



Transforming the culture of dying

Death and dying deserve at least as much attention and care as does birth.

How it Started for Me

My first memory related to end-of-life care goes back to my years as a family medicine resident in the late nineties. A young couple came to our primary care office seeking support because they wanted to honor the wish of their terminally-ill parent by caring for her at home and keeping her comfortable. I remember how awkward I felt. I could only offer to send her to hospital to die, which was the usual practice then. No home care services were available for the dying. I remember how disappointed this couple was when I could not help them. I knew almost nothing about symptom management and had no skills with end-of-life issues.

At that point, I realized how important end-of-life is for patients. This topic was never addressed at medical school. The little I knew about the topic was primarily related to its ethical aspects. I had the privilege of being tutored by Bela Blasszauer, an internationally well-known bioethicist who translated into Hungarian Elisabeth Kubler-Ross' famous book. I worked with him at University at the Institute of Behavioral Sciences where he taught me about patients' values, as well as respect for autonomy and dignity.

While at university, I became acquainted with a Summer Exchange Program entitled 'Patient-Centered Medicine' which brought together medical students from Northeastern Ohio Universities College of Medicine (NEOUCOM) and Pecs University Medical School to study patient-centered care. Through this program, its leaders John D. Engel PhD and Lura L. Pethtel M. Ed introduced me to a holistic approach in hospice care. They modeled the way for my work and life, opening my eyes to the psychosocial and humanistic dimensions of patient care, active listening, and the importance of patients' stories.

My introduction to the philosophy of hospice occurred during my first visit to Ohio in 2001 when I encountered a patient-centered program. We visited Malachi Hospice House in Cleveland, Ohio, and this visit was a career changing/finding visit for me. I was so impressed to see love and respect for dying, homeless people and to grasp the complexity of care that the multidisciplinary team provided.

I felt my calling to hospice and palliative care. As a family physician in Hungary, I had never encountered this approach to end-of-life care for the terminally ill. My eyes were opened!

In 2002 at Cleveland airport, Lura Pethtel and John Engel enquired about continuing collaboration, and I indicated that I wanted to transform treatment of the terminally ill in Hungary through hospice care. This led to a return visit to Ohio in 2003 to focus on learning about hospice and palliative care practices in the USA. On this visit, I gained fresh confidence to establish a hospice program at Pecs. I seized on every opportunity to learn about the field. Upon return to Hungary, I sought to understand what others were doing in my country by visiting hospices to learn about existing care practices. At Erzsebet Hospice House in Miskolc, my transformation as a doctor of palliative medicine continued. I spent a two-week training program there with founder and director Csaba Simkó who taught me the practical and theoretical essence of palliative medicine and symptom management.

During the second week of my visit, I was the sole doctor in the hospice house. As I was writing notes, a nurse came to me saying, "I believe Mr. X is dying." I hurried into his room recalling the steps of CPR that we were taught in emergency medicine, and considered what injections would be available. Mr. X was breathing irregularly with apneas though he showed no evidence of pain or suffering. I measured his blood pressure and was confused about what to do next. The nurse noticed my confusion, kindly suggesting, "I believe you should call his wife to come quickly." I called her, but I don't remember what I said. I know I felt very uncomfortable. Later, I kept wondering how I could save him because I was trained to save lives. But there in the hospice room seeing him lying in peace, I realized that aggressive intervention would be inappropriate. The nurse said, "He is in peace. Don't worry." I was relieved and I sat with him waiting for his wife to arrive, watching his breathing get increasingly more shallow. He died quietly and peacefully 30 minutes later with no CPR, no ECG, and no injections. It was unbelievably difficult for me to do nothing except be present, but my transformation culminated then and there.

Establishment of Pecs-Baranya Hospice Program

Hungary's first Hospice Program was founded in 1991, and the Hungarian Health Care Act has named hospice as the best possible care for terminally ill patients. Nonetheless, services were only sporadically available in the mid-1990s. No hospice existed in our region of Baranya and Pecs largely due to lack of funding but also due to a lack of appropriately trained health care workers. In 2004 the Hungarian government initiated a two-year trial during which the National Health Insurance Fund reimbursed programs for providing hospice. I realized this was a great opportunity to initiate a new program to care for the terminally ill in our region. I discussed my ideas with colleagues and asked for their support. Fortunately, Prof. Lajos Nagy (my supervisor at the Department of Family Medicine) immediately supported the proposed hospice program, and has since pioneered end-of-life topics in the curricula at the University of Pecs Medical School.

I also invited prominent locals to be founders of the program. We established the Pecs-Baranya Hospice Foundation/Program to participate in the trial project, and thereby established the first multidisciplinary hospice team in the region.

We faced a number of challenges. Although our group was dedicated, we were just learning the field and had no expertise in how a multidisciplinary team worked. We nurtured the multidisciplinary approach with weekly meetings to discuss our patients with all team members, and learned to respect each other equally. We didn't know how to introduce our service to patients and families, let alone pioneer psychosocial aspects of care. As well, we learned much from our patients and families

by simply listening to their stories (and learning to read between the lines). We also faced real challenges related to easy access to opioid analgesics, especially during weekends or holidays.

We held a monthly Balint group where we could discuss difficult cases in depth and learn from them. In addition, we built close collaboration with pharmacies to facilitate flexible availability of opioids at any time. We joined the World Hospice Day movement in 2005, knowing that advocacy is vital for health care professionals and the community. We learned from the excellent, pioneering example of the Hungarian Hospice Foundation directed by Katalin Muszbek MD who supported our development with several educational opportunities and advocacy programs. I am grateful our team was so collegially supportive and eager to learn from our mistakes and successes through these years.

Fulbright Stories

I first met John Mastrojohn III, MSN, MBA in 2002 when he was lecturing on end-of-life care at the Summer Exchange Program in USA. Later, he mentioned he was planning to apply for a Fulbright Fellowship to come to Hungary. I could hardly believe that the director of a hospice-palliative care program would come to Hungary! His initiatives involved developing our Hospice Program, teaching hospice-palliative care at our University and doing research. He spent the academic year 2004/2005 at our University and hospice program. He was there at the best-possible time – just when we were starting our program. As a part of his Fulbright program, we began a research project called “Barriers of the Implementation of Hospice Care” (knowledge, attitudes, perceived barriers). The study questionnaire was assisted by regional family physicians. Mastrojohn’s experience and knowledge gave us tremendous theoretical and practical help. Recognition of our work led to our Program organizing the VIIth National Hospice-Palliative Care Congress in Pecs, May 2006. Mastrojohn and his expert colleagues were invited by the Institute of Family Medicine to lecture at the Congress and University.

As Mastrojohn concluded his Fulbright year, we discussed moving hospice care forward in Hungary. He asked, “Why don’t you apply for a Fulbright Scholarship?” It seemed impossible because I had three children, the youngest just four months old. Furthermore, how I could leave our recently-started program? But he ‘put the bug in my ear’ and I realized I needed more knowledge. After long discussions with family and colleagues, I successfully applied for a Fulbright Scholarship. During the academic year 2007/2008, I was a Fulbright Research Scholar at Summa Health System in Akron, Ohio with my aim being to conduct research on end-of-life care. I worked primarily with Summa programs but visited several other hospice and palliative care programs across the US Midwest. I conducted two research projects and published the results. I am grateful to Teresa Albanese PhD for assistance in creating, analyzing and publishing my research; to Steven Radwany MD for teaching me symptom management and communication skills; to the Hungarian Development Panel, Open Society Foundation, and Summa Health Foundation for financial support during my Fulbright year. Returning to Hungary, I sought to apply my newly-acquired knowledge and skills to enhance our program and educate medical and nursing students/residents on end-of-life care.

Treating Pain with Opioids at the End of Life

During two years in hospice, I saw many patients in pain, but one case made me realize further education was needed to break down myths surrounding opioids and cancer pain. I was called to a flat to see a 58-year-old woman with breast cancer with metastases to the lung and bone. She was propped up in bed with her knees pulled up to her chin and her hands behind her back to support

her. She was unable to lie down and could only touch the bed with her feet and palms, and occasionally her buttock. She remained day and night in that position because this was the most bearable position she could find. She experienced shortness of breath and tortured facial expressions. I was shocked when I gently examined her and found that she had decubitated both heels and palms. How many hours had she spent in that position to have such deep wounds? She had only analgesics at step one and two of the WHO pain ladder. I immediately started her on subcutaneous morphine. Soon she could lie down in her bed, and she died couple weeks later with much reduced suffering.

Following this incident, I kept asking myself why she had not received adequate pain control? I called her primary care physician to enquire how she saw her case/patient from the point-of-view of pain management. She said she offered to start with fentanyl patches but the patient refused them. I remembered that during my visit the patient had mentioned two things when I asked her about taking stronger opioids. First, she stated that one doctor told her early in her illness that cancer is a very painful disease. Also, her neighbor had cancer but after starting opioids, she rapidly died. These images shaped her beliefs about cancer pain and opioids and perhaps explained why she refused opioids even when suffering terrible pain. I then realized how much work we have to do in educating not just health care professionals but also the public about cancer pain and opioids.

The Leadership Development Initiative (LDI)

My LDI started in Salzburg at the course called “Psychosocial Aspects of Palliative Care” where Kathy Foley asked, “What do you need in your context that would help you to be more effective in advancing palliative care?” I answered that our program lacks leadership and management skills and needs confidence when meeting with high-level people or policy makers. I was struggling simultaneously as a clinician, program manager and administrator, all of which would benefit from leadership experience and skills. Subsequently, I was invited to apply for the inaugural class of LDI. As a medical doctor I had never been trained in leadership or management. Given the growth of our program, I felt inadequate in addressing conflict and time-management problems. I felt that I really needed to learn more about leadership.

Most importantly, LDI has made me understand that I actually am a leader – something that I never realized before. The very thought of being a “leader” was stressful but tools and support from the LDI team alleviated this anxiety. Reading about leadership theories was very helpful by giving me basic understanding of the concepts. More importantly, I learned a great deal about myself. I learned it was important not just to have a vision inside but to share it loud and proud, to see the bigger picture, to recognize opportunities and limits, and realize challenges can be met. Before LDI, I was an intuitive, unconscious leader. Now I am clearer about what I do, and about why and how I could be more effective in achieving my goal. LDI has empowered me. It equipped me with techniques and skills which help me lead and coordinate our team as we expand our services to provide care for increasingly more patients in need. As a Board Member of the Hungarian Hospice-Palliative Association I practice my newly-acquired knowledge nationally. Working with colleagues from across the country is another opportunity to influence the improvement of hospice-palliative care in Hungary.

Apart from the formal aspect of LDI, I acknowledge the hidden curriculum. I met wonderful colleagues from all around the globe who are facing very similar challenges – albeit in different contexts and stages. I now realize I am not alone with my struggles and challenges. The enthusiasm,

dedication and honesty of these colleagues constantly recharged my batteries. The mentors' and founders' personal experiences shared during residential courses and beyond taught me important lessons. The whole LDI team modeled the way with respect, encouragement, professionalism and humanity. Their personal and professional stories provided additional opportunities to experience diverse leadership attitudes/styles. I am proud and deeply grateful to have been a part of the first cohort of LDI.

My Research and PhD on End-of-Life Care in Hungary

I believe that well-documented research is fundamental to advance end-of-life care and the field of palliative medicine, and this was the main reason I started a PhD program. I am deeply grateful to Katalin Hegedus PhD supporting my research work with her expert skills delivering and publishing several papers on the field in Hungary. Since hospice care has only recently been added to the Hungarian health care system, my research aimed to identify Hungarians' attitudes regarding end-of-life care. The results were published in the "Journal of Palliative Medicine" in 2008, and I am grateful to Charles von Gunten MD, PhD, FACP, FAAHPM for his editorial support in publishing "Hungarian's Perspectives on End of Life Care".

It was also important to survey end-of-life care providers to learn about their perceived barriers and challenges in caring for the terminally ill. That's why my second research project focused on family doctors through a national survey of primary care physicians' knowledge and attitudes regarding end-of-life care. The results were very helpful in identifying educational needs and barriers in caring for terminally ill patients in their homes. A paper was published in "The Journal of Pain and Symptom Management". Another result of our fruitful collaboration with Summa Health System in Akron, Ohio, is our ongoing research, "A qualitative study examining the relationship between spirituality and physical symptoms in hospice patients and their caregivers."

Although I fulfilled the requirements to complete my PhD with these published papers, I was not sure that I actually want to conclude it. However, LDI made me see the greater picture and to appreciate what steps were needed to achieve my larger goals. An academic degree would open doors to develop new services and to introduce more comprehensive palliative care educational programs that can transform the culture of dying in Hungary. So in 2010, I concentrated all my efforts on writing my PhD thesis and completing my degree. In June 2011, I successfully defended my PhD thesis and received the first end-of-life care PhD in the country's history.

Barriers and Opportunities to Expand Services

Major systematic barriers to expanding services remain, including low reimbursement for hospice care and lack of recognition of palliative care as a medical field. Although it is clear that hospice-palliative care should be introduced at all levels of health care system including social services, the reality is that only home care and inpatient hospice are reimbursed at present. Hospice-palliative care services should be extended using a business-case perspective. The introduction of a palliative care consulting service and the development of palliative care out-patient clinics are achievable next steps. These services could be established with a relatively small investment, and discussions are already underway at senior university level. Policy changes should be introduced through the recognition of palliative care as a medical specialist field. Resistance is strong, especially from leading oncologists, but resistance can be reduced using international examples, highly-respected guidelines and careful introduction and explanation of the field.

Plans for the Near Future

My plans include establishing an academic palliative care program at our university and promoting the acceptance of palliative medicine as medical field.

To achieve these goals, academic centers and centers of excellence must be established. Our university-based hospice-palliative program aims to be the first in Hungary. I have met with several stakeholders to gather support, and the proposal to establish the hospice-palliative program has been sent to the University's Board of Professors.

One program objective is to combine clinical practice with well-grounded research and educational programs at undergraduate and postgraduate level. Another objective is to establish a certification process and introduce palliative medicine as a subspecialty. Since research funds are very limited in Hungary, we must continue to develop new research programs and participate in European-wide research projects. We must join in worldwide advocacy and continue to develop new local campaigns.

Some Final Thoughts to Share

During the last decade I have been fortunate to experience palliative care practice in various developed countries. I learned how services were introduced in the 1970's and developed since. I ask myself, "Can this twenty-year period be reduced? If so, how?" I appreciate that change needs time and that people change slowly. We must make our own mistakes and learn for ourselves. Recipes can't always work because ingredients and spices are different in each context, but cooks do their best with the available ingredients and use available spices to achieve the best outcome. But others' examples and expert support can give us courage to persevere. All things are possible with clear vision, commitment, patience and humility. Let everyone know what you are doing and share your plans for advancement. Inform them, invite them, and grab every opportunity to spread the word of hospice and palliative care.

I view my patients and their families as vulnerable people who shouldn't be abandoned just because they cannot be cured. Instead, I support them with expert medical and humane care. They need considerable help during difficult times – with medical and social measures but with community support, too. Local and national advocacy campaigns can transform society's perception of death and dying. We must educate kindergarten children with programs like "Fields of Dignity/Hope" to nurture a generation which views end-of-life as an important, valuable time of everyone's life, not a failure or something about which to be ashamed. Integration of palliative care services will reduce suffering and ensure better quality end-of-life in Hungary. Attitudes are changing here but we have a long way to go. We need to introduce palliative care from the terminal stage and then widen our scope to include all stages of care. Eventually collaboration and commitment will integrate hospice-palliative care into the health care system. I see a very challenging twenty years ahead. But I also see a slowly-unfolding cultural picture transforming death and dying in the minds and practice of Hungarians. Though the picture is huge, we need to use every daily opportunity in our lives to make a difference.