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In the early nineties, the Kenyan government through the World Bank offered scholarships for post-qualification medical training to those of us at Kenyatta National Hospital. I was picked to study for a fellowship in neuro-anaesthesia in Britain. The hospital consultant at Liverpool's Aintree Hospital arranged a three-part rotation period -- in theatre, then pain clinics and finally hospice. I had little interest in the pain clinic and hospice because the practice seemed inapplicable to Kenya. Returning to Kenya, I quickly began an intense program in the hospital giving anesthetics to patients with neurological problems.

Early one morning in 1999 my father rang me, which was most unusual. He said he was having problems swallowing. I asked what made it difficult. He wasn't sure and hadn't considered the cause. I knew he was elderly, diabetic and loved his alcohol, but antibiotics and good diet would solve things. I reassured him it must be an infection that needed treatment and advised he see his regular physician.

Three days later, I arrived home late and noticed an X-ray envelope on the dining room table. It was clearly left there for my attention. I was tired, not in the mood for more medical work, and decided it could wait until the next day. The next morning as I prepared to leave, I checked the X-ray. I was startled to see it was my father's barium swallow. I quickly opened the envelope and read the report; it suggested the patient most likely had cancer of the food pipe (oesophagus). It recommended a biopsy to confirm this. Convinced that the X-rays must have been mislabeled, I decided to visit the radiology department later that day. Calmed by my thoughts, I pushed the report to the back of my mind.

The next day, I went first to radiology then to the cardiothoracic department to discuss the X-rays and misdiagnosis with the surgeons. The surgeon picked up the X-ray and commented what beautiful pictures he observed of cancer in the upper one-third of the oesophagus. I was so shocked that I needed to sit down to steady my nerves. I stared at him in disbelief, feeling confused and alone. I decided to seek a second opinion before informing other family members. Four cardiothoracic surgeons' opinions later -- none offering a

different opinion -- I gave up.

## Different Reactions to Bad News

I drove home with a heavy heart and told the other family members what had transpired, still wondering if I had erred somehow.

My mother said she had a friend who could heal my father through prayers and he needed no other treatment. My father wanted nothing to do with the healer (prophetess) who decided to move into my parents' home. She demanded a self-contained room and supply of protein-rich food. She would seclude herself in that room, opening the door only to receive her meals.

My siblings felt I should arrange for some form of medical treatment to cure our father. Lastly, I spoke with my father. He said he knew cancer was a terminal disease and wanted no treatment -- just to be allowed to die in peace.

I decided my father was in shock and, given time to adjust, would want treatment. I sought advice on other options such as a biopsy followed by radiotherapy or a stent.

In the nineties, in Kenya, stent procedures could only be performed at Tenwek Hospital, which is some distance from Nairobi. We arranged for him to travel for the stent surgery. Seemingly accepting these plans, on departure day my father declined to go, reminding us he wanted no intervention. On reflection, I realized we had not discussed the plans with him and had assumed he would agree.

Eventually he could not swallow anything. He agreed to a biopsy followed by radiotherapy and eventually was able to swallow.

He was to be seen monthly at the cancer treatment clinic. But after the second visit he declined to go again. He felt their advice -- no alcohol -- was inappropriate. Arguing he already had cancer, how did avoiding alcohol benefit him? How appropriate is the advice we give patients?

A few months later he was referred to the hospice. I had never visited the hospice and had vague memories of what I had witnessed in Britain.

He continued to attend the hospice for the next few months until he finally died comfortably at home in his sleep.

The funeral was hectic with lots of people visiting and helping in different ways. We received gifts -- money, food, bedding and crockery -- to cater to the many visitors we had.

As I went through the motions of burying my father, meeting many people who knew and loved him, I wondered whether it would have been possible to tap into all this support when we actually needed it.

After the funeral, everybody suddenly left; this abrupt change brought further confusion. As we resumed our normal lives, new stresses arose concerning inheritance. My brother felt he

was now the man in the house and demanded his due recognition, while my mother insisted on maintaining status quo while she was still alive.

The question everyone asked was, "Where was my father will?" It was a good question but somebody should have asked for it before he died, perhaps when his diagnosis was made. I wondered when -- and by whom -- the will should have been discussed.

## **Changing My Career – Start of the Palliative Care Unit**

Once back at work, my outlook towards patients changed.

I began to try to determine what information patients and families knew about the diagnosis and suggested treatments. I discovered many patients knew nothing about their disease or the treatment they were facing -- and more importantly, they wanted more information.

One such patient was Dominic who was admitted to the hospital for an examination of his airway (bronchoscopy). He'd had a cough for a long time and X-rays showed a mass in his chest. He needed a tissue biopsy to diagnose the disease.

During my preoperative visit, I discussed with him the possible diagnosis of infections, like tuberculosis or lung cancer, and was surprised at his lack of information. I encouraged him to ask his doctor more details about his diagnosis and treatments. The next day we successfully performed the procedure.

I did not see Dominic for four months until I was asked to see a patient for an orthopedic procedure. It turned out to be Dominic. This time he was withdrawn and angry. "Why did you not tell me my diagnosis when we met?" He continued, "Why did you not tell me my cancer would spread?"

I had no good answer, but I felt it was not my place to discuss this. I was not his doctor -- or was I?

Dominic asked me seriously, "Would you make sure that once you put me to sleep, I do not wake up again?" He felt the pain he was going through was too much to continue bearing.

I told him I would not leave him to sleep forever but would do my best to control his pain after surgery. This was not done very successfully. Thinking back, I was not adequately knowledgeable about how to do it. I had nothing more to offer Dominic and stopped visiting him. How easily we abandon our patients.

However, his request that I end his life on the operating table made me think of the intense suffering that makes one prefer death. Was it not possible to change that?

Some days later, I was asked to see an elderly man who was bleeding from a leg wound due to the spread (metastatic) of cancer. On an assessment to check for fitness for anesthesia, the elderly man forbade me to give him anesthesia because he would rather die than have an amputation. I recorded his sentiments in the file and left.

My medical seniors were unhappy. I was asked to review the patient's profile again and arrange for amputation. This time I met the family who were hostile to me as they felt I was listening unnecessarily to the patient. We agreed I should arrange for a different anesthetist to see the patient.

However, I still attempted to discuss surgery with the patient, and found he was unwilling to have an amputation and was comfortably discussing death. He told me that as his spirit left his body when he died, he wanted to look down and see a whole physical body left behind. I felt a great desire to support his choice and continued to visit him until the end.

My colleague took over but all attempts to perform an amputation on the patient failed because he became violent when taken by force to the theatre. Eventually, he had a massive bleed and died.

Weeks later, the family visited me. I was apprehensive as they streamed into my office and sat opposite me. Suddenly they started thanking me profusely for helping their father die in dignity, exactly as he wanted. I was pleasantly surprised. Suddenly, that patient reminded me of another patient -- my father -- who taught me to respect patients' decisions. I would only appreciate years later the 'Principle of Autonomy'.

In 2006, the Anaesthetic department in Kenyatta Hospital did an audit on pain management -- during surgery and up to three days post-operatively. The analysis of the results brought a surprising result: a small group of patients had a high degree of pain after surgery and it got worse with time. It turned out these were patients with inoperable cancer.

I saw a chance to start a Palliative Care unit and, based on this finding, I made an appeal to the head of the department and the hospital management. In setting up the steering committee, two members of the group were a great inspiration. They were the hospital director, Dr. Kibosia, who previously helped set up a free-standing hospice in another hospital, and the hospital nutritionist who had set up the nutrition department within the hospital.

It also became apparent that I needed to educate myself as I embarked on starting the practice of Palliative Care. I took all available opportunities to learn both locally and internationally. This included one week at St. Christopher Hospice in London in 2006. Visiting St. Christopher Hospice was especially inspiring as this was the place where modern hospice care began.

Once our unit was established, I realized I lacked necessary skills to move it to the next level. Luckily, I saw a call for a Leadership Development Initiative (LDI) offered by the Institute for Palliative Medicine at San Diego Hospice. I was successful with my application and LDI has helped open my mind to new ways of thinking. It has helped me generate new ideas of doing things in my unit and see connections I had previously missed.

## A Typical Day in the Unit

The early part of the week tends to be very busy. In a typical day, we have consultations from the wards, attend ward rounds, see outpatients and teach students on attachment.

Today the first patient is a young lady who is hysterical because she has just been told she has breast cancer and is adamant that she does not want any treatment. We calm her down and assure her once she comprehends the situation, we'll allow her to make an informed decision that we will respect.

The next patient also has breast cancer -- an elderly lady who has declined radiotherapy treatment. She has a breast wound that bleeds constantly. She gives an ultimatum that if the pain in her hip is controlled, she will allow the radiotherapy. With that concession, I turn to speak to her caregiver. To my surprise, the news that 'all is not lost' does not elicit the reaction I had hoped for -- as an angry middle-aged man insists I admit her because she has ruined his family. He is angry that his wife spends all her time with her mother.

For the next two hours I hold an impromptu family meeting that has its theatrical moments. The family's respect for culture appears to have done more harm than good. Culture demands that a man cannot share certain spaces in the house with his mother-in-law. This man's mother in-law currently controls a larger portion of the space in his house, so he feels like a prisoner in his own home. I can offer no solution; I listen and hope that once we control the bleeding, she can return to her own home.

The next patient has cancer of the stomach and appears to be in more pain than one would expect, given that he is on very high doses of pain medication. I decide to share my thoughts with him. I explain to him the concept of total pain that takes into account psychological and social pain, thus encouraging him to share other painful aspects of his life. That opens a floodgate of tears as he tells me of his many unfulfilled dreams, of his love for his wife, of never having children to carry on his family name. Feeling he has more he would like to share privately, I ask his family members to allow me speak to him alone. He confesses he is pained because of two children he is leaving behind -- never having acknowledged them. Suddenly he looks at me and says, "We are going to look for my children and make it right."

That, I suggest, will not be difficult because his family would be willing to help. "No," he says, "None of my family members must ever know." Now, that sounds tricky to me and I wonder if I should share my thoughts that the children might not even be his? I decide not to say so because I have learned that *hope* is an important anchor in life.

As George Saville wrote, "Hope is generally a wrong guide, though it is good company along the way." With a plan that inspires hope, my patient is now pain free and feeling much more comfortable than when he arrived and -- more importantly -- needing no adjustment to his medication.

## How Long Do I Have?

The question of how long a patient has left to live is often asked in the Palliative Care unit, and I am usually confident that I can tackle it.

Take Milka, a patient with cervical cancer who asks me, "How long do I have, Doctor?" I remember what I have been taught: one needs to explore, find out why the patient has asked that question, and I do. "Well," she says, "My husband and I have always wanted a baby and I feel it's the one gift I can give him as my life comes to an end."

Does she really not understand that her body cannot perform certain functions? Is this my chance to discuss death -- or is this denial? Denial is a great coping method and sometimes one is forced to encourage it. It is the end of the day so I take the easy way out. "Yes." I agree, "It's a wonderful gift and we can discuss that issue when you are feeling better." That is work for another day.

It's the end of the week, Friday is a slow day in the unit and time for reflection is available. The last two years have seen the unit expand and my Mentor at LDI Professor John Ellershaw has inspired a great vision: the Palliative Care Unit at Kenyatta National Hospital will transform into a Palliative Medicine Institute that will offer inpatient and outpatient care, education and research for all those with life-threatening illnesses.

I smile as I plan the weekend ahead and think of the wonderful gifts of life around me, because...

*"What sunshine is to flowers, smiles are to humanity. These are but trifles, to be sure; but scattered along life's pathway, the good they do is inconceivable."*

Joseph Addison

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