



My Journey in Palliative Care

*"I feel the capacity to care is the thing which gives life
its deepest significance and meaning."*

Pablo Casals

For me, it was by choice -- not by default or chance -- that I stepped into Palliative Care. I commenced my career as an Anesthetist at the Regional Cancer Center (RCC), Guwahati, in 1989 just after completion of my post-graduation course. I was the sole person in the department for a couple of years, but took delight in doing things single-handedly. Often, my colleagues and I would embark on taking new ventures in terms of prolonged surgeries with much enthusiasm. Sometimes I even stayed back with patients following surgery for more than 24 hours in order to monitor them postoperatively.

Following our initial hard work, the success of our team manifested itself in several ways. We developed more skill and reasoning. Gradually, we began managing those patients who suffered pain. A pain clinic attached to the Anesthesiology Department was finally launched in 1996. We had a large number of patients in the clinic with diverse needs. I remember once, a post-operative patient with rectal cancer sought advice regarding the possibility of expanding his family if they wanted to -- because he was not sure of his sexual capability.

At that stage, I certainly did not have the knowledge or advice to offer to this couple. My idea of pain management was very vague. I could not possibly imagine that expanding a family would be feasible after prescribing morphine for pain. I was intrigued by the fact that there was so much to learn and so many avenues to be explored to be able to guide my patients accurately.

My quest for knowledge and exposure to scanty resources available within India encouraged me to increase my efforts in pursuing this line of medicine. The increasing network that I

began to develop was not much appreciated by the management at the RCC. So much so that even the external support for developing Palliative Care was rejected outright on the unsubstantial grounds that, "It's a missionary's job."

That led me to accept Palliative Care as an even greater challenge on behalf of those in distress. I put all my efforts into developing a Palliative Care center in the community, in spite of knowing that I would be under tremendous pressure in managing two things simultaneously -- my job and my community service. Retrospectively, when I reflect upon this I am filled with satisfaction that I made the correct decision. It was a turning point in my life and I was prepared to take risks.

While I was in school, I came across a book which belonged to my elder brother. On the cover of the book was printed a sentence, which excited my intellectual and emotional admiration. It read as follows, "*First Plan Your Work, Then Work Your Plan*". It was a lesson for my life. And so, every night before I retire, I try to work out the plan for the next day -- and sometimes the distant future. I realized that I would have to confront difficulties in carrying my mission forward. But it did not deter me from concentrating on my work. My hard work culminated in the formation of Guwahati Pain and Palliative Care Society (GPPCS), a community-based service in the year 1999. This was a phenomenal personal achievement. Since then I have been a voluntary caretaker nurturing GPPCS.

Risks and Rewards

Another concept I realized in my school days was that to be able to lead required great physical and mental effort. It also involved risks and rewards as well. In fact, there always seemed to be groups of students who truly liked to be in the forefront -- by any means. To me, they are the people who have the potential to lead. Crucial responsibilities lie with the lead person.

To illustrate this point, I would like to briefly relate an episode which I still vividly treasure in my mind. One of my early mentors was Mr. Mokibur Hussain who taught Mathematics in standards IX and X. He used to encourage a few students -- including me -- to come up to the board and deduce mathematical problems while he remained a strict proctor in the class. At the end of the period, it was almost a routine practice to cane those students who were unable to complete the task. Indeed, I used to have a feeling of self-respect for completing my work. This was not arrogance, though, but rather came from a sense of satisfaction.

However, this special treatment made the other students envious of us and sometimes we were at the receiving ends at the back of the class! To make matters worse, Mr. Hussain used to lead us by the nose requiring us to provide remedial coaching for those students or face consequences. This was a kind of mixed taste of risk and reward for being able to lead the class, which later I realized to be an exercise in teamwork -- encouraging the heart, enabling others and sharpening the saw.

I developed a strong conviction that I would be able to lead our Society (GPPCS) in controlling cancer pain. At the time, most of my contemporary colleagues were -- and still are -- of the view that charity cannot be part of our life in India. However, I wanted to show them that, in fact, charity can be very much a part of our life. The opportunity to offer pain relief to our countrymen afflicted with cancer came into my life. This was consistent with my background knowledge as a clinical Anesthesiologist working in a Cancer Center.

Though I came from humble beginnings, I was confident that I would be able to gather even more passionate people around me to help promote the cause of Palliative Care. This, despite living in one of the most impoverished states of India -- Assam. In Assam, my environment is often dysfunctional and challenges are many, but my efforts were consistent. I continued to utilize the knowledge which I gained yesterday as resources for tomorrow's challenges. Failures were many -- but I continued searching for ways to move forward both from a personal and organizational perspective.

Nonetheless, it never occurred to me that I would be able to lead in true sense of the term -- until I tried my luck knocking at the door of the Leadership Development Initiative (LDI) at the Institute for Palliative Medicine at San Diego Hospice. Today, I exult at being selected by LDI and being able to learn what leadership is all about.

Always stick to your Values and Principles

I was a good student from my earliest days. My parents created my identity as budding doctor, a role that I promised to strive to achieve. I was happy to choose Anesthesia as my post-graduation subject. While my teacher Professor Kutubuddin Ahmed, for whom I had deep respect, wanted me to take up specialized Anesthesia, my interest slowly inclined towards Palliative Care. I began to ascend the learning ladder of feeling, reasoning and then reflecting on the issues encountered; this was a solitary process, though.

My career as Consultant Anesthetist in the RCC was respected by most, until one day when I was challenged by my supervisor. He called me on an issue when I requested leave to attend a Palliative Care training program in the year 2000.

This denial of leave was a contradiction to his own earlier approval. However, I gathered courage to withstand the challenge based on moral excellence and virtuousness. Amidst uncertainty, I completed my training abroad at my own expense, though I was warned of consequences. Subsequently, the management imposed certain restrictions in my job. There was interference at every step that I wished to take. In spite of being provoked, I remained calm. Things did change for better afterwards, because management withdrew the punitive measures imposed on me, unconditionally. But in the meantime, I lost all interest in the job. Deep in my mind, I had already decided to quit my service. This was a tough decision, though, for me at my age.

My concern for my family -- with two children -- and my new charitable mission was held in balance for quite some time. The mental turmoil that followed led me to seek advice from a

fatherly person whom I hold in great esteem, Dr. Bhabendra Nath Saikia. He was a connoisseur of science, arts and literature. He told me that whatever I chose to pursue, I should see that my family did not suffer. His advice imbued in me a spirit that has been a guiding force in my mission since then.

I shared my thoughts with my wife, who has always been helpful and supportive. In the process, I began to enjoy the work that I was doing for the Society. Therefore, I resigned from my job at the RCC in 2003. It was my own choice -- no one else was responsible. This was risky to some extent. Nevertheless, at the end of the day, the pleasure that I derived from my work pacified the personal tumult.

You are not alone, supports are always available

I was fortunate enough to have learned the ABCs of Palliative Care from stalwarts in this field. These include the late Valarie Hunkin (Val) who was also the Patron our Society, Dr. Robert Twycross, Gilly Burn and few others. Gilly Burn awakened me to the fact that to deliver Palliative Care, we do not need much money. We only need our minds and attitude. Skills can be developed. Among other subjects, Val taught communication skills. We had no prior exposure to communication training. I was inspired by the teachings of Robert Twycross, and still apply his dictum in my work to, "Start low, go slow, and do so".

Robert and Val introduced me to another great benevolent person, Mr. Bruce Davis, who primed the finances for GPPCS activity in Guwahati. Our team shall ever remain indebted to Bruce Davis for his ongoing support.

I started "low" with a group of like-minded friends. It is difficult to name them all. Prof. Ranen Mahanta (Urologist), my teacher at medical college, encouraged me to move ahead with my plan and he volunteered to be the founding Chairperson of the organization. Noted Gandhian, Padmashree, Natwar Bhai Thakkar always blessed me with his estimable advice and presence whenever I turned to him. It would be extremely unjustified if I fail to mention the name of Dr. Gautam Khaund (ENT Surgeon). Dr. Khaund is a young man of gentle nature, temper and disposition who has been a constant support to me and the GPPCS. My list would be incomplete without citing Mr. Hari Prasad Bora who, as one of the beneficiaries of our service, later joined our team as a volunteer in the early days of the Society. Together Mr. Bora and I published a book on communication in cancer care in 2005.

Though we were a small group at GPPCS, we were able to successfully host our Annual National Conference of Palliative Care in our city of Guwahati in 2005. This opened many avenues for our organization. I take the opportunity to thank my team members and well-wishers for their untiring dedication and support for our mission. I served the Indian Association of Palliative Care as the National Secretary during the period from 2005 - 2008.

Way forward

Over the years, we have been facing the problem of getting medical manpower. Many of the doctors trained in our center are now working in different places in India. The GPPCS and our team gradually started gaining momentum which was evident from the fact that a house in heart of the city was donated to us in the year 2002. Mr. Satyamrit Kagti, another of my close friends, has been instrumental with his philanthropic contributions in mobilizing community support. Link centers were established in places like Digboi, Silchar, Jorhat, Bongaigoan and Nalbari. Since 2009, we have been associated with Sacred Heart Palliative Care center for hospice care.

The members of the team now feel that our activities should expand to different areas in Assam, and strategic planning for this has recently begun. The avenues for training of medical and nonmedical personnel are to be increased to meet the demand. My leadership fellowship with San Diego Hospice has given me immense opportunity at a time when our organization is moving through hectic periods. My mentor Dr. Mhoira Leng and all others in the LDI team have helped me to grow individually and organizationally. I feel that I have been able to infuse my team with the thought of making our organization vibrant, creating a culture of work, happiness and most importantly trying to reach out to everyone in need of Palliative Care in the state. Here I would like to thank different international agencies who supported our project from time-to-time.

In Conclusion

The driving force to achieve my goal has been my conviction to be able to lead, confront challenges, build team and make a right decision -- though I have miles to go before I rest.

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