



If You Can't Be the Sun, Be a Star!

"If a man write a better book, preach a better sermon, or make a better mouse trap than his neighbour, though his house be in the woods, the world will make a beaten path to his door."

Ralph Waldo Emerson

Influences

If you can't be a highway, then just be a trail.

If you can't be a sun, be a star.

It isn't by size that you win or you fail.

"Be the best of whatever you are!" (Lines quoted by my father.)

A locum post in the psychiatry department, caring for a patient whom no one else wants to see.
Listening, listening, and then again listening.

A neurolytic block for a patient with cervical cancer, alleviating the misery of a young lady by a simple procedure.

My affinity for vulnerable people.

My Strengths

My mother who has always encouraged me and supported me in everything I do. She has done everything possible (sometimes at a huge personal cost) to help me achieve my goals. We -- her

children -- always came first in her list of priorities. She is the first person I call when anything happens in my life.

My husband Shabbar who has shared each triumph, wiped many tears, helped type assignments, critiqued my presentations, and helped (and rehearsed with me!) with difficult negotiations.

The Beginning

In 1997, I was appointed along with a surgical oncologist, medical oncologist, radiation oncologist and pathologist.

Our challenge was to start the first comprehensive cancer centre in the state of Rajasthan, India. This is one of the larger states in the country with a population of 58 million people.

Ours is a centre run by a Religious trust. In the initial four-to-five months, the patients gradually trickled in. Almost all of them were incurable, or with a recurrence, or were not responding to therapy. My oncologist friends had no treatment to offer and referred these patients to me because they knew that I wanted to establish a "Pain Clinic".

I wanted to give nerve blocks and eradicate pain.

But most of these patients had pain which was not amenable to neurolysis. What was also worrying was that many had major symptoms without any pain. I did not know what to do with these patients!

The Challenge

I needed to see an entirely new population of patients. I did not have the knowledge or expertise to take care of them. Surely, compassion was not enough.

The hospital trustees and other colleagues had not heard of this discipline of Palliative Care. In those days very few of us had access to computers or the internet. Furthermore, information was jealously guarded and textbooks on Palliative Care were not available on the internet or in the stores. In fact, these resources are still not available in any bookstore in my city, which is the capital city of one of the larger states of the country.

A colleague gave me a photocopied version of one of Dr. Twycross' early books on how to treat pain. Our head of Department of Surgery, Dr. Patni, had had the foresight to apply for a morphine license very early on. He had worked for several years at Tata Memorial Cancer Hospital and knew how important morphine was for cancer patients.

From 1997 onwards, our hospital has been the source of almost all the legal morphine in the state. Initially, access was sporadic but for many years now it has been available in a steady and uninterrupted supply.

On April 24, 1998, I formally notified all the trustees and all five colleagues that we had started Pain Relief and Palliative Care Services in the hospital. My colleagues were most supportive as were the trustees. I used all available resources to look for a method to teach myself Palliative Care. My husband Shabbar downloaded all available literature, courses and algorithms.

Meanwhile, our founder trustee developed metastases and pain. He was one of the first patients whom we saw at home for palliating the pain.

Opportunity: Life-Long Learner

*"In my walks every man I meet is my superior in some way,
and in that I learn from him."*

Ralph Waldo Emerson

In 2001, we heard that at a centre in Calicut, Kerala, Dr. Rajagopal and Dr. Anil were planning a 10-day course in Palliative Care. Seats were limited and applications would be screened by a committee.

I was delighted when my application was approved! The hospital management agreed to give me a 14-day leave.

Then as luck would have it, an American team of Urologists wanted to conduct a free Paediatric surgical camp at our hospital. My hospital management would not allow me to go traipsing off to Kerala when a surgical camp was to be held. I could not hold it against them, considering that I was the only Consultant Anaesthesiologist in the hospital.

In 2003, I had the opportunity to do a course in Pain Management at The Royal North Shore Hospital in Sydney, Australia. I did a course in Acupuncture and I attended CMEs at conferences.

Dr. Rajagopal sent me details of a course in Palliative Care run by Flinders University. IAHPG gave me a grant to study in a unique environment at Singapore's National Cancer Centre with Dr. David Currow, Dr. Rosalie Shaw and Dr. Cynthia Goh as faculty. They inspired me to be a 'life-long learner'.

Learning the art and the science of Palliative Care wasn't easy. It has been a difficult journey. From an aggressive "Cure" and "CPR for all" approach to "comfort all" and "AND" (allowing a natural death) has been a gradual, painful but rewarding process. Every time that I can relieve someone's pain or help a family, I feel blessed. But, there have been "difficult pains" which I could not treat, suffering which I struggled to alleviate.

Again, Dr. Rajagopal gave me the opportunity of attending a boot camp organized by the American Cancer Society. One opportunity led to another. I received a grant from The American

Cancer Society which I used to appoint a doctor, nurse and psychologist and buy a syringe driver.

The bereaved family of one of my patients donated syringe pumps. One thing led to another. Others sponsored free medicines and school fees. Dr. Vivek Khemka, Dr. Rajagopal and I -- along with other colleagues -- worked on EPEC India. The Indian Association of Palliative Care recognized our centre for its certificate courses.

This led me to Dr. Mhoira Leng, the Indo American Cancer Association grant, and the Leadership Development Initiative (LDI) at the Institute for Palliative Medicine at San Diego Hospice and OhioHealth.

Today, we have a full-fledged department staffed by five part-time consultants, four residents, a Clinical Psychologist and two nurses. We see approximately 300 patients a month in the outpatient department. We have started free homecare, free day-care and in-patient care over the last 15 years. We teach and train, and we conduct small research projects. We help in educating the bereaved children of our patients.

It is the only department in the state.

Hard Work

"Heights by great men reached and kept were not obtained by sudden flight but, while their companions slept, they were toiling upward in the night."

Henry Wadsworth Longfellow

It has been a hard journey, for the mind, body and spirit. We were setting up the state's first comprehensive cancer centre. We were struggling to provide Anaesthesia Services, Critical care services, Central Venous Access and Acute Pain Management. It was a lot of physical work. There was also the tremendous mental strain of a new environment, new colleagues and huge responsibility. On the personal front, my family pitched in, helping to take care of my children.

Since I was one of the first few doctors employed by the hospital, I have had to start everything from scratch. In the last fifteen years, I have set up the department of Anaesthesia, the operation theatres, the Intensive Care Unit, Acute Pain Service and the Palliative Care Service. We started the IAPC course and ran the DNB programme in Anaesthesia.

Yes, I have had to work very hard, and I learned only recently that being a workaholic can be a risky thing.

Audacity

Along the way there have been times when there has been a difficult decision or an unexplored path -- and I have been scared to take the next step. One has to be audacious to walk into a

Minister's office, to commit to doing something beyond your personal experience in order to help your cause.

I have hesitated often, but when I have taken the courage to do something bold, it has usually been rewarding... Like the time I went to a high-ranking official in the Ministry of Health requesting him to depute ten doctors and nurses for training. After three meetings, he deputed 243 doctors and nurses!

One thing led to another, and this year the Chief Minister announced the posts of lecturer in Palliative Medicine in all medical colleges in our state. This is unprecedented and a first in the country.

What Next?

*"For I have promises to keep and miles to go before I sleep,
miles to go before I sleep..."*

Robert Frost

With Pallium India, we have initiated a six-week intensive course in Palliative Care at our centre. This is the only centre in North India!

The big picture? I want our centre to be recognized as a centre of excellence for Palliative Care in the country. I hope to start a post-graduate programme for doctors – an MD in Palliative Medicine. I know it will take a long time and much more hard work.

Reflection

I don't see anything unusual in my story. I see it as a job that needed to be done. No one was there to do it so I had to do it. I am simply a pragmatic clinician who tries to do her best. The challenge for me was, "How to go about it?" So I set about acquiring the requisite skills. The difficulty was doing this alone.

I chose to do it, though I was not paid for any work in Palliative Care and was being paid really badly even for my Anaesthesia duties. More than once, I have been given the opportunity of working in more lucrative settings, but those hospitals did not have Palliative Care. Therefore, I'm staying the course in my current position.

You might ask, "Why?" The response is, "Satisfied patients and families, the satisfaction of relieving pain, the joy of connecting, the ability to make a difference. I also experience the joy of teaching and meeting new people."

The stress comes from doing Anaesthetics, Critical Care, Acute Pain, Central Venous Access and Palliative Care all at the same time. I have given up being part of Critical Care. Now I only do Anaesthetics, Acute Pain, Central Venous Access and Palliative Care. And that is such a relief!

There is a proverb in my mother tongue of Urdu which I am paraphrasing. This is the guiding principle for my life:

*"Make yourself so strong (so good, so competent, so skilled)
that when God decides your future, he will ask you what it is that you want to do."*

Carpe Diem!

*After death, God will decide your fate depending on your answer to two questions:
Did you find joy? Did you bring joy?*

Egyptian proverb

Seize the moment, grab the opportunity, and live each moment!

The patients I see in my clinic have had an impact on me, my goals in life, and my relationships. There are many patients whom we are able to help, for whom our medicines, our ears, our time and therapy work. But every day you hear stories which break your heart, many "Whys?" to which you have no answer. They make you value your family, your health, your life.

When I went to Sydney for my Palliative Care course, naturally I did the course. I also went to Taronga Zoo and fed the Koalas. I wrote to Professor Michael Cousins for permission to be an observer at in his unit for a week. I attended grand rounds at Royal North Shore, I observed his chronic pain blocks, and I attended multidisciplinary meetings. I went for a bush walk, I spent time with a dear friend, I explored Hunter Valley, and I went cheese-and-wine tasting. I got permission to observe the ICUs at St. Vincent's. I tasted Damper bread (no billy tea, though) and listened to the didgeridoo. I observed the use of sevoflurane (which was not available in India then) in the St. Vincent's ORs and climbed up Harbour Bridge (yes, you *can!*)

Am I burning out? Am I working too hard? I don't know...but I do know I am blessed.

By the grace of God, I have the love and support of my husband, children, parents and parents-in-law.

I am doing work that I enjoy -- treating, teaching, negotiating, and badgering. Not to mention eating, singing, mourning, and growing. That satisfies and often exhausts me but I get to see the world. I get to eat all kinds of food. The latest treats were Tilapia Fish Tacos in San Diego and Haggis in Edinburgh.

I also enjoy new experiences – like seeing a breaching whale and the sun setting on the Pacific. It is a privilege to learn and to teach. I have new mentors, more friends, I acquire new learning every day, and I am actually (in a small way) giving back to Society. I hope and pray that I will always grow.

I don't think I'll ever grow up, though!

Anjum Khan Joad, MD, DNB, MNAMS

Department of Palliative Care Medicine

Bhagwan Mahaveer Cancer Hospital and Research Centre
Jaipur, India