

THE INSTITUTE FOR PALLIATIVE MEDICINE at San Diego Hospice

INTERNATIONAL PALLIATIVE CARE Leadership development initiative Ondrej Slama, MD, PhD Brno, Czech Republic



I grew up in Communist Czechoslovakia in a Christian family. At that time, the public sphere was dominated by Communist ideology and most people coped with that by withdrawing from public life to a private family life, focusing on hobbies and close friends. Education was ideologically-driven, too. The Communist party allowed University education only to childern from families which conformed and were loyal to the political regime.

This was especially true for professions that would have an impact on other people, such as teaching and medicine. Czech citizens at that time couldn't travel abroad to western capitalist countries so we lived in relative isolation. Christian congregations at that time represented islands of relative freedom, and provided a platform for discussion about a broad range of religious, political, cultural and general human issues. There were frequent contacts and links with people from abroad.

In the mid-1980's during my college studies -- being interested in biology, theology and philosophy --I first encountered the the work of Elizabeth Kubler-Ross. It touched me deeply. I dreamed about becoming a doctor, though I had little chance of being accepted to medical school because of my church activities. In reading Kubler-Ross about the care of the dying, however, it became clear to me that areas linking medicine, psychology and philosophy were stimulating and resonated with my deepest interests and aspirations.

The other source of my motivation was the Christian perpective of doctoring as a service to those suffering in the neighbourhood and community. My biggest heroes then were Albert Schweitzer and Mother Teresa. Despite all pessimism, I was admitted to Brno Medical School and started my medical studies in 1986, three years before transformational political changes occurred in our country and in the whole Central and Eastern Europe. I finished my medical studies and graduated in 1994.

When I look back to my medical studies, I can recall some teachers who were very strong in their areas of expertise. Some of them were effective lecturers, but there were few (if any) teachers and mentors who could inspire us through their personality, integrity and approach to patients and students. I cannot remember any real leaders.

I started my residency and fellowship in internal medicine at the Regional hospital Moravska Trebova. It was a time of clinical reality as I realized how limited my medical school skills and competencies actually were. Gratefully I remember my colleagues, fellows and attendants who helped me with technical and medical advice.

When it came to patient-physician communication, as well as difficult end-of-life decision-making, my medical teachers oft-repeated their wisdom, "There is no right way to do it. You must find your own way. But be careful! The most important thing is to avoid any legal suits."

So I tried to find my own way. After four years, I passed my certification in internal medicine. Around the same time, I met my future wife Regina who was then working in a Palliative Care unit nearby Brno. After our wedding, I applied for a fellowship in the Department of Internal Medicine and haemato-oncology at the University Hospital Brno. My new family life started at the same time as my arrival at one of the most dynamic biomedical depatments in Czech Republic. I worked with the bone marrow transplantation group and witnessed major achievements in aggressive modern medicine. We could provide nearly half our patients with the prospect of long-lasting complete remission -- a cure! But it came at the price of extreme adverse effects: pain, infection, isolation, etc.

I developed a special interest in supportive care in hametooncology. But often at the same time, I witnessed the failure of aggressive curative effort, relapses of disease, extreme life-threating toxicities, and situations when patients' status suddenly changed from "critically ill" to "terminally ill". This important shift was often not recognized by the health professionals. Care was not appropriate and did not meet the patients' needs, caused needless suffering for patients and their families, and frustrated nurses and physicians.

During that period, I was privileged to work with Professor Vorlicek, head of the Department of Internal Medicine Haematooncology. In clinical rounds with the fellows, he stressed open communication and principles of palliative medicine. We pursued this and wrote several papers on communication with patients suffering advanced cancer. These papers have been widely referred to and cited in the Czech medical world. We worked extensively educating medical students and junior physicians about different aspects of supportive and palliative care. It was a honor and challenge for me to lecture and write about these topics, because I was still relatively young.

Profesor Vorlicek encouraged each young fellow from his department to acquire some clinical training in well-established cancer centers in Western Europe and the U.S. His aim was to help us grow professionally, and he opened doors for us to do so. At the same time, he required impeccable clinical work, ongoing personal studies, and provided us with very open feedback -- sometimes critical and straightforward, but always fair.

That is how I came to Jules Bordet Cancer Institute in Brussels in 1999. I spent more than a year there as a fellow in clinical oncology. My mentor was Professor Jean Klastersky, one of the gurus of supportive care in cancer (i.e. concept of febrile neutropenia). He is a brilliant clinician, medical oncologist, teacher and lecturer. Personally, his collegial and sometimes fatherly approach to medical students and residents was a great experience. He demonstrated how clinical training could be done. I remember his oft-repeated idea that there are no "trivial" clinical situations and cases. By that, he meant that every clinical encounter has the potential to be (or become) clinically and humanely interesting and rich. We as physicians should train and develop the ability to enjoy this richness.

I worked in Brussels for five months in the Unit of Acute Supportive and Palliative Care. Working together on the team headed by Dr. Body was my first experience with a real multi-professional team working in an interdisciplinary way. I realized that something I had only been dreaming about thus far could actually work and provide a very effective model of health service.

I returned to Brno with an enthusiastic determination to build up such a team in my department in Brno. But after my return, I quickly fell back into the busy daily routine of heametooncological inpatient care. The workload was so heavy that I couldn't find enough time to work on developing a palliative care team. It was quite frustrating, all the moreso because I was not able to convince my supervisors that I need more time and resources to realize this project.

Finally, I changed my position and started to work as a consultant in internal medicine at the outpatient clinic in our department. This was a completly different clinical experience. I was one of the liaison contacts for internal medicine in the stroke unit and neurological ICU. One day per week, I held consultations in a long-term care hospital outside Brno. The experience of clinical decisionmaking involving old and very old frail stroke patients provided me much deeper insight into the challenges of clinical, ethical and legal aspects of palliative and end-of-life care in non-cancer patients.

Some years later I conducted research into clinical and legal aspects of CPR in terminally ill in Czech Republic, and received my Ph.D. degree for that work.

As a part-time job, I initiated a relationship with the University Hospital Pain Clinic, and I developed an out-patient clinic of palliative care within the Pain Clinic at University Hospital Brno. The cooperation of other team members -- anesthesiologist, neurologist, rehabilitation doctor, psychologist and nurses -- was an enriching experience. The patient volume was quite low at first, and I wasn't successful in building the number of referrals. This caused my clinic to be financially unsustainable, which became an issue. So I had to reduce my consultation time to four hours twice a week. Looking back I see that my marketing of the new service was very poor, and I failed to educate and integrate the other members of the Pain Clinic Team.

In 2004, we started to work – together with Professor Vorlicek and the director of nursing at University Hospital – developing an in-patient palliative care unit. There was a suitable space at the former unit of infectious diseases, and the hospital managers were looking for a new use for this facility. At that time in our country, in-patient hospices were the only model to be found. Our ambition was to develop a new type of palliative service: serving more acute cases and offering more medical support than in-patient hospices.

Initially, everything seemed to be quite promising. We negotiated intensely with medical and financial leaders at University Hospital about the parameters and models for this new service. But over time, disagreements increased. We disagreed on unit size (I proposed 15-20, but hospital managers asked 30 at minimum), number of beds in each room (I considered single-bed rooms an absolutely necessity, hospital managers proposed 2-3 bedrooms because of "efficiency and economic sustainability") and funding for the service (hospital leaders assumed very low medical and nursing input in the new service).

After more than a year, I concluded that at that particular time, the development of an in-patient palliative care unit was impossible. This realization caused me considerable frustration and a sense

of personal failure. From today's perspective, I clearly recognize that the project was – from certain aspects -- unrealistic and grandiose. An important reason for its failure was my unwillingness to compromise and find a win-win agreement.

In spring 2006, I was invited by the medical director of Masaryk Memorial Cancer Institute in Brno (the biggest cancer center in Czech Republic) to develop a Palliative Care Program there. It was a big challenge for me. Several supportive services were already available in MMCI including a pain clinic, psycho-social care, spiritual care, nutritionist, and rehabilitation. But these services were not well-coordinated, and aimed preferrentially to patients in curative settings. Their availability to advanced cancer patients was quite limited.

Soon after my arrival at MMCI, I discovered that the expectations of MMCI managers were quite ambiguous. The palliative care department was not expected primarily to improve the quality of care for palliative patients, but to facilitate the discharge and transfer of these patients anywhere else (i.e. home, hospice, another hospital) and to prevent their readmission to the oncological unit.

We started to meet regularly with people from all the above-mentioned supportive services and developed a very good working co-operation. Many of us became good friends. There were two other oncologists who were interested in palliative care and who planned to specialize in palliative medicine. Most palliative patients were cared for on an out-patient basis, and the numer of consultations began increasing. We worked closely with local home and in-patient hospices.

The medical board of MMCI progressively changed its mind and accepted the idea that palliative care of advanced cancer patients should be an integral part of comprehensive cancer care, and that the availability of good quality palliative care in MMCI would add to its reputation and prestige. Today, the palliative program is supported by the medical board of MMCI. However, pressure is building to increase the number of consultations. It is a challenging and time-consuming issue to negotiate. But despite that, palliative care remains an effective model of health care delivery. So, I spend six or seven hours daily in consultations, seeing 10-15 patients per day. This necessarily limits my capacity to work on other, much-needed managerial and developmental tasks. Further negotiation and advocacy will be needed to have non-clinical tasks recognized as being worthwhile aspects of my work load.

## **Teaching and education at Brno Medical School**

Since my return from Brussels in 2000, I have been teaching medical students. Initially, I taught pain and symptom management within a course for Internal Medicine and Oncology. In 2006, we introduced an optional one-semester course in Palliative Medicine. From the first year, more then 30 students annually apply for this course. I enjoy working on palliative care issues with these motivated young people, and they have provided positive feedback. Some of my former students have become my assistants and have begun participating in the teaching process over the past three years.

One positive side effect of our course in Palliative Medicine is the development of cooperation between local hospices and our medical school. Our under-graduate curriculum was recently adopted at Charles University Medical School in Prague.

# **Specialization (Post-Graduate) Training in Palliative Care**

From the beginning of this century, we realized the importance of recognizing Palliative Medicine as a distinct discipline in the medical world. We were convinced that this was the pragmatic way to get more appropriate funding from health insurance, ease problems developing new services, improve access to grants, etc. Initially, we created a coalition with pain specialists and coined a new subspecialty -- Pallaitive Medicine and Pain Management -- which was officially recognized in 2004. Since then, more than 130 physicians (mostly with an anestesiological background) completed the one-year training and certification exam. In 2010 we agreed with the algeziologists to separate into two distinct subspecialities: Palliative Medicine and Algeziology.

We are now developing a network of teaching hospices and other facilities to provide fellowships in palliative care. One current challenge is how to motivate/encourage hospice physicians to upgrade their formal training to become real specialists and mentors for other physicians.

## Working in Czech Society for Palliative Medicine (CSPM)

In another pragmatic step to make the message of palliative medicine more visible, we founded the Czech Socitey for Palliative Medicine in 2008. One goal is to create a platform for all health professionals interested in palliative care. Another goal is to advocate for palliative issues with state, professional and other institutions.

From the beginning, we have been surprised by (and sometimes unprepared for) the huge, growing agenda. This includes changing health care legislation, increasing awareness and public discussion about end-of-life issues -- all framed in terms of our current economic crisis. But this agenda presents many opportunities to contribute to the improvement of end-of-life care in Czech Republic on different levels. There is a huge workload, but there are very few workers.

However, I have the privilege to work as secretary to Ladislav Kabelka, president of CSPM. He is a real leader, working systematically on discussing priorities, finding, involving and encouraging people to work together towards a commom goal. I have learned a lot from him. This experience of working together -- with an inspiring leader who at the same time is a good friend -- is crucially important.

### My Wife, Family and Private Life

My wife, who is also a hospice physician, and I often ignore the wise recommendation to leave work issues at work. But it is inspiring, enriching and important for both of us to reflect on our work, share our feelings and sometimes even discuss clinical cases at home. Other than that, we try to live a non-palliative life within our partnerhip, family, friends and church activites. We realize the importance of a balanced, rich and satisfactory family life to keep us human. We try to practice spirituality everyday which helps us to enjoy the beauties of ordinary life, and inspires us in our profession to remember service to our suffering neighbors.

### **Final Remarks and Reflections**

Reflecting on my life to perceive a path of leadership is challenging for me. I was not raised to feel like a leader. Personally, this term has always implied exaggerated ambition, misuse of power and manipulation of other non-leaders. I never had such ambition.

One insight into my personal view of leadership can be explained by my Myers-Briggs Type Indicator, which labels me as an Introversion-Perceiving personality type. I never dreamed of becoming the

'frontman' and have always preferred to be the 'second' -- reflecting, analyzing, advising, etc. The problem in my palliative career was that there have often been situations where nobody wanted to play the frontman, nor was anyone interested in my analytical advice. Leadership was needed!

Thus, my participation in the LDI program at the Institute for Palliative Medicine at San Diego Hospice has been an ongoing personal revelation since 2010. Thanks to LDI, I could reframe my understanding of leadership. The inspiring residential courses in San Diego, discussions with colleagues from other countries, reading recommended books about leadership (especially Covey's "Seven Habits" and Kouzes and Pozner's "The Leadership Challenge") started me along the process of reflection, prioritizing, learning new skills, working more effectively and -- finally -- enjoing it all.