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International Palliative Care
Leadership Development Initiative

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Leadership Story

Introduction

I was born in 1974, the third-born in a family of six children, during the treacherous regime of Idi Amin Dada, then President of Uganda. My Mother was a teacher and my Father was a Banker. There was considerable insecurity at the time and the soldiers, who were illiterate, were persecuting the educated citizens -- accusing them of being rebellious to the regime.

In 1977, the situation was unbearable so my parents decided that we should leave the country and go into exile in Kenya. At the time, I was three years old and extremely sick with measles. My mother had just given birth to our fifth sibling and had suffered prolonged labour. After failed suction and instrument delivery she was delivered by caesarean section, she was extremely weak and had suffered significant brain damage in the process. There was a lot of insecurity in the city with soldiers roaming all over and shooting aimlessly.

After a couple of days on the road and hiding in different homes, we finally managed to cross the border into the neighbouring country of Kenya, where we lived for the next three years until 1979 when the Amin regime collapsed.

Background

During our time in exile, I received medical care and recovered from measles. However, my young sister who had suffered significant brain damage developed epilepsy. While in Kenya, we met another exiled Ugandan family who were friends of my parents. The head of the family was a doctor whose first name was Sam. Dr. Sam used to visit us frequently and treat my sister -- and any of us who were unwell.

I became very fond of him and used to observe him going about his work with keen interest. He noticed my keen interest in his work and, at the tender age of four years, both he and my parents started calling me "Doctor Sam". All through my early years of school when we moved back to Uganda, I had it in my mind that I needed to work hard and become a doctor.

While in high school as a teenager, I thought of changing my career plans and pursue a business course to become a banker like my Father. However, he didn't agree with my choice. Given my childhood experiences, he set me back on track to pursue science subjects at advanced level so that I could become a doctor. In October 1994, I realised my dream when I was admitted to Makerere University to study medicine.

Unfortunately two months after I qualified, my Father suffered a heart attack and died at the emergency unit of the hospital where I was doing my internship. It was such a terrible time for our family and, to make it worse, my graduation ceremony came barely a month later. Three years later my sister who had epilepsy also passed on, following a prolonged heart and lung disease. As a child, my siblings and I participated in caring for her. I took time off work got her admitted into hospital and dedicated all my energies to ensure that she got better. However, this was not to be and she eventually passed on while I was by her side.

Introduction to Palliative Care and Public Health

During my years in medical school, the HIV/AIDS epidemic was at its peak. We had many, many children and adults dying with AIDS and in a lot of pain at the hospital. It was an extremely frustrating situation with no antiretroviral medication at the time. Treatment for opportunistic infections was the only option and some of these infectious treatments were extremely expensive. I clearly remember a patient who had fungal meningitis that required him to take antifungal medication on a daily basis for life. This medication cost approximately $5 a day, so he had to sell his house to be able to afford this treatment.

After my graduation and internship in 2001, a friend told me about a job opportunity at Hospice Africa Uganda. She told me that they cared for patients with AIDS and Cancer by controlling their pain and symptoms. I was attracted to this branch of medicine because it provided a solution to the needless pain and suffering that people with AIDS were experiencing.

I joined the organization and was introduced to Palliative Medicine by Dr. Anne Merriman (MBE) who taught me about holistic care, pain and symptom control for people with AIDS and/or Cancer. She also taught about the need for compassionate care, spirituality, ethos of hospice, and communication skills. With this new information, I found that I was a better doctor because I could treat patients holistically. I worked with Dr. Merriman for three-and-a-half years until July 2004, and then moved on to the Joint Clinical Research Center. This was an up-country post where I helped to set up a Paediatric AIDS clinic and also run the adult clinic.

During my time at Hospice, I made very many friends. One of those was Dr. Margrethe Juncker, a Danish doctor who was really passionate about caring for very poor and vulnerable people. During one of the home visits at Hospice, she was taken to a community of internally-displaced persons who had fled war in one part of the country and had moved to live near the city. Many of them were extremely poor and dying with AIDS.

Dr. Juncker was so touched by their plight that that she visited this community even during her free time to treat the sick people. She became so attached to this community that she teamed up with the local Catholic Parish priest and started a new organization called "Reach Out Mbuya".

During the early days of the organization, Dr. Juncker invited me to help train the nurses she was working with, specifically relating to Palliative Care for AIDS patients. I learned a lot from her and saw how she mobilized the community to come together, assemble resources and start helping the sick people.

The organization was very successful and in 2003, she was able to receive the first batch of antiretroviral medicines from the US President's Emergency Fund for AIDS Relief (PEPFAR). In August 2005, she invited me to join her and work in the new organization. I accepted her proposition. I was impressed with her sheer determination, resilience, love and ability to identify with underprivileged people in the community.

Personal leadership challenge

In May 2007, I was invited by a friend to do some part-time work in a private medical center on the outskirts of the city. The clinic was based in a large slum area and many of the patients who came had HIV/AIDS associated illnesses. With my background in caring for socially and economically deprived patients, I convinced my colleagues to provide some free care for a few patients -- including home visits.

Word about this service spread like wildfire in the community. As we went about our business, more and more people started coming to the clinic requesting care for their patients dying with AIDS in the community. As the numbers of patients seeking free care grew, I was faced with a great challenge of providing ongoing care for the patients without any resources. I however went ahead and quickly mobilized more friends and colleagues -- especially nurses and counsellors -- to come on board to provide this service. I also approached some friends and former work colleagues, who provided monetary and material donations.

On July 26th 2007, we had our first team meeting to assess our capacity, and went out on our first official home visit as a team. At that time, we had only 300,000 Uganda shillings (the equivalent of US$ 120) but a very enthusiastic and determined team.

I approached a Danish nurse, Anni Fjord, and asked her to join our team. She also had a great passion for community work and she agreed to join the team. After a few weeks, the owner of the medical center asked us to leave the facility, since our work had deviated from his initial plans.

Thus, we found ourselves on the streets and without a base from which to operate. The situation had changed drastically so I rallied the members together. We made a plan and agreed on days and times when we could meet and go visit the patients in the community. A couple of days later as I drove to the arranged location, I wondered if any team members would show up. We had agreed to meet at a Petrol station on the side of the road at 9:00 a.m. I arrived at 8.45 a.m. and found only three team members of nine who had agreed to come.

Quite disappointed, I began to wonder if this new initiative was going to work. I was still engrossed in thought as other members continued arriving, and by 9:00 a.m., ten people showed up including an extra community volunteer. Our team had a lot of energy and we spent the entire day visiting our patients in the community. The team was so passionate about our work that sometimes we would work late into the evening visiting our patients.

From that day onward, I knew that this was something that I had to do and I would dedicate all my mind and effort to ensuring that the organization would grow to become a strong Palliative Care organization. That evening I discussed my plans with my wife who was very supportive, and I remain very thankful to her for her role in making my decision so easy.

We are now six years down the road and we have a highly vibrant organization that has provided care for over 2,900 clients. Currently we have 1,733 active clients. We have a multidisciplinary team of 54 staff and community volunteers who provide holistic care to patients and their families. It has been a very challenging six years that have helped me develop my management and leadership skills.

Our Palliative Care organization is now very well-known. Thanks to my role models, Prof. Dr. Anne Merriman and Dr. Margrethe Juncker, I have been able to design a program that provides good pain and symptom control for patients with life-limiting illnesses. We also provide good psychological, social and spiritual support using a community-based model of care. The outcomes of our care are good and our clients are living a much better quality of life.

The Leadership Development Initiative

In February 2011, I joined the International Leadership Development Initiative at the Institute for Palliative Medicine at San Diego Hospice to help me improve my leadership skills. As I planned for my journey to the San Diego, I had no idea that what I was about to experience would change my outlook on leadership and management.

This course has exposed me to the five practices of exemplary leadership. These practices are very powerful and, in my opinion, are the fundamentals of good leadership. I have used these five practices in my work, and I have achieved tremendous results from my team. Our principals, Dr. Frank Ferris and Dr. Shannon Moore, have really modelled the way and exhibited great leadership skills in running this course. My experience with them has really been great.

I have also especially worked on certain skills where I had some weaknesses, such as relationship-building which was a huge challenge due to my introverted nature. Now I can freely meet with strangers, and strike up and maintain meaningful conversations. I have also perfected my public speaking skills, listening skills and presentation skills, among others.

I was also very fortunate to have Prof. John Ellershaw, Professor of Palliative Medicine at the University of Liverpool, as my mentor. He has taught me not only to practise using the five exemplary practices of leadership. He has also enabled me to understand myself and be analytical of my input in any work situation. This has helped me to trust my team more and, in turn, enable them to perform their duties to the best of their abilities.

The Future

I am highly motivated and determined to lead my team and grow our organization. I want us to be a well-managed and efficient Palliative Care organization that provides compassionate, holistic care to patients and their families with life-limiting illnesses. The need for Palliative Care services is still very high in Uganda in particular and Africa in general. I therefore hope to set up branches of the organization in three other major regions of the country -- starting with my home area in memory of my late Father and Sister.

I also plan to study for a Masters of Palliative Medicine to help me provide better care for my patients and become a stronger advocate and trainer to scale up PC services in Uganda and Africa.

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