

International Palliative Care Leadership Development Initiative

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My Story

"And Moses said unto the LORD, Wherefore hast thou afflicted thy servant? and wherefore have I not found favour in thy sight, that thou layest the burden of all this people upon me?" Numbers 11:11

I was born in a fairly prosperous and wealthy family in Armenia. My father was the chair of the pathology department at the Agricultural Academy, and my mother was a chemist at the research center. I went to music school and my future was seemingly destined: after leaving school, I would probably become a professional musician.

However, there were always discussions about medicine in our family, that it would be worthwhile and interesting to be a doctor. We subscribed to popular science magazines on health topics. Despite the fact that I attended a specialist music school, my parents did not limit my academic choices. Gradually, I became more and more interested in medicine. I wanted to treat people, to save their lives. Thus, medicine became my career choice from childhood.

My first leadership experience began in 1996 when I -- despite being quite young -- become the head of the Department of Anesthesiology in one of the largest clinics in Yerevan. Everything changed in a minute as soon as I found myself in this position. I was just one of the regular doctors in the department. Suddenly -- for all of us -- I was thrust into this position.

However, I was inexperienced. I went through a very hard series of difficulties and mistakes. But gradually I managed to find my way. Much of what I was taught about leadership during the Leadership Development Initiative (LDI) at the Institute for Palliative Medicine at San Diego Hospice, I learned intuitively from my own experience. I never anticipated that I could be educated in leadership, particularly in Palliative Care.

I first heard about Palliative Care in 2003 from my colleague. We were at a medical conference of Anesthesiologists in Yerevan. To tell the truth, I did not truly understand what he was talking about that time. It was a very strange and interesting topic for me, however, but I didn't go deeply into his story. To me, it was just a conversation between two Anesthesiologists. I forgot about this meeting shortly afterwards, and continued to work as an Anesthesiologist.

Later, we met again and he asked me, "What do you think if we implement Palliative Care in Armenia? It seems to me that you can help me develop it here."

But the idea about end-of-life care was strange to me because, as an anesthesiologist and intensive-care specialist, I was trained completely in the opposite direction. I struggled fervently for each patient's life, and did everything I could only to save him/her.

This time I was more attentive and felt that it was worthwhile to consider it.

Actually I was more interested in the subject of pain management and dreamed about the establishment of pain-management service in Armenia. Then my colleague said that I should let go of these thoughts, and embrace Palliative Care. He suggested that I become Vice President of the Armenian Pain Control and Palliative Care Association. I accepted his proposal and that was that.

However, we got stuck at this stage.

When I tried to do something, all my attempts were foiled which left me doubtful. Okay, we decided to work together, but how were we to move this forward? I did not know anything about Palliative Care and had no information about it. I still was focused on the aspect pain management and I was trying to move this service forward. But nobody else seemed to care. This man wanted to be known as the founder of Palliative Care in Armenia, but he was unwilling to do the actual work to get it going.

I was very disappointed and decided that I would never return to Palliative Care -- until Destiny once again led me down that road. I truly became acquainted with Palliative Care when I participated in a seminar in 2006 in Salzburg which addressed end-of-life care in Geriatrics.

In comparison with other participants who attended the seminar, I was a rookie who had not seen or treated a single Palliative Care patient. For me, it was simply a new and very interesting topic, but nothing more. I didn't "feel the patient with my skin." At the seminar, I met interesting people like Dr. Frank Ferris, Director of International Programs at The Institute for Palliative Medicine at San Diego Hospice. I also met Dr. Kathleen Foley, medical director of the International Palliative Care Initiative of the Open Society Public Health Program, and Mary

Callaway, project director at the Open Society Foundations. They were the inhabitants of heaven for me.

I was absolutely fascinated by those people. I felt that if such interesting people were working in Palliative Care, it had to be a very interesting field and I must pursue it. I was eager to know more and transfer my knowledge to others in my country.

One day at lunch, I approached Frank Ferris and very bravely said that I want to create a postgraduate curriculum in Palliative Care for our university in Armenia, because I believed that without theory nobody can work. I was determined that Palliative Care must be taught in medical university. I was so naïve! Frank looked at me very ironically, and said that to be able to create the curriculum, I had to do a huge amount of work. I needed to read many professional books, see many Palliative Care patients -- at the minimum -- and then, maybe, maybe, I could then very carefully think about curriculum.

I was relieved and returned to my everyday lifesaving duties, thinking that this was the end and I would never again revisit the subject of Palliative Care. As an Anesthesiologist I was very happy and satisfied. I believed that my work was very important -- specifically, saving people and seeing the result of my work every day. I was not keen to deal with the chronically ill -waiting for some temporary improvement, knowing that the disease is still not radically cured. Watching hopeless and incurable patients was not very appealing to me. I am a person who is "here and now" and I have to see immediate results from my work

But Life is an interesting journey, and Fate once again threw me for a loop and put me face-toface with Palliative Care. Two or three months after my return from Salzburg, I was faced with a terminal illness in my own family. My brother-in-law was dying of liver cancer and was in terrible pain. I frantically tried to remember what I had been trained to do in Palliative Care. Once again, I looked though the handouts and tried to figure out how I could help him. He begged me to do something to reduce the pain, at least. But I was powerless. He cried out to me, "Aren't you a doctor? Please...do something!"

Even though I was an Anesthesiologist and worked with opioids, there was little I could give him to alleviate his pain. Existing pain killers were inadequate for his situation. The only way to help my brother-in-law was to take him to the hospital and give him opioids, but no one would admit an incurable patient to hospital. Eventually, he died -- in enormous pain and suffering, leaving me frustrated, hopeless, dissatisfied, and in a great deal of personal PAIN.

This experience was awful for me. I realize that I did something, more or less, trying to help him. But what about those people who are very far removed from medicine or treatment? This was a decisive moment for me -- the point of no return. I knew I had to hit the ground running, putting aside personal grievances. Seeds, planted imperceptible to me, began to germinate! I became interested in Palliative Care, and read any literature I could find about end-of-life care. Gradually I became immersed in Palliative Care, trying to do anything I could, but those attempts were very limited. What can one do with severe cancer pain without opioids, without any medication? Neither physicians nor patients knew about the existence of Palliative Care service, per se. I decided to inform people, beginning at the personal level.

In 2010, I attended my second seminar in Palliative Care. This time I returned more confident with several plans in my head, thinking how I could move Palliative Care forward in Armenia. I established a homecare service named after Dame Cecily Saunders ("Saunders Center") to provide palliative homecare, and I began to work independently.

I believe that Palliative Care is a philosophy of how to deliver care; it is also an attitude towards teamwork; finally, it is also a medical specialty. One cannot gather an effective team when people need to earn money just to live. Motivating people to dedicate their time and effort to Palliative Care is very difficult. When you do not offer them money, they are not interested in that job. Moreover, I faced very strong resistance from oncologists who did not accept the idea of pain relief by opioids. Their opiophobia was enormous, plus the paperwork related to opioid prescriptions is complex and challenging. I couldn't continue my work in Palliative Care because I was faced with lack of opioids and prohibitive legal restrictions in prescribing opioids. I had to stop my activity until the law changed.

I headed the Department of Anesthesiology in University Hospital. My position was very stable but I couldn't motivate myself or others to commit to Palliative Care.

Currently I am an assistant professor of Anesthesiology and Intensive Care chair of Yerevan State Medical University. These roles provide very good leadership opportunities. I am leading the group I teach. Every time I begin working with a new group of students, the situation is challenging. It requires a lot of time and effort to inspire them to follow me. I feel satisfied when -- by the end of the course -- some of my students say that they want to be Anesthesiologists. For me this is the greatest token of appreciation, knowing that I could light the fire in their hearts.

Luckily, there was certain progress because our Ministry of Health became interested in Palliative Care. MOH formed a Task Force in Palliative Care and I became involved, as a person responsible for education from Yerevan State Medical University. The consultancy of our group was provided by Dr. Stephen Connor, the brilliant, well-known specialist from the World Palliative Care Alliance. Dr. Connor provided the needs assessment in Palliative Care in Armenia, and later become our good friend. Since that time Palliative Care has moved from being deadin-the-water to a very hot topic. I was very much inspired and I definitely feel I am a member of the team.

Gradually, information about Palliative Care has spread throughout Armenia. People, physicians, and the media began to talk about it. Finally, the Ministry of Health launched a pilot

project for palliative homecare. I headed one of the mobile homecare teams. We were very happy to have the opportunity to alleviate pain and other symptoms of patients suffering from cancer.

In parallel, we worked on the legal issues surrounding opioid prescription, following the standards in the guides to Palliative Care.

Those days were very difficult for me. We still don't have oral opioids. Our Oncologists are fighting strenuously to block opioid prescriptions until the last day of patients' lives. It was unbearable. The project started before there were any changes in legislation. Nevertheless, we worked with enthusiasm and spared no effort and time.

But after each challenging patient, I was completely devastated and exhausted. Again and again I asked myself, **"Am I at the right place? Did I choose the right profession? Can I go on?"** The hardest part was treating children. I could not bear the deaths of children. I had a constant feeling of guilt, even though I knew that it was impossible to do anything more. Doubts were increasingly creeping into my mind.

But early one morning about three months ago, I received a phone call that removed any doubt that I was on the right path. That phone call came from a patient's wife. The day before, we had been online all day long while I provided consultancy. She asked me endless questions, and I patiently replied to each one.

But then, for her to call again the next day! I began to feel somewhat annoyed because I had nothing further to tell her. I had already explained everything to her in detail. Regardless, I picked up the phone, and she told me that her husband had passed away. She was calling me to express her gratitude and appreciation -- and that of the entire family -- because their loved one had died very peacefully.

I immediately burst into tears. I cried with them, for them and for me. At that moment, I understood that everything was as it was meant to be. I realized I was, in fact, at the right place in my life and was doing the right thing. I realized that suffering people and their confused relatives actually really needed me! It was an overwhelming feeling!

At that very time, I received one of the regular newsletters from Frank Ferris with the suggestion that I apply to the Leadership Development Initiative Cohort II at the Institute for Palliative Medicine at San Diego Hospice. I applied without any real expectation that I might be chosen. I understood that I had limited experience and no real achievements to my name. It seemed audacious to apply, but anyway, I did. Once I submitted my application I completely forget about it.

Within a month, I received a congratulatory letter advising me that I had been chosen for LDI Cohort II. I looked at this letter for about two minutes before I realized that I had actually been selected!

This is really unique opportunity for me to be trained as a leader. To be a leader in Armenia -formerly one of the Soviet Republics -- is very difficult. It is especially difficult if you are woman. It is particularly difficult if you are a successful woman. You can be placed in any position, you must behave with frank servility and submission, and you must strictly follow the orders and wishes of those who appointed you. Personal initiative in gets punished. If you are proactive, it leads to increased attention -- and our society responds to that very negatively because nobody loves a prominent person. It can be a very painful experience. Western people have real trouble imagining and understanding this situation.

To be a leader you have not only to be tough, clever, organized and disciplined, but very brave. You need to be able resist the tension that surrounds you. Sometimes society begins to put pressure you, and sometimes organizations try to eliminate your position if you do not fit into its structure. But if you're a leader, you are the leader -- and you must embrace that.

I realize that I must do something for those people who are out of appropriate medical service because of the nature of their illness.

I decided to be proactive; I initiated informative lectures in distant regions, and am currently working on postgraduate Palliative Care curriculum which will be taught in Yerevan State Medical University for primary care physicians. I hope that better times for Palliative Care in Armenia are just around the corner. Because I see progress, I am aware that more and more people are becoming informed about Palliative Care service, and we PC specialists are in great demand. This is very encouraging and warms my heart.

The most valuable thing is this: people who have been involved in Palliative Care because of their loved ones' sickness are sharing information about our work, making us increasingly popular. I hope that in the future we can connect with our neighbor, Georgia, and create a good regional Palliative Care network.

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