

International Palliative Care Leadership Development Initiative

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My Leadership Story – The Path to Find a Meaningful Life

Let me begin with a story from October of 2013. I was in Columbus, Ohio, USA. We were just finishing the Leadership Development Initiative (LDI) Program, an international course to develop leaders in the Palliative Care field. We came from all over the world and we had been training and learning leadership skills for two years. It was a wonderful, unique opportunity to share experience in Palliative Care with physicians from so many different countries and cultural backgrounds. More than experience, we shared our life stories. We shared our paths. Somehow, I had a strong feeling that our lives would never again be the same. However it was a tale that needed to be written, so this is my leadership story.

I believe that everyone's story starts in childhood because this period is when our values and personal characteristics bloom. Memories of my childhood elicit strong feelings inside me. I was a lonely child, despite being surrounded by my parents, brothers, cousins, neighbors and friends. Deep inside, I had a feeling of loneliness. I would say I was rather a melancholic child and it was difficult for me to find my place in the world. I often preferred being with adults than with other kids. Books and cartoons were my best friends at that time. I used to ask questions about everything, "Why this? Why that?" People used to say that I was a smart and intelligent boy. This kind of comment made feel proud, but I was still uncomfortable, still looking for my place in the world.

I remember one day when I was about six years old, I started thinking about the purpose of my life and about death. Why should I die? I felt that I would never die. I believed that my

existence, my individuality, my personality could not just end. More than that, I felt I already existed before I had been born. This kind of existential thought that I was immortal -- because I always was alive -- brought me comfort as I worked through the questions of my childhood. I have a strong belief that my Palliative Care story started at that time of my life.

During my adolescence, I was a rebellious teenager. I had an impulse to break the rules and challenge the status quo. This phase caused some problems in my relationships with my family and teachers, but my confrontational behavior was a step in my search for my own path in my life. About this time I started working in a bank and making my own money. I thought I was the owner of my life. I had friends, I had a job, I had money and I had responsibility. In fact, I thought I had embraced my inner truth. However, feelings of loneliness were still a big part of my life. I still had to find my own place in the world.

The transformational point in my life story happened when I was about 17 years old. It was Christmas time, and some friends and I organized a campaign at school to collect toys for poor orphan kids in a children's home. I went into all the classrooms at school to convince other students to support this campaign. It was wonderful to see everyone's engagement in the cause of giving toys to orphans in the children's home. I felt I could inspire others to a shared vision. I realized I could be happy leading my colleagues, encouraging their hearts to do their best on behalf of a shared goal.

As the outcome of this campaign, we took toys to orphan kids from five different children's homes. It was a wonderful experience for me and my peers. To be in touch with these children, each with a story of suffering and abandonment, brought me a sense of gratitude for my own life. I realized these children were part of me, a part of me that was in pain. Maybe I could do something to heal this illness.

That was the point! I was finally able to do something to mitigate this suffering -- not only the children's suffering but my own personal suffering, too. I could become a healer.

Finally, I had found a meaning for my life. This experience changed me forever. The feelings of loneliness were gone. I finally realized that to be happy as a whole person, I would have to do something to make others happier.

This self-awareness guided me in choosing my career. It was clear to me that I would thrive in a job where I could do and be my best. I needed a career aligned with purpose and meaning. With this in my mind and in my heart, I chose to go to medical school to become a doctor.

I started medical school full of the best intentions to be a dedicated physician and help people in times of illness. However, medical school taught me to diagnose patients and to offer treatment for disease. Doctors had the scientific knowledge and patients had to follow their directives. It was like the sheep following the shepherd. It seemed like doctors were superior to the others. The majority of my teachers and senior physicians did not see patients as human beings, but only as complex machines with broken parts that needed to be fixed. I was very disappointed.

Despite that, I studied hard and learned a lot during my medical school days. The best part -- or at least the part I liked most -- was the practical bedside training with patients and their families. These people had wonderful life stories behind their diseases. I felt privileged that they let me know them as persons. Patients and families looked at me not only as somebody who could give them a diagnosis and some medicine, but as somebody they could trust. They showed me -- and they led me to my role as a doctor. They taught me that I would be with them to take care of them, opening doors and windows and showing pathways, but nothing more than that. They were the captains of their lives, but they appreciated having a doctor whom they could trust. I am not afraid to say that my patients were my best teachers.

My encounter with Palliative Care began when I was starting my fellowship in geriatrics. I have to confess that it was love at first sight. I had graduated in medicine three years earlier and I had completed my residency in internal medicine, suffering through Brazilian medical priorities in emergency rooms and intensive care. But I asked myself, "What about the dying patients with chronic diseases? What about seniors, the very elderly patients dying alone in ICU without specific instructions to be there? What about patients dying in unrelieved pain and suffering? What about the families?"

Palliative Care, as a philosophy of care and as a medical specialty, provided answers to these questions. In 2004, I started as a volunteer in Palliative Care in the small outpatient service at the Internal Medicine Department of Hospital das Clinicas, in Sao Paulo University, Brazil. Everything was new for all of us in this service. We were full of ideas and were excited by this new knowledge called Palliative Care. For us, it opened up new opportunities to help patients and their families in a special way. I found myself comfortable in the role of a doctor who took care of patients, who took care of suffering in different life dimensions -- not solely in the dimension of physical distress. Happily, I was in a medical specialty that took care of human beings, not machines.

As a pioneer in Palliative Care in Brazil, I was invited to lead a new-born department of Palliative Care at Barretos Cancer Center. Barretos is a small city in the countryside of the state of Sao Paulo, Brazil. Although the city was small, the Cancer Center was huge. The Palliative Care unit alone had 62 inpatient beds. We received more than 100 patients each week in the outpatient consultant service, and in the homecare service, we visited about 15 patients each week.

At that time I was just 28 years old. I can state that I was a good doctor to my patients and their families. However, I did not have any previous experience as the leader of a team. I was the head of the Pain Control and Palliative Care Department at a big cancer center, but

unfortunately I was not trained to be an effective leader. Of course, I had learned a lot during the four years that I was in this position. I grew as a person, as a doctor and as a leader during this phase. I am sure it was one of the hardest times of my life, however. I learned under pressure -- and with a lot of heartache, maybe moreso than that of my cancer patients in Palliative Care. They had a team to take care for them, and I was on my own. Once again, though, close contact with patients and their families was the painkiller in my growth as a leader. They raised me up and I became a better person than I had been before that experience.

It is true to say that life changes all the time. Happily, in 2009 it was time to move back to Sao Paulo, the biggest city in Brazil and a place where I had friends and other opportunities to learn and grow. That was the year when I was invited to join the board team of Casa do Cuidar, a nonprofit organization that advocates for education in Palliative Care for healthcare providers and healthcare organizations. At the same time, I had the opportunity to become a doctor in the Hospice of Sao Paulo Cancer Institute. It is the biggest hospice in the state of Sao Paulo with 50 beds and lots of opportunities to learn more in the field of end-of-life care. I was happy starting a new life with my family.

In 2010, I joined the Visiting Scholarship Program at San Diego Hospice and the Institute for Palliative Medicine in San Diego, USA. It was a wonderful experience. I spent one month at San Diego Hospice with other doctors from different countries -- learning about Palliative Care, sharing experiences and becoming aware of ourselves as persons and as Palliative Care leaders in our home countries. Being part of the routine in a center of Palliative Care excellence opened my mind to the wonderful things that I could achieve in my home reality in Sao Paulo.

When I returned to Brazil, I was full of new ideas and I tried to implement them. Although I wanted to improve my practice and transform the places where I used to work, I had to find a way to overcome some barriers. However, I lacked the skill to do that. The institutions and the people who worked there did not want to move or change. They were comfortable in their positions.

By 2011, I knew I was not happy with my professional life. I realized I needed to acquire leadership skills. I was aware that the second cohort of the Leadership Development Initiative (LDI) was about to begin training in San Diego in 2012. I applied to become a Leader and was invited to join this group. Sometimes when you feel inside that you are lost, you must find a way through -- find a light to follow. You need a new goal for your life. It was not clear to me at that time, but I needed to follow a different path. LDI opened the gate for me to walk through.

When I began the Leadership Development Initiative, I clearly knew that this was the most appropriate time for me to embrace change. What followed with LDI were two years of improvement in self-awareness, growth in leadership skills, and development of a new kind of personal relationship – the mentor-mentee relationship. I was able to be in touch with people from all over the world. We could share many unforgettable moments together.

More than that we shared values, we shared a vision of a world with no more unrelieved pain and suffering. We built a big world Palliative Care team. Personally, I realized that to accomplish different outcomes I would have to do things in a different way.

What will be the next steps? Actually, I do not know. I do know that I look forward to use all the tools I have learned during these past two years. I am confident and prepared for what the future has prepared me for. I recognize my pathway in Palliative Care as an ascendant spiral -- a spiral that will take me to the core meaning of my life.

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