THE INSTITUTE FOR PALLIATIVE MEDICINE
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INTERNATIONAL PALLIATIVE CARE LEADERSHIP DEVELOPMENT INITIATIVE

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In The Thick of Palliative Care

Introduction

I have never been comfortable writing about myself, and even my first resume had so many gaps that a colleague literally had to sit me down and teach me the steps of how to introduce myself on paper. But it is an honor to be able to tell the story of my palliative care experience in the last eight years.

I graduated from medical school in the year 2001. I undertook my undergraduate studies at the University of Nairobi's Medical School between the years 1995 and 2001. I remember our dean telling us during our last week of medical school that they were releasing us to the "unsuspecting public". What he meant was we were greenhorns -- but patients had no choice other than to be served by us.

However, as I was to learn during my early years of practice, we are actually the "suspects" when it comes to relationships with our patients and their families. I did my internship at Forces Memorial Hospital, the military hospital in our country located in Nairobi City, before being posted to Nyahururu District Hospital situated 300 kilometers from Nairobi. This is a rural hospital that serves an area more cosmopolitan than the city itself. The hospital catchment area includes both pastoralists and peasant farmers. It is an area at a very high altitude and hence is extremely cold.

Entry into the Field of Palliative Care

Barely six months into medical practice, as we conducted a ward round one day we came across a patient who had received her histology results indicating she had cervical cancer. All indications were that her disease was advanced and was in Stage 4. My senior told the patient she had a very bad disease and it would kill her sooner rather than later. He requested to see the old lady's son in his office.

As we moved on to the next patient, the old lady simply gazed at us. I strongly felt that something was terribly wrong with the way we had treated her. I felt a strong urge to return to the patient, but I couldn't do so since my supervisor had decided we must continue.

Two days later, we were back to the same ward and the old lady was still there. When she saw us, she covered herself up. We just passed by her and moved on to the next patient. Nobody bothered even to lift the bed cover and see who or what was under it.

I felt more needed to be done, and this impulse drove me deeply into the field of palliative care.

The nearest palliative care service centre was 150 km away in Nyeri, the provincial headquarters of Central province. At Nyeri Hospice, there was comprehensive care for patients and families facing life-limiting illnesses. Because it was becoming clear there was a need to set up a hospice in our hospital, I made several visits to this hospice. There I gained real insight into the challenges of dealing with patients and families facing life-limiting illnesses. I gladly joined forces with a nurse and other like-minded people. With the assistance of this hospice, we were able to begin to provide this important service at Nyahururu hospital.

Thus began a working relationship for which I had not been trained: specifically, functioning on a team as an equal member with people from diverse backgrounds. We had a pastor, a lawyer, a businessman, volunteers, clinicians and administrators. However, my training had taught me to work on teams comprised solely of doctors. It was a huge challenge for me to accept this new dynamic scenario -- but over time, I adapted to it. This was largely because of the interest I had developed in palliative care.

The biggest challenge was knowledge and skills about palliative care, since our medical training did not include this field as part of the curriculum. I had to depend on internet sources for information on palliative care.

The other major challenge was the fact that I was still in charge of the wards, so I could only see patients and families facing life-limiting illnesses in the evenings or at night.

When the chance for training arose, I had to work day-and-night for a full week in order to get five days off to attend the training. Armed with a certificate, I went back to my workplace to scale up the provision of this crucial service -- only to find that the nurse with whom we had been working so closely had been transferred to a maternity ward. A new nurse, who had no idea whatsoever about what palliative care entailed, had been sent to the hospice.

This was not right, so I went to the nursing officer in charge and told her as much. To my relief, she agreed to repost the experienced nurse to the unit. This determination to change things that needed fixing in the health care system has been a great asset as I grow as a leader in this field.

Thus for five years, my typical day consisted of waking up in the morning and operating ward rounds and clinics for outpatients. Then when my work shift was finished at 5:00 p.m., I would begin seeing patients and families facing life-limiting illnesses. Within two years, the hospice had served 2000 patients.

I must admit that at one point I felt it was too much for me, and I had to take my accumulated leave days. The challenge of patient numbers was already overwhelming and on top of that we had to work on

ways to sustain the service. We had to arrange for a charity walk to create awareness and also raise some funds. My participation in these arrangements had to occur either before 8:00 a.m. or after 5:00 p.m. At one point I realized that burnout was a threat to my continued functioning in my roles and, as such, decided to take up my option for leave. My rest days were very useful because I was reminded that rest is a revitalizing aspect to our working energies. Since then I have always recommended to my team mates the importance of taking off days to rest.

We became a centre of excellence in less than two years partly because of the commitment of the team and partly due to the unwavering cohesion that existed. Thanks to this, I was invited to study for a diploma in palliative care via distance learning, which I completed successfully. The Diploma was run by Nairobi Hospice in a franchise with Oxford-Brookes University. The course was organized in three blocks each with two modules and there were three residential sittings each one week. This took a total of 18 months to complete. Through this opportunity, I gained much knowledge which made me more and more engaged in palliative care. My academic interest in palliative care grew its roots then.

Becoming More and More Involved in Palliative Care

By now I had a family who lived in Nairobi, the capital city, while I worked 300 km away. This was a strain on us because we could not share as much time together as we wished. Travelling via road all the way and covering such a distance was strenuous. So when a chance arose of working in Nairobi, I grabbed it and joined the hospice in the city to gain much-needed exposure, and also to be near my family. This happened in the year 2007.

In Nairobi, the only patients I could see were those requiring palliative care, so I was finally able to immerse myself in this field, to become more involved in its development and to specialize.

At the same time in 2007 the Kenya Hospices and Palliative Care Association (KEHPCA) was formed with the aim of scaling up palliative care in the country, and we assembled a formidable team in the fight for this service.

The same year I started my Master's degree in palliative medicine at the University of Dundee in Scotland, UK. I was now charged with being the leader of a large team of clinicians who had skills, knowledge and training in palliative care. As with any team, there were conflicts from time-to-time, most of which arose from increased workload and burnout. The morale of the team was also low.

To address these issues, I insisted on the need for every team member to participate in meetings, and ensured each person took time off when it was due. I also created an environment that allowed any member of the team to attend seminars and conferences, providing they first wrote abstracts. This entrenched the culture of reading and reflecting on practice for practice.

Though the team was well trained, the quality of care that existed was wanting, so I introduced medical audit interactions to discuss family feedback and the teams' own assessment of care. This has greatly improved quality of services offered and also enhanced team cohesion.

Though well-meaning, some of the changes I introduced at this unit were eventually to cost me a great deal, because there were people on staff who wanted to maintain the status quo. They felt I was overly

ambitious and a threat to their standing in the organization. At that time, HIV and AIDS were a big challenge in Kenya. Palliative care for these patients was non-existent at the unit. I met many stakeholders in this field at the district level and demonstrated the need for palliative care for HIV and AIDS patients.

To do this, I conducted a study which revealed that one third of the patients at the hospice were suffering from HIV and AIDS-related cancers. Armed with this data, the hospice was recognized as a HIV testing centre and also as a care centre for these patients.

I cannot claim credit for this because my team played a very crucial role. The fact that they agreed to be trained in different aspects of HIV and AIDS care was an important step in the realization of this goal.

Deepening and Broadening Palliative Care

At the time I came to Nairobi, there were only seven hospices in the entire country. I was involved in training health care and non-health care professionals in a program to provide increased service. At the same time, I became one of the consultants with the national association. We were able to hold our first national conference in palliative care. Since then, we have held two more palliative care conferences.

We formed an opioid availability task force charged with enhancing the availability of opioids to the population. We have developed a national palliative care curriculum. As the current cancer bill was being drafted palliative care was initially featured slightly. We had to fight to demonstrate why palliative care was an important component of cancer care.

Happily, the bill—which is now before parliament-- recognizes that palliative care is a 'must' for patients receiving cancer treatment. The legislation will lay down in law that palliative care services must be offered side-by-side with cancer treatment.

I have assisted in setting up hospices and palliative care services throughout the country. As the old adage goes, *small opportunities are the beginning of great achievements*. With this, we have seen the number of hospices and palliative care units rise to a total of 43 across Kenya in the last three years.

Leading others has not been easy. Resistance and challenges have provided impediments. Enabling colleagues to work to the best of their ability, giving them support when they falter and encouraging them to move forward are crucial skills I have learned through seminars with the Leadership Development Initiative at the Institute for Palliative Medicine at San Diego Hospice.

After all, *a candle loses none of its light by lighting another candle*. The only comprehensive cancer care centre in the country has engaged me to start palliative care services at the unit.

Looking to the Future of Palliative Care

We are currently working with the medical board to have palliative care recognized as a specialty in its own right. Though this goal might take time to be realized, once we reach that point the provision of palliative care will greatly improve throughout Kenya.

As the field of palliative care grows, it is imperative that more clinicians become involved. There is a need for many more people to be trained and to begin practicing palliative care.

As with any other endeavor in life—and on reflection -- not all decisions made have been the best or most welcomed. But as George Bernard Shaw said, "A life spent making mistakes is not only honourable but more useful than a life spent doing nothing." I urge my colleagues to soldier on, and not to fear or give in to the challenges facing palliative care.

One day, one time, the history of palliative care practice will judge us fairly and I call upon my colleagues to join me in writing it.