

International Palliative Care Leadership Development Initiative

## Chitra Venkateswaran Kerala, India



## **My Leadership Story**

"Two roads diverged in a wood, and I – I took the one less travelled by, And that has made all the difference." Robert Frost

I shall be telling this with a sigh Somewhere ages and ages hence:

For me, the journey of my life is essentially related to the way I have grown as a doctor and an individual. To care for others and make a difference to another person's life means so much to me. To reflect on self and introspect has been my nature. This adds to my need to care for others and self.

My father was in government service and served in different parts of South India. Moving from place-to-place and into geographical regions with different languages and cultures, there were occasions when lack of and continuity of medical care were an issue.

Thus, when my mother often used to express that one of her children should be a doctor, it had both personal and social dimensions. To become a doctor was a matter of respect and pride. These have encouraged me to go forward into this field.

I think that my choice also signifies the values that have been instilled in our childhood by the culture in which we grew up, holding great significance for compassion, relationships, sense of equality, general and social justice.

In addition, while growing up I remember having many friends. I still have. I help them out often, sort out issues and provide solutions. When I look back now, I always had a compelling urge to balance needs, vulnerabilities and meaning.

There have been several crossroads in my life, and each time, there has been a road of convention and a road less travelled. I have often chosen the latter. The roads have been often a rocky path. I have fallen down and hurt myself, but I have picked up myself to continue the journey.

I graduated in medicine from the Medical College in Trivandrum, South India, and then came upon diverging paths. I had begun my post-graduate specialty training in Anaesthesiology in the All India Institute of Medical Sciences (AIIMS), in the national capital of New Delhi. AIIMS was considered one of the premier medical training centers in India. There were many who regarded such a training post prestigious; I was very lucky to get such a post. But deep inside, I had a restlessness which kept questioning me, "Am I doing the right thing? What did I want to achieve as a medical professional?"

This constant search for a role which I could identify with my inner need finally led me to choose a specialty on the other end of the spectrum. I chose Psychiatry which was -- or still is -- regarded as one of the less glamorous specialties in India. The challenge for me was to take a risk, a step which would enable me to do something for a group of people who are ignored, neglected and not allowed to be part of mainstream society. I had the opportunity to access the popular and remunerative areas of medicine, but I am so glad my goals soon re-established to deeper issues and altruism.

Specialising in Psychiatry was certainly not the "in thing" among a large number of my peers. I was deeply troubled by the stigma with which a psychiatric patient was perceived by dominant sections of Indian society. I wanted to contribute something to reduce this stigma -- in whatever little way I could. This field involved elements of adventure, struggle and opportunities. Working in mental asylums, understanding the distress of families, the enormous burden of stigma, poverty and paucity of community-based facilities -- all this deeply stirred me.

I was fortunate to have trained for Psychiatry in the medical school in Calicut in Northern Kerala where, around the same time, Palliative Care was gearing up to become a pioneering movement under great people like Dr Rajagopal. I consider this as a significant milestone in my journey because Palliative Care plainly provided me with the much-needed foundation. I clearly recall Dr. Rajagopal encouraging me to take the "risk" of moving out of my comfort zone and step into a new world. I took the challenge and went ahead into a new horizon.

To grow in Palliative Care with my background was unique in many respects -- and at the same time, it was a daunting task. My role was unconventional in the realms of Palliative Care. It was a great challenge -- and often a struggle -- to perform to both as a Palliative Care physician and a psychiatrist.

A different kind of struggle emerged, too, because of conventional perceptions within the Palliative Care community. Basically, Palliative Care was quite rooted in physical pain management. There were times when psychological and emotional issues were missed -- or were not properly addressed and managed. But the leadership of the Palliative Care group with whom I worked clearly understood this value.

My main agenda was to integrate the psychological care into all levels -- clinical, education and research. A significant component of my work was to empower and enable the team members, including innovative communication skills training. As well, I provided supervision and support to volunteers to offer psychological care. Further, my focus was in introducing modules in advanced communication skills (in the local language) and of psycho oncology in existing courses, and training the team members -- in particular the volunteers. I initiated research projects related to screening of psychological distress in Palliative Care.

I also had the opportunity to present our work in national and international forums, especially the International Psycho oncology Society (IPOS). I had the chance to share, listen and learn from experts all over the world.

In 2004, I moved to another part of Kerala, and continued working with Palliative Care in Kochi with a specific role as a psycho oncologist at Amrita Institute of Medical Sciences, Kochi. I actively continued to promote and integrate psychological care in Palliative Care.

Slowly but steadily, psychiatric care was accepted as part-and-parcel of Palliative Care. I also had opportunities to spend time in Leeds, UK, as part of an UICC Fellowship (American Cancer Society Beginning Fellowship) in 2005.

I consider this phase of my life to be a turning point as it gave me insight into the manner in which I wanted to continue as a doctor. Time away from my usual setting made me realise that I had to do something that followed my heart. Community-based services with a social dimension were something with which I identified completely. In addition, being part of the innovative Palliative Care movement helped me to plan the nature of my work later in my life.

All these experiences crystallised my vision, leading me to focus on the interface between Palliative Care and mental health. In 2008, I decided to take another road less travelled. I founded a community-based mental health service (Mehac Foundation- Mental Health Action) based on Palliative Care philosophy and practice. Mehac also means Fragrance in Urdu, the fragrance hoping to dispel the darkness in the lives of suffering people.

The crux of how Palliative Care has been integrated into this model is that we reach out to people with mental illnesses and their families -- at their homes -- and provide long-term holistic care. The group consisted of pioneering volunteers from Palliative Care, psychiatrists, socially-committed writers, close friends and family.

Our focus was to establish partnerships with Palliative Care teams, to include mental illnesses as part of the various chronic diseases we looked into, to deliver care as a team, and to provide homecare services. We have successfully offered long-term care to at least 1200 patients since 2009. We have been able to develop models to deliver care suited to local needs. As before, I have focused on integrated models – training and awareness programs with our clinical work. The next step is to start developing research projects.

Recently the National Rural Health Mission (NRHM) -- a national health scheme focused on strengthening health services in rural India -- has accorded recognition for Mehac Foundation's initiatives. It sanctioned funds for medication for one of our homecare projects in the southern Kerala district of Alappuzha.

It is unusual enough to do home care for end-of-life. It is much more unusual to go to the homes of people who are often chained because of the enormous stigma of mental illness. Mehac not only focuses on services but also strives to challenge and change the values of the healthcare system. When the government recently agreed to collaborate with us to establish programs, it was a huge step forward for us.

In addition to the community programmes, I have also initiated a Psycho oncology clinic in Amrita Institute in 2009, where my post is with the Department of Oncology and Palliative Care. This is growing as a liaison service, and I plan to initiate research projects to enable the service and give us credibility.

At the national level, I continue as National faculty participating in many training programs. Another door has opened for me through associating with Cairdeas, International Palliative Care Trust, Scotland (led by Dr. Mhoira Leng). I am currently involved in initiating Palliative Care programs in North India, collaborating with Pallium India as well as Emmanuel Hospital Association -- which runs a number of services in distant rural parts of India reaching to the marginalised and vulnerable. Again, these steps are true to my values. We have initiated innovative training programmes in communication skills, self-awareness, leadership, teaching and mentorship.

I strongly believe that it was this background that led me to be chosen as one of the Leaders in this Leadership Development Initiative. Mentorship by Dr. Carl Johan Fürst from Sweden has led to an enabling relationship leading to collaborations and greater sharing. The LDI course has helped to me focus on self-awareness and self-reflection. It has boosted my confidence. I feel more like a leader and perform like one now, being part of the LDI team.

These are, of course, challenging phases as I am liaising with a lot of partners -- in the institution, in the community and beyond. This gives me opportunities to face completely new issues almost on a daily basis. But I look at this as a means to grow as a leader.

Our nation is so diverse with huge inequalities. A large majority has no access even to primary healthcare. This stark reality struck my mother, too, when some four decades ago she thought that becoming a doctor was the only way to serve humanity.

Now, when she hears about our team reaching out to the deprived, sometimes traversing through slush, dirt and other impediments, she is happy that we are trying to do a mite to fulfil her idea of service to humanity. This response, and the ray of hope that it sparks, does indeed illuminate our lives.

Life brings us so many opportunities in different ways. Taking risks and following the road less travelled leads to unique and adventurous journeys. It gives us the belief that we could reach out to many more needy people who are deprived of the touch of humane care.

"One's destination is never a place, but a new way of seeing things." Henry Miller

## Chitra Venkateswaran, мо

Founder / Clinical Director, MEHAC Foundation Kerala, India Professor in Psychiatry, Consultant in Psycho Oncology, Department of Oncology and Palliative Care, Amrita Institute of Medical Sciences Kochi, Kerala, India