



Palliative Care: A Life Philosophy

It has been a year since I sat alone on the balcony of my home staring at the sky and the stars. It was cold and calm night. I had just received a call from potential partners to establish a model for palliative care in Jordan. My proposal was rejected like many others before. They liked the idea, but they were not ready to take the risk.

I started to sing and repeat, "I have a dream...." My wife joined me and asked, "What you will do now?" I replied, "It is so clear to me at this moment. I can see the future of this initiative, yet nobody else can. Not from the public sector, private or NGOs. I will do it alone!"

There are many moments in our life that are critical in shaping our personality, our way of thinking and our character. Nevertheless, I will not forget the great 'click' which happened to me when I was invited to attend a course for palliative care in King Hussein Cancer Center (KHCC). They told me that the course would be given by a group of health care workers from the Institute of Palliative Medicine at San Diego Hospice under the leadership of Dr. Frank Ferris.

When I joined the course, I had anticipated it would be a chance to learn some skills in pain management and end-of-life care. As we moved into the bedside teaching phase, I began to experience a great change in myself regarding my career and practice.

The holistic approach to suffering, the passion and the teamwork gave me the answers to many questions that had gone unanswered for the previous two decades. None of my teachers had been able to address these subjects. From my earliest days as a medical student, I often wondered about the role of physicians. Were we to prescribe pills and not pay attention to the suffering of our patients? What about social, psychological and spiritual issues? Most importantly, what will happen to us when we ourselves become older or terminally ill? How do we promote our quality of life? How can we better understand the value of our life?

Palliative care was a difficult step for a young physician in a country where the concept of palliative care was not well established and the pathway was not clear. In my practice of internal medicine, I

could see patients suffering, yet we were unable to help them. Was it not our job to relieve their suffering and maintain their dignity? What about patients who spent days and weeks in the ICU suffering and paying extra money when their condition was completely hopeless?

But I saw it as an opportunity for making real change in my society. Perhaps I could pioneer palliative care because if not, who else would step up to help these unfortunate people?

My thinking was simple: I just discovered myself at that very special moment when I first met Dr. Frank Ferris. I had no fear of the future as long as I dedicated myself to this mission. I could not wait for opportunity to find me -- I had to seize this chance to create my future and develop palliative care in Jordan. It was clear to me. I knew that the real risk lay in *not* taking the step forward, and this was the right opening for me. I must not let it pass me by.

I said, "Dr. Frank, thank you so much for this great course. Please tell me, how can I become a palliative care specialist?" And that was the beginning.

More than six years have passed since I started my palliative care career by joining the international fellowship at the Institute for Palliative Care at San Diego Hospice, and working at KHCC. We were proud that we managed to establish a model for palliative care at KHCC but I have come to realize that success is limited to certain places in Jordan. Today the majority of Jordanian patients who need palliative care still have no access to it.

I had many ideas, such as creating home care service to serve patients anywhere in the country, creating training and education centers to teach palliative care for health care workers, and offering wellness areas for out-patients. While these were good ideas, clearly they were not of interest to the KHCC administration.

This led me to question how long we must continue to attend international meetings just to listen? Can we not have our own experiences that we could share and that would inspire others? Can I use what I have learned through palliative care to help people enjoy a more peaceful and meaningful life? To achieve this, I knew I needed to leave KHCC and build a palliative care centre that realizes this vision.

As I looked beyond the palliative care unit at KHCC, I realized how many patients were suffering from pain. Their lives were destroyed by their disease life stressors. I knew that palliative care provides the perfect solution for these people, and I could see how to apply it. I could see that we could build a culturally-sensitive model for palliative care in Jordan.

Yes, I had the vision and the passion, but I did not have the power. I spent more than two years trying to convince others -- at KHCC and outside KHCC -- to share this vision and transform it into action. I failed again and again. For some time, I felt frustrated. I was unable to realize my dreams and I was limited by those who didn't share my vision. It seemed that there was no move forward.

But then I reconsidered and thought of 'bit-by-bit' gains. Maybe God closed one door, but at the same time -- perhaps -- opened other doors. I just needed to look, listen and pay attention. Oh yes, I realize that many people only respond to actual, tangible proof -- not theories written on paper. I knew I had to do it my own way -- and alone.

I conceived the first palliative care clinic in Jordan in September 2011. In this simple 110 metre square, my dreams were to come to life: pain management, family meetings, holistic approach,

wellness, a monthly club. It would take a year to settle in and then we would start academic teaching, training and much more.

I was elated and excited while many others were surprised. Some liked the idea and supported me, and others thought it was doomed to failure. Fortunately, my mother and wife were completely supportive of my vision.

The challenges in the first year were huge: resistance, partners who failed at critical moments, limited income, and a huge workload. But I remained completely satisfied, motivated and optimistic. Perhaps my enthusiasm comes from seeing the future clearly and enjoying the taste of freedom. Furthermore, I am continually learning so much every day and things are full of promise and reward, thank goodness!

It has been almost a year since I moved to my private palliative care clinic. This was followed by launching the Jordan Palliative Care Society (JPCS). The clinic and the society work like twins: I am leading both organizations and they occupy the same physical space.

When you come into my clinic, you can see, touch and smell my dreams. It is here where we see patients with chronic illness and provide pain control and relieve suffering. It is here where interdisciplinary teams work together. Every month, the clinic invites people for a talk about issues related to quality of life. In this place, the JPCS plans training for future leaders in the field of palliative care. The wellness room is the place for relaxation, meditation and stress management.

Yes, it has been a year since this venture began, but the goal remains clear: building capacity for a palliative care clinic and making palliative care available to Jordanian people. And now, we have just begun the next phase. As I prepare for the new year of 2012, I have established the Bushnaq training and development center. We have started teaching diploma courses in palliative care and pain management, along with a variety of courses and programs for health care workers and the general public.

For both the clinic and JPCS to thrive and be effective, we need to plan projects in collaboration with strategic partners. But the truth is this: no matter what the challenge, it is the vision and the ability to share dream with others that will lead to success.

The timing was difficult, especially considering what is going on currently in the Middle East. Many friends may let you down at difficult times but I learned from the experience.

I learned to give more but expect less.

I learned to walk alone for a while until I inspired others to follow me.

I learned that rewards can come from unexpected results.

I learned that taking calculated risks will never fail you.

This is how you trust God. Nothing is more rewarding than being under your own control, working with a group of people for a great goal.

Meeting a group of people for five minutes might be enough to change the life of one person. So be careful what you say to them!