



Change of the Heart

“There's more at stake than our personal happiness or spiritual growth. As ethical beings we're called to improve the lives of others, our children, and our communities, a vocation that requires not simply accepting things as they are but imagining something better and working toward it.”

Philip Simmons, “Learning to Fall”

My first meeting with dying patients did not take place during my medical undergraduate studies, but after graduation from medical school -- on the first day of my house-staff training in internal medicine. I was asked to examine an old man with metastatic lung cancer in the last room of the internal medicine ward at the Military Hospital in Ljubljana.

As I approached him, I noticed a tray with untouched breakfast at his bedside. Gently, I tried to wake him up but he didn't respond. He was breathing in a pattern which was unfamiliar to me in connection with end-of-life, but in a way that was familiar in different acute situations where we have to react. Nothing happened for nearly for a minute and then suddenly he quickly began breathing again.

A nurse noticed my hesitation about what to think of our patient, and she helped me by explaining that the process of dying had started. I felt a strange feeling of not being prepared for this situation.

My patient's family members came to visit and get the most current information about his condition. I was filled with my own emotions and I did not have the slightest idea how to talk to them. I could talk about the results of latest exams, I could explain about lung cancer and its treatments, and I could talk about statistics. But all these facts with which medical school equipped me seemed useless. I felt deeply in my heart that something very important was missing there.

My path in medicine first led me to bone marrow transplantation. Together with a team of hematologists and radiologists, we brought the processes and organization of bone marrow transplantation to Slovenia in 1987. But soon afterwards I felt dissatisfied. I felt I still had to learn more and work harder in order to achieve a feeling of fulfillment.

Instead, I became increasingly frustrated with the aggressive procedures which we imposed on every patient. More than that, I was disturbed by situations when patients' systems rejected their transplant, or when other complications set in. We didn't have useful knowledge to offer solutions to alleviate end-of-life suffering. I realized that I was not functioning as I hoped to back when I chose medicine as my career. I had changed somehow, and seemed to be working in a completely different gear.

But if one takes a closer look, palliative care was a logical next step for me. I started to search abroad for information and education about this field. I traveled and studied extensively, visiting different hospices, palliative care units and universities in Europe, Canada and United States. I joined the evolving hospice movement in Slovenia, which included home visits, activities for public awareness and education for clinicians and volunteers.

Shortly after my first experiences with Slovene hospice, I realized that our public health care system urgently needed systematic development in palliative care. The Open Society Institute from New York, with the assistance of Dr. Kathy Foley and Mary Callaway, gave Slovenia some financial support, introduced us to internationally-known experts, and offered various educational opportunities. We also received moral support -- which was very much needed and appreciated by the palliative care movement in those early times of limited public awareness. As a result, The Palliative Care Development Institute was founded in 2000. Our initial main goals were to inform, raise public awareness, and conduct extensive educational activities. We also wanted to work closely with the Ministry of Health and the Ministry of Social Affairs to effect necessary changes in policy in the health care and social systems, so that palliative care could be better integrated into existing structures.

But in the first place, I wanted patients and their families to receive better care because during home visits I regularly experienced all the pitfalls within our underdeveloped palliative care system. It was not enough to know about clinical work and how palliative care should be organized. I needed skills to communicate with policy makers, and to understand the influences of societal changes.

In 2004, I entered a two-year program on policy studies at the Central European University in Budapest. This gave me knowledge and skills in planning policy change, taught me how to write a policy paper, imparted skills in short briefings, and gave me insight into actions that might raise awareness with the public and clinicians. With this knowledge, I worked successfully with different committees at the Ministry of Health, where negotiations with policy makers and health insurance officials took place.

After the National Strategic Plan for Palliative Care was written, I became actively involved in writing an Action Plan for the National Strategic Plan. This has now been implemented and is guiding Slovenia's palliative care developmental changes.

I am a former president of the Advisory Board for Palliative Care at the Ministry of Health and our group regularly presented suggested improvements to the minister of health. Currently, I am President of the Slovene Society of Palliative Medicine, and significant developments in palliative care have taken place since the first activities of the Palliative Care Development Institute. Opioid consumption has risen slightly above the average European level. Educational palliative care courses have been introduced at medical and nursing schools. Postgraduate education in palliative care is

becoming a regular study for many health care professionals. There are new palliative care teams and units evolving in health institutions throughout Slovenia.

International Fellowship Program in San Diego

With the invitation from Dr. Frank Ferris to join the International Fellowship Program at the Institute of Palliative Medicine at San Diego Hospice, I entered a new chapter in my career. I witnessed a group of professionals – who shared a very high degree of enthusiasm and effort – work to bring change to patients and their families, to health care professionals and to society as a whole.

I had a unique opportunity having been invited as a fellow. I was able to perform daily clinical work under the supervision of my mentor. I not only worked in the Palliative Intensive Care Wards at the Institute of Palliative Medicine at San Diego Hospice, but along with my clinical work I also received bedside teaching and in-depth classroom learning. I could enter patients' homes and learn about teamwork during home care visits. I could rotate in pediatric and oncology wards, the intensive care unit, nursing homes and AIDS clinic. Along with clinical knowledge I learned about organizational systems. I acquired communication skills that were extremely well taught. I studied processes of ethical decision-making. Above all, I gained confidence and began to see palliative care in two ways: as the changing force at my very core, and as a silent revolution moving society towards solidarity, compassion and equality.

Establishing a Palliative Care Unit

At the University Clinic for Respiratory and Allergic Diseases at Golnik, I experienced probably the best possible environment to develop a model of palliative care unit with a holistic approach to end-of-life patients and their families in Slovenia. We developed residents' rotations on our unit, consultations for other hospital wards and an outpatient clinic -- including early palliative care for metastatic lung cancer from the first treatment with oncologist onward. Gradually we developed palliative care educated nurses, physicians and other professions in palliative care team. We established organizational processes for generic palliative care at each acute ward of the hospital. We designed a system of coordinated discharge and follow-up for home care teams, which was also a significant achievement.

During the process I sometimes felt frustrated to the edge of giving up, due to the resistance of some hospital staff to our team's input. The key to overcoming this was learning the best ways to resolve conflict, staying focused on long-term goals and not taking temporary failures to heart. I've come to find that patience also has humor and playfulness. I can develop patience and a sense of humor about my own imperfections and exaggerated high ideals. Sometimes I recall a slogan for patience, "Lower your standards and sometimes relax as it is."

In cooperation with the Ministry of Health in 2009, I was appointed to lead a one-year pilot study to implement organized palliative care in three regions of Slovenia. In four hospitals and in primary care offices in all three regions, we worked closely to establish data on necessary steps to advance palliative care in Slovenia in a systematic way. We achieved consensus on standards of clinical work, processes, necessary documentation, and generic quality indicators. Along with clinical work and cooperation with the project, we better knew and understood each other -- oncologists, anesthesiologists, interns, primary care physicians, emergency physicians and nurses, social workers, psychologists and others. Patients and families gave us a valuable feedback on our work. One patient

with chronic obstructive pulmonary disease said that without us, the way he was treated before did not offer him a life worth living.

This important cooperation challenged my leadership skills. It also challenged the relationship with policy makers, because our results and observations led to recommendations that increased pressure on policy makers to act more quickly in developing palliative care.

Leadership Development Initiative

Along with these activities I participated at the LDI program, where I became more aware of my own leadership strengths and weaknesses. Focusing on these, learning about them, and meeting other colleagues in very similar situations around the world helped me to grow more quickly and act more effectively. It is likely one of the greatest challenges in society today: how do we cope with an increasing rate of change in every aspect including clinical processes, team work, changes of expectations and economic uncertainty? Among core leadership knowledge and styles, I learned valuable skills with small group facilitation, team-work dynamics and effective ways of solving ethical challenges in group dynamics.

I once learned about pottery and was taught to start by slapping a lump of clay on the wheel and centering it so that it spins smoothly. To shape the clay, you press the spinning lump between your palms, gouge your thumbs into its center, and pull the whole mass toward you so the clay's rotation is no longer centered on the wheel but on the space between your hands. Squeezing between thumb and fingertips, you pull upward from base to rim, pulling the pot into form and then gently releasing it to spin smoothly on the wheel again. You must let go and let the clay find the center of the wheel. If you try to force it there, the pot will wobble.

Being in the first raw stage of development of palliative care in Slovenia for many years, it became obvious on the first occasion of meeting my followers that I should let go of expectations based too firmly on my own ideas of development. This is not a simple act, but it is part of my personal process as I walk down a path filled with many possibilities.

Learning with Patients and their Families

Who am I? Who am I beyond birth and death? Working in palliative care is a journey of self-reflection and I look more closely at what's going on in my mind and heart. I have a choice to open or close doors, whether to hold on or let go, whether to harden or soften. Patients and their families are teaching me that behind resistance -- definitely behind aggression, judgment or *any* kind of tension -- there is always a personal soft spot that we all try to protect. This understanding also helps tremendously when pioneering the development of palliative care while facing the resistance of clinicians, policy makers and the public.

In the end, what I'm advocating in the Slovene health care system is not only palliative care, but also something that requires courage -- the courage to have a change of heart.