

THE INSTITUTE FOR PALLIATIVE MEDICINE at San Diego Hospice

INTERNATIONAL PALLIATIVE CARE Leadership development initiative Sofía Bunge, MD, Buenos Aires, Argentina



"We will either find a way, or make one." "Encontraremos un camino y sino, lo crearemos."

(Anibal Barca, 247-183 B.C.)

A feature of my personality throughout my personal and professional life, which I still retain today, is the ability to see difficulties as opportunities. This is known as 'optimism' and for some it is seen as a defect, for others a virtue. However, I think that optimism is what has allowed me to grow and project myself beyond events and circumstances.

I was 15 years old on a school trip with 40 fellow students. When we were 1,770 kilometers away from our home town of Buenos Aires, we were involved in a bus accident at 3:00 a.m. We were taken to the Emergency Room at Jujuy Public Hospital and the whole hospital was mobilized and took care of us. Some of us had wounds, others had fractures -- we suffered all different kinds of injuries. Some of us were under observation for several hours, others stayed in hospital for months and had to undergo several surgeries. We cared for each other, we visited each other, and we all finished school that year.

After completing high school, given that there are lawyers and architects in my family background, I entered law school. As I was finishing my first semester, I realized law wasn't my vocation. The experience of the bus accident a few years earlier had marked my life. I felt I wanted to serve and help others, as I had been cared for few years before. I decided to change my career and enter medical school.

I graduated as a physician in 1996 in Argentina. I chose to do my residency in Internal Medicine in the Buenos Aires British Hospital (1997-2001). However as soon as I started, I knew that once I completed the residency I would want to specialize in another area. This was a gradual realization, but I felt I needed to know more and gain more confidence in what I was doing.

In the British Hospital, clinicians coexisted with other specialties. We shared the follow-up of patients in the surgical area -- involving cardiology and oncology among other medical fields. Undoubtedly the first time I felt anguish, triggered by a lack in my training, was when I began follow-up work with cancer patients who had uncontrolled pain. I knew nothing about them, who they were, or what their problems were. Most importantly, I had never been taught to alleviate their suffering. I didn't know palliative care existed. What I knew about the treatment of pain was insufficient to address their problems. They were patients with uncontrolled symptoms. And there we were: clinicians, lacking proper tools, disoriented, asking peers, superiors, unable to find solutions or do anything about the pain -- despite the fact that we were doctors.

I felt frustrated and helpless meeting people in severe physical, emotional, and existential distress, yet not knowing what to do to improve their situation. We graduated as doctors, nurses, dentists and pharmacists, but the truth of the matter is that we were trained how to cure, not how to care.

I remember feeling distressed when I opened the door to their rooms. However, I connected with my empathy and compassion. Despite the limitations from my training in medicine and pharmacology, I took care of these patients by providing support and being available for them.

I was not satisfied with this reality. I was an internist providing highly complex treatments, but with limited tools to meet the needs of this particular group of patients and families, with no guidance other than my own intuition, common sense and humanity, and with no palliative care skills or knowledge learned during my undergraduate degree.

At that time, I was in the middle of my residency in Internal Medicine at Buenos Aires British Hospital and I faced the dilemma of what direction I would next take. I had a colleague who was Chief of the Emergency Ward. She and I studied difficult, complex cases together during our Sunday shifts and in our free time.

It was she who said to me one day, "I was at a dinner with friends where one doctor talked about something called palliative something.... She explained what it was, how they work with patients and I think it's for you. I think that's what you're looking for. I talked to her about you and she is waiting for you to call back."

The palliative care doctor in question was Mariela Bertolino, Coordinator of the Palliative Care Unit at the Hospital Tornú in the Programa Argentino de Medicina Paliativa-Fundación FEMEBA (PAMP-FF).

I called Dr. Bertolino and went for an interview to the PCU (PAMP-FF). I agreed to do a clinical rotation exercise and registered for the palliative care course they were offering.

I still remember how I felt when I started looking into palliative care. "This is me, this is my place in medicine. It is what I dreamed about when I went into medicine." This 'new' way of practicing medicine in an integrated manner, looking at the individual and the family as a whole, made me feel more comfortable in my practice. It was a caring approach. I noticed that palliative care workers paid full attention, focusing and listening to the patients' needs and assessing their symptoms. I realized that 'doing palliative' is not just about prescribing medicine appropriately, but more about respecting the person for whom we are caring. Many times doctors just write down symptoms and prescribe drugs, but some patients need much more than that.

And I had a dream, "This is the place I would like to be."

I learned about the small big things in life. For example, just because one is a doctor, we do not have special rights such as opening doors without knocking, or initiating a study without notifying the patient, etc. I saw that I could do things differently, and the style of the traditional health system wasn't the only way to deal with patients.

As my goals were becoming clearer, some personal boundaries emerged. Using morphine was the first of those. I had many fears about the risks involved with morphine. I felt that as a clinician I had no authority to use or prescribe it. Hence, my first challenge was overcoming my own "opioiphobia", to educate myself on the use of opioids and learn to feel comfortable prescribing them.

A second challenge emerged when boarding the patients. I discovered that when we finally control the pain and manage the other symptoms, we then face the individual -- with his/her joys, fears, losses, regrets, life circumstances, personal and family problems. It's like opening Pandora's box when you realize that symptom control is not the end, but rather the beginning.

Once I completed the palliative care course and clinical rotation in the PCU (PAMP-FF), I was in my fourth year of residency and had the opportunity of a two-month rotation abroad. I chose to spend one month with the Grey Nuns PC Unit in Edmonton (Canada) and another month in St. Christopher's Hospice and King's College, London (UK). Both are models in PC where I experienced the essence of palliative care. I learned that palliative care is a philosophy, a way of doing things, and that there are no geographical barriers. We all can do PC.

On my return, a nascent project was waiting for me: developing a palliative home care program with the Head of the Oncology Department of the British Hospital and palliative care doctors I had known in Tornú Hospital. We worked together with doctors, psychologists and nurses, among others. The program lasted until 2003-4 when it was disbanded as a result of the economic crisis in Argentina. This crisis was terrible and devasted all aspects of our national systems. Devaluation occurred, there was no available cash, medical supplies (payable in US dollars) skyrocketed in price, and many institutions faced economic calamity.

After I finished my residency, I was absolutely sure I wanted to devote myself to palliative medicine. By this point I had acquired additional tools. Once a week I participated in the Palliative Care Unit of Hospital Sommer (PAMP-FF). On June 2001, I was called for an interview with Mariela Bertolino for a possible job, and in August I started working at the PCU of Tornú Hospital PAMP-FF. I was fulfilling my dream.

What initially began as a solo personal search became reoriented and transformed into a group endeavor. No step of my professional career in palliative care would have been possible without the context of a team. Teamwork enabled me to make the passage from "I" to "we" and completely changed my approach to medical care.

Working with the team brought me into the world of teaching. The PAMP-FF, led by Robert Wenk, dedicates considerable time, effort and activities in teaching different courses and levels.

On 2004 my husband received a great job offer in Olavarria, a city 350 kilometers from Buenos Aires. It was a very hard decision for me to move, though, because I had to quit my job. I was very happy with my role and being part of the team. Fortunately, the team suggested I could keep working with them, and were able to rearrange my responsibilities and activities. Now I work long distance, travel to Buenos Aires once every two weeks, and I was able to start a palliative care program in Olavarria – all while remaining part of my team.

This led to an opportunity to enrol in a course on E-Learning with the University of Calgary, CEDER. It was my first experience with distance learning and with e-learning. Once again I was student on a course -- this time online interacting with learners from different countries. It was tremendous to have the experience of learning this technique. Shorly afterwards a proposal came along to create something similar for our Palliative Care Program: a distance-learning course for doctors and nurses in Spanish for Latin America. Through this program, we were weaving a huge dream for palliative care to be included at the undergraduate level with the Faculty of Medicine at the Universidad Austral , Buenos Aires. All this began to take shape in 2010. Thus, the initial motivation to specialize and build my practice was joined by another goal: to continue spreading palliative care.

Since 2010 I have been a participant in the International Palliative Care Leadership Development Initiative at The Institute of Palliative Medicine at San Diego Hospice. LDI has been a great opportunity to improve my self-confidence. I am doing a lot of self-reflection.

I was given tools to recognize the importance of identifying our circles of influence, keeping focused, seizing opportunities, continuing to work as a team, and collaborating as part of the development of palliative care.

Today, in addition to LDI assistance, what encourages me most is the opportunity to advance palliative care making it available to more people, the community, professionals and patients. It is a matter of educating and raising social awareness that there are specialized teams -- professionals who can do a lot for patients/families with advanced diseases who are facing pain and suffering -- abandoning the old belief that medicine has nothing new to offer. This is the challenge I face now, both from a professional and personal point of view.

As a team, we are motivated to project and promote palliative care, and contribute to its expansion and dissemination. This may serve as a model: when someone in Argentina or Latin America faces an end-of-life situation, we hope he or she will remember that palliative care exists and that help is possible.

Integrating palliative care philosophy changes the perception that we have as professionals and as persons. Not only does this type of assistance actually enhance the patient and family, but also ourselves.

Without doubt the biggest challenge for the future before us is to ensure palliative care expands beyond the experience of those who practice palliative care today, spreading it to other areas of health care. We must promote that palliative care means we work as a team, contributing to a more human-oriented medicine that integrates with medical technology today, and is an integral part of the comprehensive care of people.

For all these reasons, I find it difficult to conceive any hardships as 'barriers'. All these obstacles along my path eventually turned out to be wonderful opportunities that have opened doors to interesting pathways filled with riches, both academic and spiritual. It's the creative path of transformation in this art which is Medicine.