods visit of friends and family is very important. These visits can reduce the isolation and anxiety of the patient.

The question of truthful information in terminal care was ranked by both the patient and the care providers as being of utmost importance. The research participants in our study resembled those in other international surveys in stating a desire to receive truthful information even in case of fatal disease. However, Hungarian doctors still in many cases avoid providing truthful information, especially when it comes to informing terminally ill patients of their true prognosis. Among the younger generation, receiving truthful information is considered more important compared to older people. This result confirms the experience that patients' expectations of medical information has changed with younger people wanting full details of their condition most times. For the higher educated respondents, truthful information is more important, which may reflect that higher educated people tend to expect to be treated as a partner in their treatment by taking a more active role in their own care process. Physicians confidence in the communication of end-of-life issues can improve if communication skills training becomes an integral part of their education programs.

Our data support the need for improvement in three primary areas, physician communication skills, pain and symptom management, and expansion of home hospice care. Graduate and postgraduate medical education need to address the first two, whereas expansion of home hospice care must come through changes in the health care system.

# **Care of terminally ill patients at home. Comparative study of American and Hungarian family physicians' attitudes**

## **Introduction**

During the past decade, family physicians care for an increasing number of dying patients in their homes in Hungary. Due to a reduction of hospital beds and increasing demand for these beds, patients are increasingly sent home in the final stages of life. Hospice care provides help and support not only to the patient and family, but also family physicians may get additional help in the care of their terminally ill patients. In order for the patients and their families to understand the benefits of these services is vital to have a picture of knowledge and attitudes of their referring physicians. Although, in many instances, anyone can refer a patient to hospice, the role of primary care physicians as gatekeepers is well understood. In the case of clear progression of the disease, they often refer the patient to hospice care. How physicians perceive this role, how openly they can communicate disease progression and offer to patients the hospice care can greatly influence hospice utilization. In those countries where hospice care is available, but physicians knowledge is inadequate about hospice care, patients referral to hospice is more uncertain. Our research aim was to assess and compare knowledge and perceptions of end-of-life care held by primary care physicians practicing in selected regions of the United States and Hungary.

## **Methods**

A 29-item survey tool was designed based on our research questions and on the review of the literature. The questionnaire was written in English and translated into Hungarian by native Hungarian members of the research team. The cross-sectional research method was used. The questionnaire was sent by post, to all primary care physicians in Baranya County (339). In the United States, the questionnaire was sent to all primary care physicians (300), affiliated with Summa Health System in Summit County, Ohio. The survey was reviewed and approved by University of Pecs's Regional Ethics Committee and Summa Health System's Medical Review Committee before mailing. The response rates were 54% in Hungary (n=182) and 48% in the United States (n=145). Frequencies and percentages were calculated to compare results from the two samples. All study data were analyzed using SPSS.

## Results

Fifty-eight percent of U.S. physicians stated that they were quite knowledgeable about hospice care compared with only 9% of Hungarian physicians. More Hungarian physicians (74%) than U.S. physicians (57%) indicated that they probably or definitely would participate in educational offerings to learn more about hospice care. In the United States, 71% of physicians rated services for terminally ill patients as exceptionally good versus 1% of Hungarian physicians.

Only 0.7% of U.S. physicians compared to 9% of Hungarian physicians stated that the most appropriate care for terminally ill patients is the continuous curative care until death. The U. S. physicians believed in much higher percentages (71% versus 59%) that palliative care is the most appropriate care for terminally ill patients. Eighty-five percent of Hungarian physicians and 93% of U.S. physicians agreed with the following statement: “The well-being of terminally ill patients is best served by sharing the management of their care with other health care professionals.” Physicians’ beliefs about the ability of terminally ill patients to maintain dignity until death also differed between countries (Hungary 41%, U.S. 60%).

Hungarian and U.S. physicians varied in their level of agreement that discussion of a terminal prognosis with patients leads to hopelessness. Only 7% of the U.S. physicians felt that this was often or usually true compared with 55% of Hungarian physicians. Conversely, 52% of U.S. physicians and 13% of Hungarian physicians believed that this was seldom true.

Forty-eight percent of Hungarian physicians believed that the patient’s right to know is balanced by the physician’s judgment of whether it is in the patient’s best interest to know. An additional 40% reported that they disclose only if asked. In contrast, 77% of U.S. physicians reported that they always tell patients when the prognosis is terminal.

## **Discussion**

Access to home-based care for terminally ill patients is greatly influenced by the physician's knowledge, skills, and attitudes as well as the systems in place to support the provision of such care. At the time the survey was administered in Hungary, home hospice services were only recently available, for this reason it is not surprising that most of the Hungarian physicians reported that services for terminally ill patients are inadequate.

The majority of the Hungarian physicians claim to have only basic knowledge of hospice care in contrast to most U.S. physicians who reported being quite knowledgeable. Yet, among both physician groups, there is a high level of interest in participating in continuing medical education to learn more about hospice care.

Physicians beliefs varied in the two countries regarding whether patients are able to maintain their dignity until death. Clearly, Hungarian physicians are at disadvantage, as providing care that assures patients' dignity until death can be a challenge even if the full spectrum of hospice services are available. Hungarian physicians in much higher number supported the continuous-curative-treatment-until-death approach compared to U.S. physicians. This may simply be a reflection of the common current Hungarian practice of aggressive curative treatment until the last days of life. U.S. physicians display greater acceptance of the combination of curative and palliative approaches, and this too may reflect the growing integration of palliative care into U.S. hospitals and health systems.

The interdisciplinary approach is widely accepted in both countries but a higher percentage of U.S. physicians agreed with the practice of shared management of terminally ill patients. Although Hungarian physicians reported acceptance of interdisciplinary care for terminally ill patients, in practice, interdisciplinary teams are rare in the Hungarian health care system.

More than half of the Hungarian physicians believed that discussing a terminal prognosis causes patients to feel hopeless, whereas most U.S. physicians respondents felt that this is seldom true. This finding reinforces the need for increased emphasis in medical communication, particularly in maintaining and helping to redefine hope while effectively disclosing a terminal diagnosis. Medical communication courses have been introduced into the Hungarian medical curricula to instruct students in conveying bad news and providing support as death approaches. More practical training would be helpful.

U.S physicians seem to be more comfortable disclosing a terminal diagnosis to patients, compared with Hungarian physicians, who report using their own judgment regarding such disclosure or disclosing a terminal diagnosis only if asked. This may reflect the fact that many Hungarian physicians are poorly trained and are not adequately equipped with the skills to discuss prognosis and end-of-life issues.

These results elucidate some of the striking cross-country differences and commonalities in physicians beliefs about the care of terminally ill patients. Many of the divergent responses may be viewed as a snapshot of each country's evolving approach to end-of-life care. Such picture, although fixed in time and limited by geography, may help physicians, educators, and administrators to pause and reflect on these findings and plan for the future in both educational and clinical arenas. Regardless of the historical duration of hospice services, having appropriately trained health care professionals brings countries closer to the ultimate goal of assuring increased access to hospice care as a means of providing relief of suffering for dying patients and their families.

## **The new results of the PhD thesis**

The following conclusions are suggested by our data:

1. Patients, even when terminally ill, wish to stay and receive care at home and most of them want to die at home. Physicians believe that the most appropriate place for terminally ill patients to die is the patient's home.
2. The patients' greatest fears at the end of life are the loss of autonomy and fear of pain.
3. Physicians believe that the current standard of care of terminally ill patients is unacceptable. They have only a basic knowledge of hospice care.
4. Physicians believe that palliative care and the multidisciplinary team approach is the most appropriate form of care for terminally ill patients.
5. Patients wish to receive truthful/honest information even in the case of a serious, life threatening illness.
6. The majority of Hungarian physicians' provides information based on his own judgment or only at the request of the patient. In their view, discussing prognosis of the disease results a feeling of hopelessness on the part of their patients.

## **Opportunities for enhancement of end-of-life care in Hungary**

To ensure that the expressed desires of patients regarding end-of-life care are realized and to address the identified knowledge and skill gaps of physicians, the following steps are needed:

### **Palliative care should be part of the National Public Health Program**

WHO pioneered a Public Health Strategy for integrating palliative care into a country's health system. It includes advice and guidelines to governments on priorities and how to implement both National Palliative Care Programs and National Cancer Control Programs into the National Public Health Program. Based on the present research results, two suggested area of the WHO strategy are discussed in more detail.

### **Development of hospice-palliative care infrastructure**

The hospice-palliative care should be introduced at all levels of health care and social services. In addition to governmental support, collaborations among professional and civic organizations are needed. In particular, the following are recommended:

1. Extension and further development of existing forms of services (home hospice, inpatient hospice) based on the WHO recommendation and National Cancer Control Program.
2. Extension of hospice-palliative care services:
  - a. Development of palliative care units within the departments of university hospitals;
  - b. Palliative care consultative teams in hospitals;
  - c. Development of palliative care out-patient clinics within the network of out-patient clinics;
  - d. Development of hospice- palliative day-care services;
  - e. Introduction of hospice-palliative care into social institutions (e.g., nursing homes).

### **Training of physicians**

The priority in palliative care training is to educate physicians not only in symptom control but also in communication skills. It is recommended that palliative care programs/departments be established at the medical schools in Hungary. These university programs/departments could introduce palliative care teaching into all levels of medical curricula.

### ***Undergraduate medical education***

- Introduce palliative medicine courses in all medical schools as a compulsory subject, to acquire a basic knowledge and skills of palliative care.
- Introduce elective courses to students wishing to acquire more comprehensive knowledge in providing palliative care.

### ***Vocational/postgraduate training***

- In all residency programs should include the different aspects of hospice-palliative care, in accordance with the specialty needs.
- In all final residency exams hospice-palliative care topics should be included.
- To ensure quality palliative care, palliative medicine should be recognized. Palliative medicine as a subspecialty should be introduced. This has been achieved in many European countries.

### ***Continuous medical education (CME)***

- In CME courses the clinically relevant aspects of palliative medicine in accordance with the clinical disciplines should be introduced.

These steps would help to improve significantly the care of terminally ill patients in Hungary. The integration of palliative care services in all level of care would reduce suffering and ensure better quality of life at the end-of-life. As final conclusion we could say that the change of attitudes towards end-of-life care has started, but it is still a very long way to go. Extensive collaboration and more committed work needed to make real progress and integration of the field. Through the implementation of comprehensive educational programs attitudes could be changed and knowledge could be improved. Extensive research programs are needed on the field of end-of-life care, for example: to examine the current forms of care and its appropriateness to determine the development of future services.

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