THE INSTITUTE FOR PALLIATIVE MEDICINE
at San Diego Hospice
INTERNATIONAL PALLIATIVE CARE LEADERSHIP DEVELOPMENT INITIATIVE

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MY LEADERSHIP JOURNEY

My Specialty and Subspecialty

I am a Consultant Internal Medicine/Hematology-Oncology at the Uganda Cancer Institute. I have practiced palliative care since 1998 and I am a Consultant with the African Palliative Care Association (APCA) on technical aspects of palliative care. I hold several positions of responsibility at the Uganda Cancer Institute as well as Mulago Hospital Complex.

Opportunities and Challenges that led me to the Field of Palliative Care

The Early Days

My path to medical school and palliative care was atypical. The second-last born of ten siblings, I was raised in a modest family, my father a carpenter and my mother a full-time housewife. My school life was filled with serious challenges which predominately involved difficulties paying school fees. Additionally, I frequently suffered malaria (plasmodium falciparum) from the rampant availability of hungry female mosquitoes. Despite these challenges, I performed relatively well throughout school and frequently received scholarships from various sources. Such small opportunities played a big role in my life and the scholarships got me where I am today.

Difficult Times

The late 1970s into the early '80s were times of political instability in Uganda associated with multiple losses of life and property. My family was not spared this tyranny: my brother was murdered in cold blood at his apartment, a death that quite devastated me.

At 13 years of age, I lost my father from cancer a disease that was associated with great suffering, both for my father and our family. We managed to have him seen in hospital by one of those brave doctors who risked their lives to stay in Uganda at that time. Sadly, his disease was quite advanced and since 'nothing much could be done' he was sent home. Following months of serious suffering he died and my elder brother took on the responsibility of caring for most of us, moving me into his home where I continued my secondary school studies.

Exactly one year after my father's death, my sister *bled to death* following a complicated delivery because there weren't sufficient resources in the hospital to help her: no blood for transfusion and no ambulance to get her to a referral hospital. I could not believe that in the presence of doctors, a patient could die from lack of blood.

Three years later, my elder brother -- the breadwinner for the entire family -- started getting sickly and was diagnosed with advanced Human Immunodeficiency Virus (HIV) infection – AIDS. At this time in Uganda, there was limited knowledge about care for AIDS patients. Like countless other patients, he wasted (slimmed) away with a multitude of complex opportunistic infections that no health worker then knew how to manage effectively. Of course there were no anti-retroviral drugs let alone primary prevention of opportunistic infections with cortrimoxazole. He was in so much pain and we all wished that he would rather die to 'escape' this gross suffering. In 1991 my brother -- my great mentor and friend -- succumbed to AIDS.

Following his death I realized there was no hope for the future because my provider of school fees, the caretaker for the family, had gone. I continued at high school with faint hope of completing it and no light at the end of the tunnel. I had to scramble for sources of income to be able pay my school fees, which was very challenging.

One great resource was my mother. Although she did not have a job herself, she gave me hope to press on. She promised she would work to help me complete school – high school, and she took on odd jobs including selling firewood but this fetched very little money and eventually there were no more trees to fell. The next resort was to work in a local stone quarry. My mother worked in the quarry to take care of us all -- and my school fees. During school holidays I would join her. This was very difficult work because we had to break the rocks into small pieces using hand-held hammers. I am glad I survived tetanus because the rocks often cut me and there was no treatment available.

Following high school, I reluctantly applied to join University without any clear idea which course to take on but I included medicine as one option. I was doubtful that I could begin University but was happy that I had at least completed high school. I recall my mother buying me a 'new' shirt for having completed school!

Medical School

I was admitted to study Medicine at Makerere University on a government scholarship but with mixed feelings. I lacked financial support, and would not have time to work at the quarry because the course was so demanding. However, I was determined to study and become a doctor, because I imagined I would be in a better situation to stop they dying epidemic in my family. I also imagined I could save many more lives in Uganda though not "all diseases" nor cure everyone! I was not sure I could cure AIDS patients because by then it was clear there was no hope for them.

As you have rightly guessed, I was utterly wrong. Adjusting my thinking started during my initial encounters with patients as a medical student when my patient I was about to present to the attending pediatrician died. I had never imagined a child could die in the hands of doctors (counting myself as one of the 'doctors'!)

All my other clinical rotations were filled with challenges of patients suffering and/or dying in various ways. The HIV epidemic was at a peak then in Uganda, with very many AIDS patients admitted but never making it home. It was usual during ward rounds to hear senior attending clinicians using such terms as, "all we need is TLC…" meaning there was no hope, for many of the patients.

The hope I had of curing patients once I qualified as a doctor was dwindling away significantly and it became apparent that I could not achieve this goal. It seemed senseless to continue training as a doctor and, given a chance, this was the point where I might have abandoned medical school and returned to the quarry to crush rocks for a living.

The Turning Point

One day in 1995 as I was walking from one of the medical wards, I accidentally bumped into an event in one of the lecture theatres. I assumed this was one of the usual medical grand rounds and I sat in to listen. Making a presentation was a *white doctor* talking about her work and how they were able to control pain and other symptoms in patients with advanced cancer and HIV/AIDS even when facing death. I listened attentively, but from my experience on the wards I did not entirely believe what this lady was saying. But somehow, I wanted to believe that she might be right, and at the end of the lecture, I approached her and asked whether that form of care could be brought to Uganda. I also asked what kind of training was needed to be able treat patients as she described. I later found out this was Dr. Anne Merriman, founder of Hospice Africa Uganda, and that she was discussing palliative care**.** Dr. Merriman accepted a small group of us to an introductory palliative care training course being held at her office. There was need for registration fees and of course I did not have the money yet, but assured her that I would pay in time. (I had begun an income-generating business – a small barber service from my University room. I knew I could raise the money and pay the course fees, though I doubt I actually paid the entire sum!)

Regardless, this introductory training to palliative care made me realize I could become a doctor. Truly, I believe that's when I *became* a doctor – one who could care for patients even if he could not cure them.

My Initial Challenges and How I Overcame Them

I have encountered many personal challenges in my life, some of which are outlined above. The earliest challenge was the overwhelming financial constraint that made life difficult. It's hard to explain how I managed to surmount these and find solutions, but perseverance and determination helped lead to success.

After medical training, most of my colleagues joined very highly paid health institutions while others left for other countries to seek a better life. I decided to apply for a position at a Hospice to care for dying patients. This was a serious decision to take yet colleagues ridiculed me for deciding to work with dying people when there was little remuneration. As a young man, I needed to find a good income stream. However, I enjoyed taking care of patients at their end-of-life because we were able to make a change in their lives. The ability to make patients and families happy by controlling patient suffering gave me considerable satisfaction.

I was challenged by my lack of training in palliative care, yet here I was 'masquerading' as a palliative care doctor. But my focus was to become a palliative care expert so I decided to learn more about the field. I did not have many people to consult with, and I had not had formal palliative-care training. But working as a team was a big advantage because I came to learn new things through sharing ideas. I did a lot of self-learning by reading the few reference materials I encountered. Hospice Africa Uganda used many volunteers, including experts in palliative care from all over the world, and I would invite them on home visits. This way, I was able to acquire various skills from each of them.

The other challenge I faced was the fact that I was expected to train others in various aspects of palliative care. My palliative care mentor and role model, Dr. Anne Merriman, was always kind enough to share her teaching materials with me. She taught me how to make presentations, I learned to search for literature on a given topic and eventually I was able to present my findings to others. The more I became involved in training, the deeper grew my understanding of clinical palliative care.

Lack of access to essential palliative care medicines -- including pain medicines -- was another challenge that we faced. Access to oral morphine was not as easy as it is today, and there were times when we would run out of stock which led to uncontrolled pain. Lack of access helped us advocate for increased availability by working closely with the Ministry of Health. Eventually government agreed to procure morphine powder for the entire country and to have it reconstituted. Other medicines for control of various symptoms were also irregularly available, so we resorted to what was available locally. This innovation helped us identify affordable and acceptable means of symptom control within our resource-restricted environment.

More Challenges and Opportunities

After two years of working with Hospice, it was time for me to return for further studies – Masters. My choice went straight to Internal Medicine because I viewed palliative care as an Internal medicine sub-specialty. I applied to Makerere University and was admitted, with funding from the Uganda Government albeit with some conditions.

I completed my Masters training program within the stipulated three years and returned to Hospice for a *Specialist Registrar in Palliative care* position. However, I did not last long at this and after a year I thought of doing something else. Was I really tired of working in palliative care? One wonders.

But what could I do that was better than palliative care? One other option was to seek employment with the government. I saw this as an opportunity to work from within and influence others to ensure that palliative care became part of routine care. But would I be able to do this when the bureaucracy was filled with senior clinicians who did not believe in palliative care, and clinicians that ridiculed those taking care of the dying? These were serious challenges. Nonetheless, I had to challenge the process and eventually I took on a job at the National Referral and Teaching Hospital (Mulago). Here I could practice not only as a general physician but as a palliative care physician, too. I know that this way I would be able to broaden my circle of influence to narrow my circle of concern – palliative care for all in need in Uganda.

Hematology/Oncology

General internal medicine was interesting but did not bring the happiness I was looking for and I imagined that Hematology-Oncology might be better. Of course this sounded like a joke to many (including myself) because even physicians practicing areas of this subspecialty gave it up. However, I looked at this as an opportunity to develop my skills and ultimately take a leadership role in this field where (technically speaking) palliative care would comfortably fit. An opportunity arose and I was accepted for a Clinical Fellowship in Hematology at McMaster University in Hamilton Ontario, Canada. I was in Ontario for just over a year and during this time I met with wonderful people many of who are great leaders. Among them is Dr. Mark A Crowther who gave me a lot of guidance and on-going mentorship. I made friends with other people here in both hematology/oncology and palliative care and I am still in touch with them. Dr. Crowther remains my mentor and I was given an academic appointment as Assistant Clinical Professor (Adjunct) at the Faculty of Health Sciences.

Following the training, I returned to Uganda and decided to start up a Hematology service in the Department of Medicine. It was a very challenging decision but I introduced my idea to the Head of Department. Initially I started a liaison service but later I was allocated a ward dedicated to patients with hematological problems. The next challenge was finding a way to sustain the unit, which required me to build an effective team to manage the growing need – including teaching students. I identified two clinicians, inspired them to join Hematology and personally trained them. As unit leader, there were challenges and opportunities but I am proudest that I was able to attract more doctors (residents) to the unit, and many based their projects in my unit. What pleased me most is that my task had been viewed as an impossible venture – starting up a hematology service with no funding! Yet it had developed and thrived.

I later was transferred to the Uganda Cancer Institute with the major purpose of integrating hematology with oncology. At the cancer institute, I had several leadership opportunities including directing clinical services and the laboratory. In less than a year I was promoted to the position of Consultant. Consultancies are very challenging positions but I saw opportunities there to integrate palliative care into cancer care clinical services. Indeed, I have drafted an interdisciplinary palliative care training curriculum that -- once approved -- will carry out in-house team training.

African Palliative Care Association

The African Palliative Care Association (APCA) was formerly established in 2004 to promote and support palliative care in Africa. I joined APCA as an Advocacy Manager working on strategies to promote access to palliative care throughout the continent. My work involved meetings with government officials at Health Ministries as well as Medical Teaching Institutions to discuss integrating palliative care into existing health systems. Among such activities was promoting access to opioids (particularly oral morphine) for pain control. This was one of my main activities and fraught with many challenges. In many countries in Africa, the first mention of access to opioids gives everyone the impression that you are supporting illegal use of controlled substances, and that you are creating a generation of addicts! I was very lucky to work under the leadership of Dr. Faith Mwangi-Powell because she gave me great support and guidance that helped us -- as an organization -- achieve tremendous results. Working together with such a dedicated team at APCA helped us move forward.

I took a leadership role in promoting access to opioids for pain control in Africa and through collaboration with other organizations -- including the World Health Organization (WHO) Access to Controlled Medicines Program, National Hospice and Palliative Care Organization (NHPCO), the Pain and Policy Studies Group (PPSG), among others, with funding from the Open Society Foundations, True Colours Trust, USAID, and elsewhere. Consequently we were able to hold four regional workshops in Africa: for the East and Central region, West Africa, Southern Africa and North Africa. Six countries were invited to each of these workshops, and each country was represented by persons from strategic positions within government and the private sector -- with potential to influence policy changes that would ensure improved access to pain medicines. Each country team developed an action plan to address what they considered barriers to access.

I regard this activity as one of the most challenging that I undertook. But I also see it as a major achievement because organizing meetings in Africa -- especially when you are remotely placed -- is very difficult. However, working through team collaboration (the APCA team), consensus can be reached and we achieved this. Right now, many African countries have improved access to pain

medicines simply because they participated in these meetings, and because we continue to provide mentorship/support to country champions to ensure they achieve their objectives.

One might wonder how we were able to influence diverse governments in Africa to buy into palliative care -- including improved access to pain medicines – with everyone coming from such different countries. The trick is that as APCA, we strategically infiltrated policy makers by working with national champions in palliative care and/or those with potential to influence government. As APCA we put in place means of empowering our in-country local partners to take a leadership role within their own countries.

On a number of occasions we arranged advocacy meetings with high-level national leaders, then the local champions would take the lead and we'd follow. This way it was always clear that APCA was implementing its role of providing technical assistance to partners in order to promote access to affordable and culturally appropriate palliative care.

Working with APCA was a very challenging experience. There were times when I would feel, "I cannot do this or that" and then my Executive Director would counter, "Henry, you can do this." Of course this would give me all the confidence to take the risk and in the end it would come out well. For example, as Advocacy Manager I was given responsibility in a leadership role to organize a three-day advocacy workshop on improving availability to opioids for the southern Africa region. We sent out invitations to all responsible offices in six countries. However, confirmation responses were very slow to arrive which impacted our pre-workshop tasks. Workshop funders wanted confirmed numbers of participants before funding could be released and, of course, this put me and the entire team under considerable pressure.

One day while on annual leave, I received an urgent call from the office requesting me to execute an on-site follow-up. This meant travelling to three countries in less than five days to ensure that we had all necessary details and to confirm the venue for the planned workshop -- in yet another country! Travel plans were made and within a day I was organized to travel to Mozambique, Botswana and then Namibia. I had never been to these countries but I was able to meet with government officials and, by the time I left on my one-day-per-country trip, I had a list of confirmed participants from each country and a workshop venue.

I had doubts but recalling my Executive Director' confidence helped me persevere. I knew there was no other option than challenging the process. My negotiation skills also helped in meetings with some of the government officials who had been described as "too difficult". Finally the workshop began -- and went better than I expected. I also managed to assemble a chain of important relationships that helped me later on when following up on palliative care activities in these countries.

While at APCA, I was also able to participate in some high level meetings on palliative care including WHO and UNODC among others.

Palliative Care Materials

Furthermore, I was able to lead the development of some APCA materials aimed at promoting palliative care in Africa. These were developed in line with APCA's strategic objective of encouraging governments across Africa to support affordable and culturally appropriate palliative care. This included promoting availability and accessibility of palliative care medicines for all in need, developing resources that enhance opioids accessibility for patients in need of pain control in Africa.

It is important to note that these are not my personal publications but APCA materials that I took a leadership role in developing. Some of these include:

APCA Guidelines for Ensuring Patient Access to, and Safe Management of, Controlled Medicines: We developed these guidelines to support both governments and health care workers including pharmaceutical companies in the safe handling of controlled medicines (particularly morphine) to ensure access for medical and scientific purposes. They cover all regulatory and administrative measures needed to balance between safely managing opioids while ensuring they are appropriately accessible to patients anywhere, anytime. It is meant as a model for governments to adapt when developing national guidelines.

To address the limited understanding of opioids use, and some fears and myths in health care professionals, we developed an evidence-based pocket guide on opioid use in pain control. The title is ***"Using Opioids to Manage Pain: A Pocket Guide for Health Professionals in Africa"***. This is an all-round guide for medical practitioners when using opioids to manage pain. It tries to address fears and demystify myths about opioids including facts on using other opioids, ensuring health professionals have an understanding -- albeit brief -- of other opioids and how they relate to morphine. Dr. Liz Gwyther was kind enough to help me by reviewing the draft, giving me extremely constructive feedback. Other pain experts also reviewed it before it was published. It is our hope that this will be very helpful to health professionals particularly those not very familiar with these medicines.

These are just some of the activities in which I have been able to take a lead role. I have other examples of promoting palliative care in Africa, which involve writing and oral presentations.

Looking Back, What Would I have Done Differently?

There are a number of things I have done, but at the time I didn't take note of how I was able to accomplish them. I could have done things differently had there been readily-available options. Certainly in my early life I did not have much control in running my life, although I was determined to get somewhere despite all challenges.

I am sure if I had had a chance to receive leadership training earlier, my approach to challenges would have been different. It was always extremely difficult for me to take a risk or confront a challenge ahead of me. My approach to some life situations I encountered would have been different. I used to focus on what concerned me without knowing that simply concentrating on my circle of influence would have helped me get further faster. I can do better now.

My meetings with high-level government personalities in various countries would have been managed in a better way, had I the negotiation skills then which I now possess. I can speak with confidence today, whether on a one-on-one basis or to a large conference audience. I am now a better public speaker, and I attribute this to the various presentation challenges I have been faced with -- as well as extra training from the Leadership Development Initiative at the Institute for Palliative Medicine at San Diego Hospice.

I would not have taken on so many tasks simultaneously if I had had better negotiation skill, assertiveness, and grasp of my capacity. I would have negotiated for an administrative assistant to help me with some of the small activities I spent time on. I would have delegated work to all team members, ensuring we shared the burden and met afterwards to celebrate achievements. This is

especially true when I was writing various reports following the regional workshops. I could have delegated some work to an assistant, had I thought to negotiate for one.

It is wonderful to inspire others and share a vision to build a strong palliative care team. I did not do this well until recently in my leadership journey, and I realize I could have done this better earlier on. In my current position at the Uganda Cancer Institute, I feel like a leader when colleagues and friends look to me for inspiration. We have been able to succeed easily in difficult situations because others have learned to take on responsibilities. I know how to appreciate my team immediately when someone does something good, and when they make errors I help them understand their mistakes.

My Hopes and Dreams for the Field of Palliative Care

Palliative care is growing in Africa and I view this in a similar way to a child's road-to-growth chart. We give this to any child born in Africa to monitor their immunization status and growth. It is used as a monitoring tool, with checks and alerts to identify serious deviation from the norm. There are national and international strategies ensuring each child grows well and infant mortality rates are reduced to insignificant levels.

My hopes and dreams are to see that palliative care grows up well -- as we hope a child's growth ensures they are within the upper and lower percentiles. Just as a child is vaccinated against killer diseases, palliative care development in Africa can be protected from various threats that might cause early-stage death. The *killer diseases* for palliative care in Africa are situations where we lack:

a) Government policies supporting the integration of palliative care in the existing health infrastructure
b) Access to essential palliative care medicines – particularly opioids for pain and symptom management
c) An educational system that includes palliative care as an integral part of medical, pharmacy and nursing training
d) A strategy to implement palliative care at all levels

We must immunize palliative care development in Africa by ensuring all African countries have strong foundations in place to integrate palliative care into their health systems. It is my sincere hope that I will continue to participate in the education of health care workers about palliative care -- especially doctors, pharmacists and nurses -- and provide them with on-going mentorship as they develop their careers.

It is my dream that governments will establish regulations and policies in support of improved access to pain medicines including directives that allow cadres (other than doctors) to be able prescribe opioids for patients in need.

I hope palliative care will grow in Africa as part of essential health care accessible to whoever needs it, supported by well-trained specialists in palliative medicine. We should stop looking at palliative care only as end-of-life care provided to a gasping patient; instead we should see it as a holistically-applied approach to improve the patient and family's quality of life from time of diagnosis.

People look at palliative care as a 'depressing' specialty and, therefore, we need to have incentives in place. It is my dream that the practice of palliative care will become a well-paid practice to attract many more health care professionals. In this way, the growing baby – palliative care – will be able to survive the very difficult times it currently faces.

Wisdom I Wish to Pass on to Other Palliative Care Professionals

My first wish is to see more health care professionals take on palliative care as a specialty, and grow this specialty until we have palliative care professionals in all African countries. I would appeal to all palliative care professionals to widen their palliative care horizons by becoming involved in leadership. Health professionals often tend to restrict activities to the clinical – forgetting that they need leadership expertise to manage their programs effectively. I challenge palliative care professionals to improve their leadership skills to become better palliative care advocates. This is the only sustainable way of growing palliative care in Africa.

I also encourage palliative care professionals to become involved in scientific research which generates evidence, so their practice is based on high-quality data. There is currently a dearth of local evidence from Africa to support what works/what does not.

All palliative care professionals should become advocates whenever given a chance, including submitting abstracts to conferences to present their work.

Lastly, as leaders in this field, we need to make palliative care an attractive profession by talking loudly about it and inspiring many others to join. We who hold leadership positions must take every opportunity to promote our cause, to ensure we develop a system that will thrive after we inevitably move on.

One may wonder that what happened to the Ddungu's family on this journey. Did he actually walk with them? Indeed, my family has been wonderful but because it's extensive, it's difficult to honor them all. My brothers, sisters, cousins and nephews are all thriving and enjoy a better life than we began with. Tracy, Tim and Patricia have been especially kind because they accept staying in boarding school allowing me to freely travel in the world of palliative care -- but the greatest person in my life remains my mother. She still takes very good care of me and has continued to provide guidance in my leadership journey