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The government order finally arrived. The Government of Andhra Pradesh had issued a gazette giving official status to the specialty of palliative medicine and the department of Palliative Care at MNJ Institute of Oncology. In connection with that, they created a faculty position and decided to take over support of the entire department. I was elated and extremely relieved. This was indeed a landmark move in the field of palliative care, not just for the state but also for the entire country.

Memories came flooding back from five years earlier when I originally came to this unknown state and walked into this hospital for the first time. Since then my life has been a rollercoaster ride ranging from periods of great joy to moments of set-back. We took slow, small baby steps towards achieving our dream, for palliative care is still a specialty unheard of among professionals and the public in different parts of India.

In 2006, the International Network of Cancer Treatment and Research (INCTR) held its annual conference in Chennai, India. During one of the side meetings that are typical of big conferences, a number of organizations came together to discuss a proposal to develop palliative care programs in different regions in India where they did not yet exist. This group included the INCTR, the American Cancer Society and a national NGO called Pallium India. The state of Andhra Pradesh (AP) was selected as one such region considered for development of palliative care.

At that point, I was comfortably settled in another part of India with a position at one of the corporate hospitals. My teacher/mentor (and one of the doyens of palliative care in India) was Dr. Rajagopal who was also my chief. Until then I had been cocooned and kept from all major responsibilities and challenges. Perhaps without realizing it, I was being groomed to face challenges. My mentor was also heading the NGO Pallium India. For some reason, he suggested my name to lead the newly-proposed program in Andhra Pradesh. Although I felt honored by their trust and confidence, I was indeed quite weighed down by the scale of this project. But the prospect of a better salary and the dramatic improvement in my profile helped motivate me to accept my new responsibility.

Soon I realized I was in big trouble. The only resources I had to start this exciting new project were the team of Dr. Durga Prasad (my present colleague) and I, and a small dusty room with piles of

bricks and cement to welcome us. I wrote frantically to my newly-assigned INCTR program chief asking exactly what I was supposed to do. He replied I should do whatever was appropriate. That started a journey that tested me.

We had a few other resources to help us achieve our goals. One was provided by partners and funders -- the freedom to experiment or try different things. These people formed a very supportive, consistent management team. They trusted us with what we were doing and were always generous with encouragement and advice. I had the freedom to call my superiors at any time to discuss any small problem. We also had an ever-increasing base of community volunteers.

I was fortunate that I had the opportunity to work with such a wonderful group of people. It was a role which connected with my core passion, which I enjoyed. This was reflected in my motivation, positive outlook and enthusiasm. Consequently, my personal growth was significant.

Prior to this, I had always reported to a superior. However, my new role provided an opportunity for me to work the way I wanted, and wholeheartedly inculcate values into my work which I had learned from my family and my teachers. My previous work experience with an NGO in the community and subsequently in a corporate hospital gave me sufficient confidence to start something new. This phase of my career also gave me the opportunity to join the Leadership Development Initiative at the Institute of Palliative Medicine at San Diego Hospice. For me, this timing of the LDI program was perfect and LDI has indirectly played a role in the Andhra Pradesh project.

I recognize that we have a great team at the department of Palliative Care at MNJ Institute of Oncology. We have not required a lot of time sorting out interpersonal issues or egos. This really helped us channel our efforts towards positive things. One team-building exercise which initially helped us was to define roles very clearly in the beginning. At the outset, I made it very clear to the hospital physician who had been running the program in an informal way that he would remain in charge. My role was to facilitate him to develop the program in the hospital and to concentrate on activities at a statewide level. He took care of all the decision-making powers related to staff and the day-to-day functioning of the program. So there was only one boss in the hospital department.

This arrangement was very helpful. There was no power struggle, which also encouraged team members to approach me freely -- as an equal -- to discuss or share issues. We sat down at the very beginning to clarify a common vision of our program and agree on certain necessary goals. This was not a one-time discussion but an ongoing process where we met as a team almost every week. We spoke and shared our activities, discussed new projects and celebrated some positive outcomes.

Sometimes when there were conflicts -- like time management, sharing responsibilities and maintaining quality care -- we tried to sort issues out by discussing them in a common forum. We continually reminded ourselves that ours was not regular 9-to-5 hospital work, but rather a program to achieve something bigger. Sometimes, I had to seek out some members of the team separately to sort out unresolved conflicts. We looked for reasons to celebrate. Others in the hospital always saw the palliative care team having some party or other!

One aspect where the team members took some time to adjust was working within a multidisciplinary team. A regular hospital maintains a strict hierarchy among its workers. It took us a while to emerge from that model to create an environment where each of us had a role to play, where we respected each other's work even though sometimes roles and responsibilities overlapped. It was an example of 'modeling the way' because my colleague and I made an extra

effort to encourage a multidisciplinary way of functioning by doing so ourselves. We tried to role model a patient-centered, ethical and team approach to patient care.

Open channels of communication and mutual respect have surely given me unstinting loyalty from my team. We are still getting used to having lay volunteers participate in decision-making, training, advocacy and patient care just like health professionals -- and we are still getting used to the idea of being questioned by the patient/relatives or a volunteer. This is new but welcomed!

The whole program was strategically located in the tertiary cancer center for Andhra Pradesh at MNJ Institute of Oncology (MNJIO). It was amazing to see how rapidly the palliative program grew from being just a department in the hospital to a regional center for training and advocacy -- not just for the country but also for neighboring countries. It was very important to have a very supportive management for the entire project. The hospital provided logistics of infrastructure, drug availability and training resources.

The biggest challenge has been the frequent change of management. We were fortunate, however, that each successive management remained supportive of our program. Presumably they saw the results of our palliative care activities reflected in the rising number of patients receiving benefit, the number of training and awareness programs conducted, and the changing regional and national profile of MNJIO.

We also made extra effort to keep an open channel of communication with management, giving them credit for their work and, in the initial years, for securing outside funding for our program. Over a period of time they assumed expenses for things such as opioids and other essential drugs, while providing these to patients free-of-cost. They also funded infrastructure and hospital staff time. Now the entire palliative care program funding is supported by the government of Andhra Pradesh, bringing sustainability and stability to the program.

Working with the AP community was a unique experience. I had similar related experience in the state of Kerala, where palliative care had emerged to become a model project for developing countries. People always expressed the thought that ‘things are different in Kerala because of a difference in the socio-political-cultural environment’. However, in AP we started exploring very tentatively a rural-and-city-based community program.

The challenges were different but there was something very common to all populations in which I worked. First, there was no support system for the dying and their families in the health system. Secondly, the psychosocial and emotional needs of patients and families were not met. There was a general feeling of frustration within the community, because it didn’t really know how to provide effective help/care for loved ones. But the community now supports our activities. This year when we were preparing for the annual celebration of world palliative care day, it was reassuring and inspiring to watch mass mobilization from all walks of life -- students from schools and colleges, teachers, media, artists and others participating in the event.

There can be problems, however, involving the community. Public demands for proper access to care may threaten professionals and policy-makers. Recently when one of our volunteers questioned the unnecessary hospital delay in caring for a cancer patient with HIV, the entire staff of the palliative care department became offended and objected to being questioned about their quality of care by a ‘lay person’. It took considerable effort to make them understand that the community has the right to demand care, and that this external feedback helps us ensure the quality of the care

being delivered. They relented but I am not certain they were convinced. Perhaps, I did not challenge the process adequately. On reflection, I could have briefed the team and introduced the concept of volunteerism and its role in our broader reach.

Advocacy soon became an important part of our activity. I still remember our early days, when we had just begun and didn't have much to showcase -- but we knew that we wanted to grow. We wrote several proposals and sent them to many people. Nothing happened. When I look back, the proposals what we made were not really that bad but we lacked the ability to show off programs or advocate our cause.

The director was very encouraging and he found an opportunity for us to meet with an industrialist one Sunday morning. We had to drive quite some distance to the family home and then wait outside for a long time, because we did not want to be late for our appointment. The meeting was short and quick. I still remember trying to project complete confidence, even though I was very uneasy deep inside. We gave them one of our proposals we'd brought along. They promised to study it and consider our request. That meeting led to what we have today: good home-based care for patients with advanced disease in the city of Hyderabad. What I learned from that meeting was to be precise and clear about what we want to convey. This is an art I am still trying to master, and I regularly practice my '20-second elevator speech' on palliative care.

One of the landmark accomplishments for our program was the amendment of narcotic regulations related to easy availability of morphine for medical use in AP state. There were many days of real frustration when we used to run out of morphine, only to see patients suffering severe pain. Families often used to vent their anguish -- and sometimes anger -- to the team. We, too, faced periods of low morale and (at one point) apathy towards our entire effort. Morphine availability required a lot of advocacy, lobbying, and long hours spent in the corridors of power. But these actions did indeed result in change.

Even though I represented an NGO, it was my affiliation with a government hospital that helped us obtain easier access to the government. One important aspect of advocacy is having a position statement or declaration from a national/international organization such as WHO. One such helpful document was the essential drug list from WHO and the International Network for Cancer Treatment and Research (IAHPC).

We had had several meetings with many officials, but it was a high-profile visit by a WHO representative from Geneva which ultimately triggered the process. I had earlier met Dr. Cecilia Sepulveda at an international INCTR conference. These distant meetings where I am learning to 'network' (as one of my mentors in LDI taught me) can increase our influence if we make an effective presentation of our cause. At that INCTR conference when I spoke about our program, Dr. Sepulveda understood our needs. I took the opportunity to invite her to visit our program. She remembered this and visited us in one of her trips to India. While there, we encouraged her to visit the State Health Secretary. This created an opening for us to access him anytime we wanted. He grasped our need and promised to facilitate the change -- and ultimately it happened!

One other significant national event which triggered the amendment for availability of opioids was litigation filed in the Supreme Court by Dr. Rajagopal on behalf of our national association and Indian people in pain. This action garnered considerable public interest. The court responded by asking for an explanation from the each state government.

When the enquiry came to AP state government, officials speeded up the entire amendment process. One of the most successful presentations of my life was directed to the Commissioner of excise. We went prepared with a presentation but we were not sure whether we could use it. It was one of those meetings where no clear consensus was emerging. At one point when the state government did not understand the full implication of the law, I took the opportunity to ask permission to do a presentation to help explain. My laptop worked, my presentation opened in time, and I did a full 5-minute presentation. That PowerPoint became the focus of discussion and the template for making the document.

This '5-minute' speech has helped me again and again in several forums. I have travelled to a few countries such as Sri Lanka, Indonesia and Philippines as a palliative care expert of PACT program of the international Atomic Energy Agency (IAEA). When one is in a group of several experts and meets ministers with a very short attention span, it can be challenging to present one's case. I always remember what I learned from LDI about advocacy: have a core message which is short and clear, and repeat the same consistent message to everyone.

Visitors representing important international organizations can help a great deal to impress state officials. This helped me a lot when working on advocacy for palliative care with AP state government. Working with our organization, Human Rights Watch (HRW) did a qualitative survey on human rights issues prevailing in our country. We took this document to a meeting with a high-profile state government official. Because we were accompanied by the representative of HRW, we were given a priority appointment – and a patient hearing by the official. The state secretary also had a personal experience of someone in his family dying in pain from cancer. This created a personal involvement with the secretary of the state, and helped bring changes to the state's palliative care policy. Even today, the state secretary still influences any decision making-process related to palliative care at the state level.

Working with Media had always been difficult for me but we still managed to bring out a series of successful media highlights on the issues of palliative care. Two important national dailies and a magazine did exclusive articles on our activities. What really influenced them to write about us repeatedly were patient stories and showcasing our program. We could demonstrate how we were able to make a difference in the lives of many suffering patients and their families.

The problem with media coverage, however, is that we have no control over scripting, what they understood and what finally emerges in print or film. A couple of times, stories were very critical of the government and named hospitals where patients were suffering but where no palliative care existed. Stories like this can damage existing relationships.

When a journalist recently came to interview me, I emphasized a few points very clearly -- again and again – stressing my praise for the efforts of the government. We provided him with a few back-up notes in simple language as further reference. This resulted in a relatively positive, extensive article which appeared on a main page in one of the national dailies.

I have still not mastered the art of speaking in the front of the camera. One day a group of volunteers came to film a small fundraising movie. I tried to remember some tricks which I had learned from LDI to be effective in the front of the camera. When the shooting began, however, I became tongue-tied. Nothing came out and they had to cancel my sound-bite. But in another shoot for a television program, I spoke quite confidently and my message came out clearly. On reflection,

the lessons I learned were that I should be prepared and rehearse a script/message, however small or simple. I should be fresh when facing a camera, not exhausted from a long workday. Success probably also depends a lot on the crew who are behind the camera.

Thinking back on my leadership journey, I never made a conscious decision to become a leader. Not many working in similar circumstances would have had the opportunity to become a leader. From my perspective, people subconsciously start taking on challenges if they want to do something different, want to grow, want to bring systemic change or choose to dream 'big'. In so doing, they evolve into a leader. Some leadership qualities are inherent and some are acquired over a period of time, by watching role models and learning from mistakes.

I always wanted to do something different and wanted to grow. I wanted to become a pilot as my father was serving in Indian Air Force and I used to watch those fighter planes and the pilots flying them with great fascination. But then I got into medicine because in those days that was a career considered safe, respectful and of great potential for women. I grew up in a family practicing Hinduism. The values and approach towards life and death inculcated by my parents in my childhood helped me in a great way in getting strength, a direction and to cope better when facing adversity.

Opportunities play an important role in becoming a good leader. Sometimes having a 'Godfather' -- or the help of someone influential -- can pave the way. I had the privilege of wonderful role models and mentors in my career, and I was fortunate when opportunities came my way. I have my own ego and self-interest and am ambitious but, as Jim Collins said, my ambition was also for the contribution.

I always thought leaders should know *how to act,* a coping style to serve the needs like *concern for image, safety, security, comfort, or control.* I learned in my training that it is all about *how to be* -- how you develop character to exude authenticity, purpose, service, openness, trust, compassion and courage.

I have personal issues which I need to overcome, like how to work with my anger. I must try not to speak/express opinions or take decisions when angry. This has always led me to deep regret because words spoken or actions taken in anger are neither correct nor appropriate. I must also remember not to make destructive or negative comments.

Some of the qualities which I believe helped me daily in powerful ways are:

- *To invest in developing other people*. Be unstinting in helping colleagues realize their full potential. Be inclusive and relate to those who less fortunate -- even though it is not always easy
- *To be concerned about due process*. People seek fairness, not favors. They want to be heard. They often don't even mind if decisions don't go their way as long as the process is fair and transparent
- *To give importance to loyalty* -- to organization, profession, community, society and, above all, family. Most of our achievements would be impossible without our families' support
- *To be conscious of the part I play*. To avoid the temptation to play God. I learned that leadership is about self-awareness, recognizing failings, developing modesty, humility, and humanity

The journey has been very exciting, challenging and rewarding both in terms of personal values and meaning in life. It has also been professionally satisfying and I feel I am providing a meaningful

contribution to society. Furthermore, the journey has given me the opportunity to meet wonderful people from all walks of life and different parts of the world. The Leadership Development course and my mentors have been like a guiding light, reaffirming and gently nudging me along the right path to my goals.