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Making Palliative Care a Reality for Many in Kenya

Sometimes I tend to think I am one of those people who like to venture into new things. Initially when I went to Turkey to study medicine in 1980, I was the first Kenyan to do so. Later on, I became the first Kenyan doctor to practice palliative care on a full-time basis.

My career in palliative care started in 1993 when I volunteered to work at the Nairobi Hospice. At the time, I was pursuing my master's degree in public health at the University of Nairobi. Volunteering at the hospice was not a coincidence. I had lost my only brother to cancer, and I thought he deserved a better death than that which he suffered. Despite the fact that I was a young doctor, I was not able to help my brother as I would have liked. If I only had known then what I know now -- with skills, insight and experience acquired over years working with patients and families facing life-threatening illnesses.

At that time, I saw other colleagues taking care of patients with terminal illnesses and I observed my colleagues faced the same challenges. I knew that I needed to do something to become a better doctor and help influence other health care providers to become better carers.

After volunteering at the hospice, I was subsequently hired to work there. First, I served as the Medical Officer and in time I was promoted to the position of Senior Medical Officer. The medical team at the hospice was composed mainly of nurses and one social -- worker.

I learned what humility means.

My mentors in this new field were nurses, and I realized there was much I had to learn from them. My situation was initially difficult, having come from a world where *'the doctor knows best'*. My patients too, taught me a lot -- especially about living, dying, suffering, crying and rejoicing. Up to this point, I had never really given serious thought to the suffering of others.

Working as a doctor at the hospice was not only challenging but rewarding in many ways. Simple things -- like spending time with a patient or family member, just listening and encouraging -- meant

something to patients and their loved ones. I saw smiles. Tranquility and hope replaced agony, helplessness, distress and uncertainty. I saw effective relief for most patients from emotional pain, physical pain and other distressing symptoms.

This was indeed gratifying for me as a health care provider. I felt truly humbled and encouraged to be part of the team that was providing care to these patients and their loved ones -- transforming their lives and those of their families at times of great agony and uncertainty.

I remember a 23-year-old patient called John (not his real name) who was receiving hospice care due to osteogenic sarcoma. He challenged me in many ways. Had I met John earlier in my career -- before I started working with the hospice -- I would have classified him as *'that difficult patient'*. John had undergone an amputation and found it very difficult to accept this new reality.

Naturally, who would not -- especially at 23?

John had big dreams of becoming a successful businessman but he had not been told his diagnosis or prognosis. John's journey during his illness was not easy. He had difficult problems and needed extensive support from my colleagues and me. He suffered from phantom pain which was difficult to treat, and he was also in denial about his disease. However, we worked very closely as a team to bring a smile to his face, and tried the best that we could to minimize his physical symptoms while paying attention to his emotional and psychological needs.

Being the only doctor at the hospice did not make it easy for me when dealing with difficult conditions. However, the medical team was very supportive. Together we improved the quality of lives of many patients. I learned to see patients as *"people with difficult problems"* -- and not as difficult patients.

While at the hospice, I attended several courses on palliative care both in the UK and Kenya. In the UK I met the late Dame Cicely Saunders, founder of the current hospice movement at St. Christopher's Hospice. She talked about the need for palliative care in developing countries and that we should be champions and pioneers -- and encourage other health providers by being efficient and effective examples. Even today, her supportive words continue to motivate me to advocate for palliative care.

In 2001 Oxford Brookes University, in conjunction with Nairobi Hospice, started the first Diploma course in Higher Education in Palliative Care. I enrolled in the course and graduated in 2002 with a diploma in palliative care. In many ways, this course -- combined with the hands-on experience I had gained -- empowered me to be a better clinician and carer.

One great achievement while at the hospice was to convince the medical school at the University of Nairobi to include palliative care training in its undergraduate program. I remember working with Dr. Brigid Sirengo, Chief Executive Officer of Nairobi Hospice, as both of us wrote endless letters to the dean to convince him and his team of the need to integrate palliative care into undergraduate medical training. Although eventually we were allocated just two hours in the curriculum, it was a good start. We continue to advocate for more hours.

Why Palliative Care?

Many times friends and colleagues would ask me why I had chosen palliative care and not a sexier field -- like internal medicine or obstetrics and gynecology. Or, since I had a Master in Public Health,

why I wasn't I thinking of working with the UN or similar organizations? I recall a friend telling me that other colleagues referred to me as, "*Doctor Death*" because, "*All my patients eventually died.*" I must say this upset me for some time, but it did not discourage me from being where I knew I wanted to be.

Furthermore, some of the patients I had seen five years earlier were still alive and doing well. I attributed this to the good quality care they received at the hospice. Some of those patients had been near death when they were referred to us.

Palliative care opened a whole new world to me, a world where patients were not '*bed numbers*' or '*that one with ca breast*'. It taught me that patients are people with special needs who want us to help them leave this world in as much comfort as possible. They need to be appreciated, and they need someone to support them along the unknown journey.

As Dame Cicely Saunders rightfully said, the message we need to convey to our patients is, "*You matter because you are. You matter to the last moment of your life and we will do all we can, not only to help you die peacefully, but also to live until you die.*"

Whether or not a terminal illness is involved, I believe the holistic approach of palliative care should be a golden rule for all patient care. I am sure it is the point Hippocrates wanted to emphasize in the doctor's oath that we take when we graduate.

Standing on the Shoulders of Giants

Working in a hospice was limiting in a way. At that time, the concept of palliative care had not been widely accepted in Kenya and I knew I had to do something about it. Like other health care professionals involved in palliative care, I had a bigger dream of seeing palliative care services expand beyond the then-existing 14 service providers to more centers offering much-needed palliative care services.

In 2006, I was given the opportunity to work part time for Kenya Hospices and Palliative Care Association (KEHPCA). Although KEHPCA was registered in 2005, the association had not started functioning fully due to lack of funds.

In 2007, I was able to secure funding for the association to start up a secretariat, employ staff and start operating as planned -- and I was appointed National Coordinator by the board. This meant I had to leave the hospice.

Although I felt sad that I would spend less time in service provision with reduced patient contact, I saw my new position at KEHPCA as an opportunity to work with others to advance palliative care in Kenya. From the very beginning, KEHPCA has had a dedicated team who share a vision of quality palliative care for all who need it. It is this vision that inspires us to work together to advance palliative care in Kenya. The number of hospices and palliative care providers in Kenya has risen from 14 in 2007 to over 40 today. This is a result of the work of dedicated health care providers across the country. We share a passion for palliative care and a dream to bring comfort to many who need it.

Under the leadership of KEHPCA, these passionate people continue to work hard to bring peace and comfort to many, despite limited human and financial resources. They want to be the "*change they see in the world*" (Mahatma Gandhi). In many ways they are leaders who are guiding others towards

a common goal. People who change the world around them do not act from a sense of obligation; they act from a sense of incredible opportunity (Mark Sanborn).

My experience as a board member on the African Palliative Care Association (APCA) played a big role in preparing me to work in my new position. It was indeed an honor to work with the then board members and the ED of APCA.

These board members may not be aware, but I learned a considerable amount from them. I was then the Honorary Secretary to the board and spent most of my time during board meetings writing -- not talking. However, I wasn't just writing; I was also absorbing and learning. I must say I stood on their on their shoulders.

Other giants whose hard work and dedication inspired and motivated me to be a better leader include Dr. Liz Gwyther HPCA. She has always been my role model of what a leader in palliative care should be and I try to walk in her footsteps. In addition KEHPCA's former board Chair, Dr. Bactrin Killingo and the current Chair, Dr. Brigid Sirengo, have also been very instrumental in developing *'the leader in me'* through their support and encouragement.

"Hold fast to dreams, for if dreams die, life is a broken winged bird that cannot fly." (Langston Hughes)

In "Developing the Leader Within You", John Maxwell talks of a leader being a *'change agent'*. As the national coordinator of KEHPCA, it is important that -- together with my colleagues -- we are the agents of change. KEHPCA's vision is *"quality palliative care for all in Kenya"*.

With the WHO Public Health Model of palliative care in our minds, we knew we had to work closely with the Ministry of Health to ensure palliative care was introduced successfully across Kenya. Until mid-2010, palliative care had not been integrated in the Kenyan public health care system except at Kenyatta National Hospital, which is the main referral hospital in Kenya. Most patients in Kenya end up being seen in government hospitals closest to their home areas, yet there were no palliative care services in these hospitals.

I remember early-morning meetings with officials at the Ministry of Health, trying to convince them why palliative care should be integrated into the public health care system. I recall one early morning when two of my colleagues and I met with the Director of Medical Services (DMS). The DMS clearly informed us that he was giving us an audience because he had a relative with advanced cancer in his house and did not exactly know how to support this person. I remember thinking that it almost always starts there: a personal story. Don't we all have one?

Through sheer determination, KEHPCA did not give up on advocating at the ministry level.

When working on the recently-launched Kenya National Cancer Control Strategy, I met the Senior Deputy Medical Director in the Ministry of Medical Services, Dr. Izaq Odongo, whom I had last seen in the mid-1990s. Dr. Odongo was ready to listen to what I had to convey about palliative care and health-strengthening systems and how, if palliative care were to be integrated into the public health care system, many patients would benefit and live a better life.

Dr. Maina, the Head of Non Communicable Diseases Department in the Ministry of Public Health and Sanitation -- who was facilitating the draft of the national cancer control strategy -- was also very

keen that palliative care should not be left out. Dr. Maina actually invited KEHPCA to take the lead role on the palliative care strategy and has been supportive since the organization was formed.

Dr. Odongo was 100% convinced that palliative care should be integrated into public health care systems and approached the DMS to further discuss this issue. On 29th July 2010, the Director of Medical Services released a circular to 10 Level Five and Provincial hospitals to work closely with KEHPCA to establish palliative care services in their institutions.

I think it is important to acknowledge that *'leadership is not communicating what you need; leadership is communicating what you can contribute'*. Before long, I realized this was the best approach. We needed to tell the Ministry how we could support them in starting up palliative care service in government hospitals, offer technical assistance, and approach them with solutions.

Be Like a Candle that Gives Light to Others

There are good times, and rough times as well. There are early-morning starts to reach remote areas of the country where roads are rough. Sometimes we must venture into not-so-secure areas, leaving our homes at 4:00 a.m. by taxi in order to arrive at government hospitals before 7:00 a.m. -- because the best time to reach hospital administrators is between 7:00 and 8:00 a.m.

Usually, a short meeting with the hospital administrator will lead to a continued medical education session (CME) for the hospital staff. The CME eventually leads to the selection and training of a hospital palliative care team who ultimately initiate palliative care services in the hospital. The early starts are not in vain.

I must say that the current generation of doctors heading government hospitals is young and ready to embrace new knowledge and bring about change in patient care. Wherever we go, we are received with considerable enthusiasm and eagerness to start palliative care services as early as possible. These young doctors and nurses are the future of palliative care in Kenya. They are the people bringing change. They are the candles that give light to others.

The Future of Palliative Care in Kenya

The future of palliative care in Kenya is bright. The recently-launched Non Communicable Diseases Forum looks at prevention as well as treatment, including palliative care and access to palliative care.

Indeed, I am encouraged that the future of palliative care in Kenya is promising. The goodwill of the Kenyan government cannot be underestimated. There is a great hunger on the part of health care professionals to train and acquire knowledge and skills in palliative care. This is an indication that we realize we need to change the way we take care of the dying, and those living with incurable diseases.

There still is a great deal we need to do. Recently, with the support of ICPCN (International Children's Palliative Care Network), we trained a team of 40 pediatric clinicians in pediatric palliative care for five days. I see this as the beginning step of integrating palliative care services into pediatric services, too.

There many who have been key players in making palliative care more accessible to more patients and their families in Kenya. The list includes donors like The Open Society Foundation, The Diana Princess of Wales Memorial Fund, The True Colours Trust, the African Palliative Care Association,

Catholic Relief Services, and Foundation for Hospices Sub-Sahara Africa and Hospice of Lancaster County. All of them are contributing greatly to the future of palliative care in Kenya.

The Leadership Development Initiative has also helped me to be a better leader as well as empower others to be good leaders. My two years in this program have brought a lot of positive changes in palliative care in my country.

"If you are big enough for your dream, your dream isn't big enough for you." (Erwin Raphael McManus)