



## My Personal Story

It was just the second day of the Palliative Care Leadership Development Initiative (LDI) first residential course. I found myself thinking, “Why does a person want to be a leader? What does it mean to be a leader? When I was deciding whether to come here, to be part of this Project, what I had chosen to do? I have principles and values. I want them to remain real.”

### Principles and Values

“To my patients....Each is a flower with charming colors. Now some have turned pale.... From them I have learned a lot about life and death....”

“To my son.... Sometimes he has had difficulty understanding the time stolen from him...trying to understand with his lovely small heart which is full of love for others and for life. To my close friend, my son, Oğulcan....”

The above sentences are taken from the acknowledgement in my medical oncology thesis.

My first year in medical oncology was filled with questioning about life and death, especially about their meaning. Throughout the year, I had read about ethical issues in oncology. Dealing with a cancer patient and his family is very difficult, but satisfying and rewarding. It raises many questions about life, real expectations, values and principles, and it reminds you of your own mortality.

Cancer diagnosis is not just “bad news” for the patient and the family; it is really bad news. A stage IV pancreatic cancer patient told me, “I have had many difficulties all through my life. I am a real warrior. I have chosen to fight each time. But this time is different.... This, cancer doesn’t just involve you. It involves everyone around you. I don’t want to continue this.... I don’t want to cause any trouble to my family anymore. I want to just give up....” He was rejecting dialysis and his family was insisting on continuing with whatever treatment

was possible. I was too new in my career to differentiate what was *possible* in his case and what was *not*.

Another patient had stage IV lung cancer. When we first shared the diagnosis, he questioned -- very proudly and courageously -- both the prognosis and treatment. Then he said to us, "Before starting the treatment, please give me a few days. I want to celebrate my life and say good-bye to my friends. I have lived life just as I wanted to live it. It was good. But, of course, just like everything else it should have an end."

Yet another patient who was dying simply looked into my eyes and said, "Thank you, my daughter. I don't want anything. I am fine." It was very difficult for me even to enter his room. But he was silent and peaceful, and *he* was trying to calm *me* down.

I have learned a lot from my patients about life and death, most especially about the meaning of life and death. I am really grateful to them...for their charming colors.... Some of them have already gone....

And I have learned the needs of cancer patients and their families are different from those of other types of patients. Not only does treatment involve chemotherapy and symptom control, but psychosocial support is also necessary. A comprehensive approach is definitely needed.

When I first encountered Palliative Care, I realized it was the treatment philosophy I was looking for. This occurred when I was at the very beginning of my career in medical oncology. I was working as a fellow in the Baskent University medical oncology unit with Prof. Ozgur Ozyilkan. He was a member of the European Society for Medical Oncology (ESMO) Palliative Care Working Group. I am grateful to him for his role in introducing me to Palliative Care.

## Meeting with Palliative Care

During my fellowship, Professor Zafer Akcali and I visited Budapest for a hospice course organized by the Hungarian Hospice Foundation in October 2005. I am deeply grateful and thank the medical director, Prof. Katalin Muszbek, and all the hospice team. It was a great experience. We visited Magyar Hospice Alapítvány in Budapest, and an inpatient Palliative Care unit in Miskolch. During the time span when we were together with them, I learned a lot -- not only academically but also as a human being -- about life and death.

During our visit to Miskolch, I saw a painting which was very inspiring. It consisted of two pages. The upper page was transparent and on it was a painting of a grandmother. Behind it on the second page, there were many items belonging to the grandmother's life. I asked what it meant, and learned that it was a painting illustrating death done by a grandchild. The grandmother had gone, but life was continuing...along with the memories of grandma. Our lives are just temporary, but our effect on earth remains....

## Leadership Development Initiative

At a meeting of the Middle East Cancer Consortium (MECC) organized in Ankara, Turkey, I met the LDI team. I was really very impressed. They were so friendly. They were knowledgeable and their presentation techniques were very attractive. I followed the lectures just like following a masterpiece performance. I fell in love with the philosophy, the content and the presentation technique.

Then a beautiful, tall, blonde, blue eyed woman came up beside me...Shannon Moore. She gave information about the LDI program and asked me whether I would consider applying to the program. I was a medical oncologist. To become a medical oncologist, I had spent a long time and studied very hard. In my country to qualify as a medical oncologist, you have to complete an internal medicine residency for five years, then work in medical oncology for another three years. And we medical oncologists were few in number. But this leadership process would take even more time and work.

Meanwhile, our Ministry of Health was working on the integration of Palliative Care into our healthcare system, and I was involved with them from time-to-time. If I were to attend LDI, it would mean direct contact with the international Palliative Care community and the potential to access their guidance for my people, for our Palliative Care project. Furthermore, I strongly believed in comprehensive cancer care and I had given my heart to the Palliative Care philosophy.

On the other hand, I have a family and my son was only ten years old. I had always had a very busy work schedule. Although I was trying hard to balance the demands of life and work, it was very difficult and I felt I had already stolen time from my family. As mentioned earlier -- in the acknowledgement from my internal medicine thesis -- my son had tried to understand this. My husband, too, had borne the responsibility of having a doctor-wife with great compassion.

I remember the period when I was working on my thesis. My son was around four years of age. I tried to give all my time when we were together. To accomplish this, I devoted all my time to my son every evening, and then woke up very early to work on my thesis. I tried to be very quiet, but nearly every morning my son would wake up just as I sat down at the table. He was so small and lovely.... I would hold him in my arms, kiss him, then carry him back to his bed and stay with him until he was asleep again. Then once more I would start to work, and again he would wake and come find me! It was hard but it was very worthwhile.

I shared the idea with my family about applying to LDI. My son exclaimed, "Of course you should do it! This is just what you want. Go after your ideals!"

I applied and I am so happy I was accepted and have had the chance to be a part of the LDI project.

There were twenty-three beautiful people, leaders from all around the world, and mentors, coaches and the LDI team. It was just like a dream to be a part of this wonderful community.

We came from different language backgrounds, different cultures, and different geographic regions. But we shared one quality: the ability to put others ahead of ourselves. I am very proud to know each of them. And I am very thankful to all the mentors, coaches and the team for sharing their knowledge and experience with us.

## **The European Association for Palliative Care (EAPC)**

*"...I would like to ask you if you would like to...chair the parallel session, "Religious Aspects in Palliative Care"...give a presentation on "Islam and Palliative Care.... Practical Implications in Turkey" in the parallel session, "Religious Aspects in Palliative Care"...."*

I couldn't believe it. I read the invitation again and again. It was true! To give a talk in the EAPC 13<sup>th</sup> World Congress? I felt just like I was flying. Then a few minutes later, I felt very anxious. To be a lecturer at an international Congress? Was my knowledge and experience enough? What about my English? It was hard to decide. It was a real challenge.

I read and read and read...not only on my topic, but also on religious aspects of Palliative Care, spirituality in general and in Palliative Care. I have learned a lot and what I have learned has broadened my view of life -- not only as a doctor but also as a human being. Thanks to the organizing committee and Prof. Lukas Radbruch for giving me this great opportunity. I also would like to thank Frank Ferris, MD, for his support during the Congress. Even though the Congress room was full, I could recognize his supportive eyes among the entire crowd.

After the presentation, some colleagues came over and shared their appreciation. Once more, I realized that all we are the same. Whatever our gender, language, religion or culture, it doesn't matter. We are all human beings, and all we need is simply to understand each other.

## **Daily Practice**

I work in an education and training hospital as a medical oncologist. We have medical oncology fellows, and some fellows from other disciplines. Being a part of education is important. To share knowledge and experience, to have a part in another's progress, is fulfilling work.

Since I deeply believe in Palliative Care philosophy, Palliative Care itself has been an important component of what I share with others. Some colleagues are resistant from time-to-time, especially at the beginning of their careers. I remember one of them said that Palliative Care had only a small part in our daily practice, so it was not necessary to spend time on it. Finally, he became someone who understood and applied Palliative Care very well. Now when we recall the past, we smile at these memories -- and he most of all. Oncologic care cannot be imagined without Palliative Care. We are dealing with a human being, not a machine -- a human being with a past and a future, with relationships, with emotions. Palliative Care philosophy is indispensable in cancer care.

## Palliative Care in Turkey

The Turkish Ministry of Health, Cancer Control Department, launched the Pallia-Turk project to be implemented in 2010. The Project focuses on two main topics: opioid availability and the implementation of a community-based Palliative Care model.

At the present time, we don't have oral morphine or immediate-release opioids available in our country. We have tramadol, fentanyl and hydromorphone. In Turkey, opioid consumption for pain management is low. The consumption of the Morphine Equivalent is 11.7 mg/capita. The barriers preventing opioid usage for pain management are not well-defined. As a consequence, this prevents effective pain management.

Lack of immediate-release opioids makes opioid dose titration difficult. The Cancer Control Department has searched for drug companies to import opioids. The Ministry is also in contact with local national drug companies for a national production capacity, which may also serve as a basis for our surrounding countries.

The Pallia-Turk project defines Palliative Care in three levels: primary, secondary and tertiary.

The primary level includes family physicians, homecare teams, NGOs and local governors. Currently, each ministerial hospital in Turkey has a homecare team. The total number of homecare teams is >600. Each team is composed of one general practitioner, three nurses, one driver and one car. There are more than 20,000 family physicians in Turkey, and every citizen has a family physician. The major goal now is education and training of homecare teams and family physicians with regard to Palliative Care philosophy, symptom control and end-of-life care.

In recent years, there has been great interest and effort in the integration of Palliative Care, and some achievements have been made. According to the World Wide Palliative Care Alliance (WPCA), the Palliative Care development level of Turkey was II (capacity building) in 2006 and IIIb (generalized Palliative Care provision) in 2011. I hope it will be IVb (advanced integration) in the near future.

## Leadership

Am I a leader? I am trying to do my job. Just my best, nothing else...

"I have principles and values. I want them to remain real..."

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