

Global Initiatives in End-of-Life Care: A Project Description in Hungary¹

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“Modern hospice”, the specialized care of terminally ill patients, began in the 1960’s in Britain and has proliferated throughout many areas around the globe ever since. Although the philosophy of care is nearly universal, variations in program development exist and are related to several factors including cultural, epidemiological, political, and resource issues. This paper will illustrate the recent development of end-of-life care in post-communist Hungary and will address the challenges associated with its implementation in a dynamic and changing environment. The paper describes the stages of a project in Pécs to assist in the development of hospice care and concludes with reflections on the experience and recommendations regarding the future of end-of-life care in Hungary.

¹ This paper is dedicated to my dear friend and professional colleague, Dr. Agnes Csikos, as a tribute to her commitment to hospice care in Hungary.

Introduction

A forty-five year old woman sits quietly in her home. She is angry, frightened, and is concerned about being a burden to her family. She is tearful and wonders what will become of her children. Both are young adults, yet she will never have the opportunity to see them marry nor have children. In spite of the many advances in healthcare, her illness is one that cannot be cured. She is now faced with decisions she never dreamed would become a reality.

If she is fortunate enough to live in a region of the world where hospice care is available, these difficult and challenging issues can be addressed with the help of a hospice team. With assistance, she has the chance to live her last days with dignity and will have the ability to spend her remaining time with her symptoms managed, assistance carrying out her final wishes, and guidance regarding spiritual issues; all within the comfort and security of her own home. Additionally, her family will receive the benefit of bereavement support and counseling after her death.

This paper addresses issues regarding the global need for the development of hospice services and specifically describes a related project in southwestern Hungary. The paper begins with a description of the global trends impacting the current and future need for hospice, and clearly defines and differentiates hospice and palliative care. A brief background describing Hungary, its political past, and the status of healthcare and hospice set the stage as an introduction to the

project. The proposed and revised project plan is outlined and two field visits are described. A relevant research survey of Hungarian Family Physicians is detailed and the development of an elective course in end-of-life care is provided. The paper concludes with reflections on the experience and recommendations regarding the future of hospice in Hungary.

The Global Challenge

The number of deaths globally each year is currently 56 million. Of those, estimates are that over 33 million people would benefit from some form of specialized end-of-life care. Given that the death of one person conservatively affects one to two others, it can be further estimated that approximately 100 million people would benefit from end-of-life care services.²

There are numerous factors related to the epidemiology of death and dying, now and in the future, that have global significance. These factors include: the aging of the world population, the global cancer burden, and the continuing devastation from Autoimmune Deficiency Syndrome (AIDS).³ These factors are broadly based and clear differences exist between the developed and developing world.

The number of elderly is increasing in

2 J. Stjernswärd and D. Clark, "Palliative medicine – a global perspective", in *Oxford Textbook of Palliative Medicine*, (3rd edition), Derek Doyle, Geoffrey Hanks, Nathan I. Cherney, and Sir Kenneth Calman, editors (Oxford: Oxford University Press, 2004), p. 1199-1202.

3 Ibid, p. 1200-1202.

the developed world and accelerating in the developing world; awareness of how we care for this population is gaining increased attention. As the birth rate falls in the developed world, and mortality rates improve in the developing world, social and economic changes will be essential.⁴ It is estimated there will be over one billion people worldwide over the age of 60 by 2025. As the population ages, the burden of chronic disease is also expected to increase. Presently, there are 600 million people worldwide aged 60 and over. This figure is expected to double by 2025 and reach 2 billion by 2050, the largest majority of those in the developing world.⁵

Due to advances in healthcare, particularly in public health, the common diseases of the twenty-first century will be non-communicable diseases such as cancer, cardiovascular disease, and diabetes. The number of new cancer cases is expected to increase in the developed world; however the impact will be most dramatic in the developing world where the cancer burden is expected to increase from 5.4 million new cases in 2000, to 17 million in 2050. Unlike the developed world, the majority of cancer cases in

developing countries are diagnosed late in the course of illness when curative therapy is less likely to be of benefit.⁶

In addition to the aging of the world population and the estimated increase of cancers and other non-communicable diseases, the incidence and impact of AIDS continues to be significant. Sub-Saharan Africa currently carries the majority global burden of AIDS with a prevalence rate of 7.5 to 8.5 percent of adults currently living with the disease.⁷ Highly populated countries such as India and China now acknowledge the disease and the future extent and impact of the epidemic in these countries is yet to be realized.

Defining Palliative Care and Hospice

The need for specialized care of those with advanced illness and the terminally ill is quite clear. In some parts of the world, the current models of care will be inadequate to provide care for the growing numbers needing expert care at the end-of-life. Models of care in various stages of development worldwide include both palliative care and hospice programs. These programs are frequently viewed as

4 The Associated Press, "World's Population is Aging Rapidly", in *New York Times*, February 16, 2005. Accessed from the web at: <http://www.nytimes.com/aponline/national/AP-UN-World-Population.html> on February 22, 2005.

5 World Health Organization, Press Release, "World Health Organization launches new initiative to address the health needs of a rapidly ageing population". Accessed from the web at: <http://www.who.int/mediacentre/news/releases/2004/pr60/en/html> on September 8, 2004.

6 D.M. Parkin, F.I. Bray, and S.S. Devesa, "Cancer Burden in the Year 2000 – The Global Picture", in *European Journal of Cancer*, 2001, 37, p. 4-66.

7 UNESCO and World Health Organization, "AIDS Epidemic Update – December 2003". Accessed from the web at: http://www.who.int/hiv/pub/epidemiology/en/epiupdate2003_1_en.pdf on March 23, 2005.

the “gold standard” and continue to gain acceptance around the globe, yet there are many regions and individuals who remain underserved.

Comparable in philosophy, hospice and palliative care are specifically designed to meet the needs of both patients with advanced illness and their families. Whereas hospice is generally regarded as a system of care for those with a terminal illness, palliative care extends the principles of hospice care to a broader population earlier in the course of illness. Recently, the WHO broadened its definition of palliative care to be more inclusive of the many needs of patients and their families.⁸

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual. Palliative care provides relief from pain and other distressing symptoms; affirms life and regards dying as a normal process; intends neither to hasten or postpone death; integrates the psychological and spiritual aspects of patient care; offers a support system to help patients live as actively as possible until death; offers a support system to help the family cope during the patient's

illness and in their own bereavement; uses a team approach to address the needs of patients and their families, including bereavement counseling if indicated; will enhance quality of life, and may also positively influence the course of illness; is applicable early in the course of illness in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.⁹

According to the National Hospice and Palliative Care Association (U.S.A.), “hospice” (from the same linguistic root as “hospitality”) can be traced to medieval times when the term referred to a place of shelter and rest for weary or ill travelers on a long journey. The name was first applied to specialized care for dying patients in 1967 by physician Dame Cicely Saunders, who founded the first modern hospice, St. Christopher's Hospice, in a suburb of London.¹⁰ “Hospice care focuses on caring, not curing; in most cases, care is provided in the patient's home”.¹¹ Similar to palliative care, a team-oriented approach to medical care, pain management, and emotional and spiritual support are characteristics of

9 World Health Organization, “WHO Definition of Palliative Care”. Accessed from the web at: <http://www.who.int/cancer/palliative/definition/en/> on March 23, 2005.

10 National Hospice and Palliative Care Organization, “What is Hospice and Palliative Care”. Accessed from the web at <http://www.nhpco.org/14a/pages/index.cfm?pageid=3281> on March 23, 2005.

11 Ibid.

8 C. Sepúlveda, A. Marlin, T. Yoshida, and A. Ulrich, “Palliative Care: The World Health Organization's Global Perspective”, in *Journal of Pain and Symptom Management*, August 2002, 24, p. 92.

hospice programs. Frequently, the terms are used interchangeably, and there is terminological confusion, even among health care professionals. Again, the significant difference being that hospice is specifically for those with a terminal illness, while palliative care extends these principles to a broader population – most often those with advanced illness.

Hungary

Background

The Republic of Hungary, located in Central Eastern Europe, has a population of approximately 10 million people. Nearly 90% are ethnic Hungarian with the largest minority population being Roma (4%), and the remainder identified as ethnic German, Serb, Slovak, and Romanian. The median age (2002) is 38.4 years with a population growth rate of -0.29% (2003). The country is 93,030 square kilometers making it slightly smaller than the U.S. state of Indiana.¹²

Hungary has had a rich and interesting political past. After a political uprising in 1956, the country was ruled by Janos Kadar, who in the 1960's introduced a more liberal communism that was later dubbed “Goulash Communism”. Hungary was the first Central Eastern European country under communist rule to allow limited decentralization of the economy and adopt aspects of a free market economy. After the collapse of

communism in 1989, these efforts helped to smooth the economic transition for the country. In 1999, Hungary was admitted to NATO, and in May 2004 joined the European Union (EU).¹³

Health Care

The current healthcare system functions as a centralized, compulsory, national health insurance system providing nearly universal coverage for the citizens of Hungary. The country had an integrated form of healthcare prior to the political transition that occurred in 1989, however, many changes have taken place since that time. Notably, funding that came from general state revenues to funding that is now mainly social insurance; entitlement of care that was universal to care that is now contribution based¹⁴ (but nearly universal¹⁵); as well as many other financing related changes. Following the reform, responsibility for the healthcare system is now shared between the Ministry of Health, the Health Insurance Fund, the Ministry of Finance, and local governments. Despite many efforts to enhance the “gate-keeper” and preventive

13 BBC News, “Country Profile: Hungary”. Accessed from the web at: http://news.bbc.co.uk/1/hi/europe/country_profiles/1049641.stm on March 24, 2005.

14 Certain populations are exempt from paying a contribution such as pensioners (retirees) and the unemployed (refer to footnote 15 for source information , p. 87).

15 Coverage is nearly universal. According to a 1999 “Healthcare Systems in Transition” (HiT) report, about 1% of the population is not covered. These individuals typically work in the “unofficial market” and are not registered with the Health Insurance Fund. *The European Observatory on Health Care Systems*, 1999.

12 Central Intelligence Agency, “The World Factbook”. Accessed from the web at: <http://www.cia.gov/cia/publications/factbook/print/hu.html> on September 23, 2003.

role of primary care, healthcare in Hungary is still largely hospital-based. It is reported there are excess capacities in acute hospital care with admissions to acute care hospitals among the highest in Europe.¹⁶

Hungary has the highest number of medical specialists (2.7 per 1,000 population) among all countries of the OECD¹⁷, where the average value is 1.2. The country also has the lowest number of nurses (4.9 per 1,000 population) when compared to other OECD countries where the average is 7.7. Compared to other OECD countries, Hungary has fewer hospitals but at the same time has one of the highest numbers of hospital beds. These factors clearly lead to an inefficient use of resources.¹⁸

There are other unique challenges for Hungary related to its healthcare system including issues such as low salaries for medical personnel, and the impact of the “informal payment system”.¹⁹ While the former has been given as at least

one reason for the latter, these issues significantly influence the ethical practice of healthcare in Hungary.

Epidemiological Factors

The need to improve access for the care of those with advanced and terminal illness is apparent based on selected epidemiological findings. Life expectancy in Hungary is low; life expectancy at birth for males is 68.4 years and 76.8 years for females.²⁰ Rates of cancer are also high. In 1999, there were 143,210 recorded deaths; of those, 24.4% (34,255) were attributed to cancer (the second highest cause of death following cardiovascular diseases), making the cancer death rate in Hungary the highest among all countries in Central Eastern Europe.²¹

Historical Development of Hospice

Prior to the fall of communism in 1989, issues relating to death and dying were considered taboo. After the political transition, along with social and other changes, the concept of specialized care for those with terminal illness began to develop. Two groups, the National Association of Cancer Patients and a group of healthcare professionals that focused on psychosocial care (both based at the National Institute of Oncology

in Budapest), cooperated to investigate more holistic ways of working with patients. From this collaboration, the first Hungarian hospice, known as the Hungarian Hospice Foundation, was envisioned.²²

On April 29, 1991, the Hungarian Hospice Foundation was formally created and the organization made education its first priority. Then and now, education has been the core work of the foundation in developing hospice and palliative care in Hungary. Numerous courses are offered each year for physicians, nurses, social workers, volunteers, and others. At present, there are courses for postgraduate palliative care education for nurses and physicians that are accredited by the Ministry of Health and offered throughout the year.²³

In 1995, the Hungarian Hospice – Palliative Association was established. The association is instrumental in the dissemination of material related to hospice and palliative care, is heavily involved in professional education, distributes a monthly e-mail newsletter, organizes meetings and conferences, promotes research, and has twice published national guidelines (2000 and 2002).²⁴

In spite of these enormously productive efforts, there have been great challenges in the development of hospice and palliative care in Hungary.

The countries of Central and Eastern Europe and of the Former Soviet Union continue to go through major social, economic, and cultural transformations. They are among the poorest nations in the European region. They face many challenges in their systems of health and social care and in the development of appropriate and more client-centered services. Against this backdrop of enormous structural change, hospice and palliative care activists in many countries have been working to realize their goals.²⁵

Regardless of these challenges many positive changes began to occur in 2004. Early in the year, The Ministry of Health invited specialists from the Hungarian Hospice – Palliative Association to develop minimum standards of care. The standards were accepted and a ministerial decree was published in March 2004. In April, the Hungarian Hospice Foundation organized a Palliative Care Policy Development Conference to establish a national strategic plan for Palliative Care. As a result, participants agreed on recommendations regarding policy development, education, and service provision.²⁶

One of the most significant goals for the development of hospice care in Hungary was realized on September 1,

16 R. Gál, Z. Mogyorósy, Á. Szende, and P. Szívós, “Study on the Social Protection Systems in the 13 Applicant Countries: Hungary Country Study” (Study financed by the European Commission – Employment and Social Affairs DG). January 2003. Accessed on the web at: http://www.europa.eu.int/comm/employment_social/publications/index_en.html on September 19, 2005.

17 OECD refers to the Organization for Economic Cooperation and Development. Countries include: Austria, Belgium, Canada, Denmark, Finland, France, Germany, Holland, Italy, Japan, Norway, Sweden, United Kingdom, and the United States. Source: OECD International Sectoral Data Base. Updated: February 2002.

18 Ibid, p. 86 and 90.

19 The “informal payment system” refers to the practice of tipping physicians for services and is a highly controversial practice that raises serious ethical issues.

20 World Health Organization, Country Profiles: Hungary (2002 figures). Accessed from the web at: <http://www.who.int/country/hun/en/> on March 26, 2005.

21 D. Clark and M. Wright, “Palliative Care Developments Across the Region: Hungary” in *Transitions in End of Life Care*. (Buckingham: Open University Press, 2003) p. 60.

22 Ibid, p. 60.

23 Ibid, p. 61-62.

24 “Hungarian Hospice – Palliative Association” web-site. Accessed on the web at: <http://www.hospice.hu/english/index/en.html> on March 26, 2005.

25 D. Clark and M. Wright, “Message from the International Observatory on End of Life Care” in *CEE and FSU Palliative Care Monthly Newsletter*, Volume 1, Number 1, February 2005.

26 Katalin Hegedűs, President, Hungarian Hospice – Palliative Association. Information presented at the National Hospice Meeting, April 26, 2004, in Budapest, Hungary.

2004, when a two-year model program was initiated under which the National Health Insurance Fund began financially supporting providers of hospice care.²⁷ This milestone set the stage for the further development of hospice care across the country. As a result, hospice programs in Hungary grew in both number and size.

A service assessment in early 2005 revealed there are currently 11 hospice inpatient units with 143 beds, 29 hospice home care teams, two hospice day care centers, four hospital supportive mobile teams, and hospice services in six nursing homes which have a combined total of 46 beds. In total, there are currently 52 organizations in Hungary providing hospice care and 189 inpatient hospice beds.²⁸

Fulbright Project

Original Project Plan

The initial project proposal focused on education. During the first semester of the grant, the primary objective was to study Hungary's healthcare system with the general goal of learning how the history, culture, and financing of the system affect delivery of care. Once this step was completed, the focus was then to specifically study the care of terminally ill patients.

27 "Hospice Care for Cancer Patients and their Families – A Major Step in State Contribution". From www.hospicehaz.hu (dated April 2004). Accessed on October 12, 2004.

28 Katalin Hegedüs, President, Hungarian Hospice – Palliative Association. Information presented at the National Hospice Meeting, April 26, 2004, in Budapest, Hungary.

The second objective was to use the information learned, as well as past experience and knowledge, to develop an elective course in end-of-life care at the University of Pécs Medical School. During the second semester of the grant, the course was to be implemented and continuing education opportunities for existing healthcare professionals throughout greater Pécs were to be offered.

Revised Plan and Project

The affiliation for the grant was the University of Pécs²⁹, Institute of Family Medicine. At the Institute, I was fortunate to have two advisors, Dr. Lajos Nagy and Dr. Agnes Csikos, who were most helpful in providing information and guidance throughout the project.

During the first semester it became clear that minor modifications would be necessary. There were needs at the University both advisors believed I could assist with, and the plan was revised. Though nothing changed during the first semester relative to the original plan, supplemental duties and responsibilities were requested and all were relevant to the project.

During this time, I was asked to provide lectures for the Medical Communications class for first year medical students. As I researched the healthcare system utilizing on-line research and personal interviews,

29 The University of Pécs was founded in 1367, has 9 Faculties (Colleges), and just over 35,000 students (as of October 2004). Information from: University of Pécs, Informational Brochure. Published 2005.

I was able to prepare and deliver the lectures. In addition, I facilitated a bi-weekly medical communication "practice lab" with a group of 20 students.

Other related duties involved speaking at the University of Pécs, Health Sciences College regarding general end-of-life care subjects for a variety of undergraduate and graduate nursing courses, as well as providing a community lecture at the American Corner³⁰ in Pécs titled, "Hospice and Palliative Care in the United States" for interested students as well as practicing healthcare professionals.

Throughout the first semester, I continued my study of the Hungarian healthcare system as well hospice in Hungary. In doing so, I had an opportunity to meet with national hospice leaders and visited two programs – one in Budapest, and one in Miskolc. Both visits included personal interviews with various staff and tours of inpatient facilities. A description of the site visits and relevant findings is described below.

Hospice in Budapest

The Hungarian Hospice Foundation³¹ is located in Budapest's third District. Since

30 The American Corner is a U.S. Department of State sponsored program. There are approximately 100 American Corners in 30 countries and their purpose is to serve as regional centers for information and programs regarding American culture, history, current events and government. The American Corner in Pécs is the first in Hungary and was opened in June 2004. Information accessed on-line at <http://www.usembassy.hu/amcorner.htm> on April 9, 2005.

31 The Hungarian Hospice Foundation was established in 1991. Its origin is credited to Elaine Polcz, a key figure in the development of hospice in Hungary and Honorary President of the Hungarian Hospice – Palliative Association.

its inception, the program has provided home-based hospice care for thousands of terminally ill patients and their families. The Foundation cares for patients within a 30 kilometer radius of their facility which includes 11 of the city's 23 districts.

In 2002, a "multi-phase" program was implemented to enhance support for patients and their families under a broader umbrella. The program assists those who are terminally ill, families who are in need of bereavement support, as well as those who are in need of rehabilitation. There are a variety of programs operated by the Foundation and include a telephone service called LifeLine, a Pain Clinic, and a Day Care Centre. These programs are available for all cancer patients and their families and are not restricted exclusively for those in the terminal phase of illness.

The first wing of the Budapest Hospice House was opened in 2002. All phases of the Foundations operations are located in the building, which continues to be under renovation. The inpatient unit of the facility, located in the second wing, is scheduled to open June 1, 2005 and will have 10 inpatient beds.³²

Hospice in Miskolc

A well-established and widely respected hospice program in Hungary is Erzsébet Hospice, located in Miskolc, a city in northeastern Hungary. The home hospice division of the program began in 1994 and the inpatient unit, located at Semmelweis

32 Personal interview with Barbara Kalló, Social Assistant, during site-visit to the Hungarian Hospice Foundation, Budapest Hungary, on October 18, 2004. Also "Hungarian Hospice Foundation" web-site: www.hospicehaz.hu/eng/rolunk-bphaz.html accessed April 9, 2005.

Hospital, started in 1995. Prior to reimbursement from the National Health Insurance Fund in September 2004, the program was supported by private donations and given financial assistance from the Soros Foundation.³³

In the Erzsébet Hospice inpatient facility, between 96 – 98% of patients cared for are cancer patients. Other diagnoses include those with neurological disease as well as terminally ill patients with other diagnoses who require pain control. The facility has 11 rooms and all are semi-private with the exception of one, providing a total capacity of 21 patient beds. Bed occupancy is high and in 2003 was 97.2%. The average length of stay in the facility for the same year was 19.7 days. The waiting time for an inpatient bed ranges from 1 – 10 days and the decision to admit is dependent on the severity of the patient's symptoms; the decision is solely that of the Medical Director.³⁴

Staff at the facility consists of two physicians, the full-time Medical Director and another part-time physician who works 24 hours per week. There are a total of 15 registered nurses, a part-time physiotherapist (10 hours per week), a part-time minister (20 hours per week), a full-time administrator and a full-time auxiliary staff member (nursing assistant). A social worker and dietitian who work at Semmelweis Hospital see patients on

33 Personal interview with Dr. Csaba Simko, Medical Director, and site visit to Erzsébet Hospice, Miskolc, Hungary on November 8 and 9, 2004.

34 Ibid.

an as needed basis. In addition, there are approximately 20 active volunteers who assist regularly in the care of patients.³⁵

In 2003, the home hospice program served 180 patients who had an average length of stay of 32 days. According to Dr. Simko, due to the size of the area (the program covers an area in greater Miskolc that has approximately 250,000 inhabitants) and the increased need for home hospice care, they had recently hired an additional physician to assist with the increased demand for visits and to further the development of the home hospice program.³⁶

Hospice in Pécs

Hospice care in Pécs was first provided by Social Net, an organization that previously provided home-based nursing care for non-terminally ill patients. A new inpatient facility was also opened and began taking its first patients in late summer 2004. However, providing hospice care was new for both programs. The program I was affiliated with through the University of Pécs, Institute of Family Medicine – The Pécs-Baranya Hospice Foundation, had just started to accept its first patients in August 2004.

It became clear at the outset of the project that additional information was needed related to the understanding of, and future utilization of hospice services in Pécs. Under the advice and direction of Dr. Lajos Nagy, Professor and Director of the Institute of Family Medicine, the

35 Ibid.

36 Ibid.

decision was made to formulate a plan for a research project regarding hospice care. After much deliberation, the decision was made to assess the knowledge, attitudes, and perceived barriers of local Family Physicians relative to hospice care. The research team included Dr. Agnes Csikos, Eric Browne, PhD, and myself.³⁷

Research Survey

A voluntary, self-administered survey was mailed to all practicing Family Physicians (339 total) in Baranya County.³⁸ The 29-item survey was used as a means to gather information and insight into local Family Physicians' knowledge, attitudes, and perceived barriers related to hospice care. A letter accompanied the survey explaining its purpose and further explained that all individual results would remain confidential and only aggregate results would be reported. The survey was reviewed and approved by the Institutional Research Review Committee of the University of Pécs prior to mailing.

The goal of the survey was to identify perceptions of the Family Physicians

37 Dr. Csikos is Medical Director for the Pécs Baranya Hospice Foundation. Dr. Eric Browne is a fellow Fulbright recipient, and served as the John Marshall Chair for Distinguished Lecturing in Political Science at the University of Pécs during the 2004/2005 academic year.

38 Located in south/southwestern Hungary, Baranya County is bordered by the Danube in the east and Croatia in the south. 400,000 residents occupy the county which has a territory of 4,430 square kilometers. The county seat is Pécs, one of Hungary's oldest cities, which has a population of approximately 160,000 residents. Accessed from the web at: <http://www.answers.com/topic/baranya> on April 8, 2005.

regarding the care of terminally ill patients and hospice. Given that hospice care was new to Baranya County, this information was critically important to determine what was known and perceived so that hospice care could be appropriately utilized. In addition, hospice-related Continuing Medical Education (CME) for Baranya County Family Physicians could be established and would be customized to focus on the areas where further development was identified. The return rate of the survey was 53.7% (n = 182).

Of the respondents, 65% were female and 35% male. Respondent ages ranged from 25 – 34 years of age (10%), 35 – 44 years of age (16%), 45 – 54 years of age (37%), 55 – 64 years of age (30%), and those over 64 (7%). Responding physicians practiced in a variety of locations throughout Baranya County ranging from urban to rural settings. Many physicians practiced in an area with a population greater than 50,000 inhabitants (41%), those who practiced in a setting with 2,000 – 50,000 were 34% of the sample, and 25% practiced in an area with a population of less than 2,000 inhabitants.

In assessing the knowledge of Family Physicians regarding hospice care, the question, "Which of the following choices best describes hospice care?", a large majority (86%) of respondents, reported correctly that hospice was "team-based care for terminally ill patients and their families".

A related knowledge question asked, "How familiar are you with hospice as a type of care?" Responses are shown in

Table 1. The majority of physicians claim only a basic knowledge about hospice care, while a total of 30% claim to be either quite knowledgeable or have more than a basic knowledge. Two questions were asked to specifically identify if Family Physicians were aware

TABLE 1.

Question	Quite Knowledge-able		More Than a Basic Knowledge		Only a Basic Knowledge		Only Heard About It		Never Heard About It	
	#	%	#	%	#	%	#	%	#	%
	How familiar are you with hospice as a type of care?	17	.10	36	.20	101	.58	21	.12	0

n = 175

that both in-patient hospice care and home-based hospice care were available in Baranya County. More physicians were aware of inpatient hospice care (81%) than were aware of home-based hospice care (71%) which had existed longer. It was surprising to learn that 21% of respondents were unaware of home hospice care and 15% were unaware of in-patient hospice care, both of which were available at the time the survey was conducted. Two specific questions were asked regarding how respondents perceived discussing a prognosis of terminal illness. The first question asked how they felt about discussing a terminal illness with a patient. Responses are shown in Table 2.

TABLE 2.

Question	Usually True		Often True		Sometimes True		Seldom True		Never True	
	#	%	#	%	#	%	#	%	#	%
Some people believe that discussing a prognosis of terminal illness with a patient gives them a sense of hopelessness, Based on your experience is this statement:	31	.17	71	.39	54	.30	21	.12	3	.02

n = 180

The same question was asked regarding the discussion with families and is shown in Table 3.

TABLE 3.

Question	Usually True		Often True		Sometimes True		Seldom True		Never True	
	#	%	#	%	#	%	#	%	#	%
Some people believe that discussing a prognosis of terminal illness with a family gives them a sense of hopelessness, Based on your experience is this statement:	35	.20	59	.33	48	.27	29	.16	8	.04

n = 179

The majority of Family Physicians believe that it is either usually or often true that discussing a prognosis of terminal illness with a patient or family gives them a sense of hopelessness. Answers such as these provide important information regarding how these physicians perceive communicating a terminal illness and also clarify a potential barrier to hospice referrals. These responses can be most helpful when designing continuing education programs so that topics such as “communicating difficult news” can be introduced. Offering topics such as these can help to increase physician understanding and confidence regarding these discussions and potentially increase access to hospice eligible patients. Of those surveyed, 73% said they “definitely” or “probably would” attend workshops to increase their knowledge and understanding of hospice care. A question related to possible barriers to hospice care asked, “In your experience, the families of terminally ill patients are capable of providing appropriate care in the home. Regarding this statement, do you...”. Responses are shown in Table 4.

Question	Strongly Agree		Agree		Unsure		Disagree		Strongly Disagree	
	#	%	#	%	#	%	#	%	#	%
In your experience, the families of terminally patients are capable of providing appropriate care in the home. Regarding this statement do you:	12	.07	65	.38	50	.30	33	.20	9	.05

n = 169

TABLE 4.

It was interesting to note the majority (55%) of Family Physicians where either unsure or disagreed that families of terminally ill patients were able to provide appropriate care in the home.

Reasons related to this belief were partially revealed in an open-ended question that asked, “List in the space below what you consider to be any potentially important problems or obstacles that would interfere with the care of terminally ill patients in the

home”. The majority of respondents replied to this question, and most replied with multiple answers. All responses were recorded and two main categories emerged – Family Issues and Resources. Each category was further divided into dimensions and sub-dimensions. Responses are shown in Table 5.

It is interesting to note the majority of barriers identified were related to family issues. The majority of responses

related to the dimension titled, “Family Responsibility” (75) and were viewed by many respondents as a barrier to providing care in the home. The responses in this dimension far outnumbered all others. A wide variety of resource issues were also identified as barriers and ranged from treatment related issues to professional education. Overall, the responses to this question provided valuable information regarding barriers to hospice care, and if addressed, have vast potential to improve access and services for hospice patients and families.

Survey results were presented in April 2005 to a joint meeting of the Hungarian Hospice – Palliative Association which included representatives from the Ministry of Health and National Health Insurance Program. Survey results will also be used as planned to design customized CME for a conference tentatively planned for May 2006.

End-of-Life Care Course

An elective course titled, “Care of Patients at the End-of-Life” was offered to upperclassmen (3rd year and above) at the University of Pécs Medical School during spring semester. The course was designed as a 10 credit, 24 hour course, and met weekly at the Institute of Family Medicine. The course was promoted on the University web-site and on flyers posted in a variety of student areas on campus. The course was designed to meet the following objectives:

Course objectives:

1. Understand the philosophies and variations in meaning of hospice and palliative care.
2. Develop strategies for communicating end-of-life care options with patients and families.
3. Articulate the psychosocial, spiritual, and physical issues relative to end-of-life care
4. Understand and describe the ethical issues that arise in end-of-life care.
5. Understand the importance of (and variations) in the delivery of hospice and palliative care globally.

Main course topics included: End-of-Life Care in the United States, Hospice Care in Hungary, Interdisciplinary Teams, Communicating with Patients and Families, Pain and Symptom Management, Cultural and Ethical Issues, Last Hours of Life, Grief and Bereavement, and Global End-of-Life Care. The course was structured in a lecture/discussion format. Two guest speakers also contributed by giving lectures in their respective specialties.³⁹ The course was designed to maximize student participation by providing students an opportunity to lead discussions of relevant articles each week.

³⁹ Steven Radwany, MD, Medical Director, Palliative Care and Hospice Services, Summa Health System, Akron, Ohio, presented “Pain Management and Evaluation”. Béla Blasszauer, PhD, retired Bioethicist, University of Pécs, presented “Ethics in End-of-Life Care”.

Family Issues	Resources
<p>Dimensions</p> <p><u>Responsibilities (75)</u></p> <ul style="list-style-type: none"> • 24 hour care too much responsibility/too busy (50) • Can't provide good care due to work responsibilities/would lose job (25) <p><u>Psychosocial/Behavioral (42)</u></p> <ul style="list-style-type: none"> • Psychological burden/lack of psychological support (22) • Negative attitude (10) • Fears (8) • Lack of patience (2) <p><u>Lack of Knowledge/Competency (25)</u></p> <ul style="list-style-type: none"> • Nursing skills (17) • Unable to provide good care (3) • General inexperience (2) • Believe patient can only receive good care in an inpatient facility (2) • Can't organize good care (1) <p><u>Family Model (16)</u></p> <ul style="list-style-type: none"> • Lack of family members (5) • Families not living together/traditional model no longer exists (4) • Lack of involvement (3) • Communication with/in family (2) • Too elderly (1) • Small children in the family (1) <p><i>n = 158</i></p>	<p>Dimensions</p> <p><u>Treatment Related (34)</u></p> <ul style="list-style-type: none"> • Limited psychological support for patients (18) • Lack of pain management/symptom control (16) <p><u>Programmatic (33)</u></p> <ul style="list-style-type: none"> • Lack of Home Medical Equipment/difficult to get (11) • Inpatient unit not large enough for needs (5) • Too difficult to prescribe artificial meals (4) • Too difficult to reach rural areas (4) • Lack of meal service (2) • Lack of sick benefit (2) • No care available on weekends (2) • Lack of infusion services (1) • Lack of transportation (1) • No ability to provide respite care (1) <p><u>Socioeconomic (26)</u></p> <ul style="list-style-type: none"> • Apartments too small/inadequate living conditions (20) • Lack of money (6) <p><u>Educational (10)</u></p> <ul style="list-style-type: none"> • Nursing issues – problems (8) • Lack of specialized knowledge – MD's (2) <p><i>n = 103</i></p>

TABLE 5.

Students also gave presentations at the end of the semester on a hospice related topic not previously covered in the course. Two exams, a mid-term and a final, were given to assess student comprehension of the material.

Participation in the course was good and students rated the course highly at the end of the semester. Student evaluations of the course suggested an opportunity for improvement would be to add a clinical experience along with the theoretical component.

Conclusion

This paper has addressed issues regarding the global need for the development of hospice services and specifically described a project in southwestern Hungary. Global trends impacting the current and future need for hospice care were provided and key terms defined. A background of Hungary's political history and the development of healthcare, hospice, and related factors served as an introduction to the project. The project plan was clearly outlined and field visits were described. A relevant research survey of Hungarian Family Physicians was detailed and the development of an elective course in end-of-life care was provided.

Based upon my experience this past academic year, I believe the future development of hospice care in Hungary is very promising. The hospice professionals I have met while working on this project are highly committed to furthering the care of patients with terminal illness.

These individuals are the future of hospice care in Hungary and there is no doubt, with continued perseverance, they will make continued progress and realize their goal of providing exceptional hospice care for patients and their families.

Major advances have been realized in 2004. It is my opinion the most significant of these is the two year program currently reimbursing providers. Reimbursement will clearly allow for increased development and access for patients throughout the country. However, further advancement related to the reimbursement of care is critical. As an example, the current model does not include the coverage of medical equipment in the home, a critical feature needed to assist families and hospice providers to maintain patient comfort.

Medication availability is another issue relevant to enhancing services. While the majority of long acting opioids are readily available, short acting liquid morphine, is not. The availability of this medication would allow providers to manage pain and symptoms in the home more effectively thereby enhancing the comfort of patients and potentially reducing readmissions to the hospital.

Few programs in the country employ nursing assistants. In U.S. hospice programs, the services provided by these individuals are most helpful for the majority of patients and much more cost-effective than having nurses perform these same duties. Resources should be dedicated to develop this role thereby allowing the nurses to attend to other duties such as patient and family support and education.

According to the Family Physicians surveyed, a major barrier to quality hospice care is related to family responsibilities outside the home. In order to overcome this challenge, a national policy similar to the Family Medical Leave Act in the U.S. should be considered as a way to allow families to take a temporary leave of absence without fear of recrimination or losing their job.

Finally, the opportunity to participate in this project has been an amazing learning experience and I have grown both personally and professionally. I have developed relationships with my Hungarian colleagues that will be life-long and mutually beneficial and for that I will be forever grateful. I wish to extend a special thank you to Agnes Csikos, Lajos Nagy, Béla Blasszauer, and Zoltan Agoston. It is my sincere hope this project, as well as the future work of the many dedicated hospice professionals I have had the pleasure of meeting, will continue to enhance the care of terminally ill patients in Hungary.

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Greenhouse Gas to Environmentally Friendly Compound: Mechanistic Study of Carbon Dioxide

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The mechanism for a Wittig-type reaction of a coordinated carbon dioxide nickel complex with an ylide to yield a nickel ketene complex and phosphine is studied using theoretical chemistry (Scheme 1). Two model systems are also examined: one in which the hydrocarbon substituents are replaced by hydrogens and a second that does not include the metal center. Preliminary data from the mechanistic studies of the carbon dioxide complex and the non-metal reveal that the intermediates in these two reactions are more stable than the products and indicate that these reactions will stop at the intermediates rather than proceeding to completion. However, analysis of the non-metal model system using various levels of theory suggests that these results may vary depending upon the level selected.