



THE INSTITUTE FOR  
PALLIATIVE MEDICINE  
*at San Diego Hospice*

INTERNATIONAL PALLIATIVE CARE  
LEADERSHIP DEVELOPMENT INITIATIVE

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## **From the molten wax of snuffed candles, perhaps a roaring flame will arise**

She was aptly named Sethunya because Sethunya means *flower* in the Setswana language of Botswana. She was beautiful; at least, that was what I saw in the picture taken a few years before I met her as a patient. She was in her twenties and a single mother of a six-year-old boy. That was many years ago when I was a young doctor.

I had been posted recently to the small, rural town of Maun where Sethunya lived. I remember the words of the deputy director of health services as I prepared to leave the capital city, Gaborone, about 1000 kilometers away. "Patrick, I know you're young but your services will be needed more where I'll be posting you."

If he only knew! I did not care about living in a city. I was looking forward to the new challenges waiting for me. I told myself, "I am sure I will learn more and make a bigger difference there."

Maun is referred to as the gateway to the Okavango Delta, the largest inland delta in the world with many serene, beautiful islands. The delta was a geographical wonder in northwest Botswana, home to abundant and unique flora and fauna. The Okavango Delta was the source of revenue for many safari and tourist companies. These companies advertised this land as a true paradise for travelers, especially for the rich and famous; Elizabeth Taylor and Richard Burton spent their honeymoon in this Delta.

But this setting did not matter to Sethunya. She had grown up with her own plans and dreams about the future far removed from the world of safaris and big tourism.

I saw Sethunya regularly on home visits. She was part of a group of patients that made me -- as a young physician -- feel impotent, helpless and full of despair. Sethunya had AIDS.

At that time, anti-retroviral therapy was not readily available in Botswana and, if available, would cost a fortune to maintain the course. Sethunya also had tuberculosis.

Sethunya's home was a small, unfinished, two-bedroom house. Her father worked as a night watchman while her mother was a homemaker. Her father's meager earnings could not provide comfort or luxury. Despite the small amount of money available at home, she grew up a cheerful, happy girl. She was the apple of her parents' eyes. They had set great hope in her finishing school and getting a decent job. Her father once told me that she promised to help finish their two-bedroom home. Her father said, "She wanted me to stop this dangerous night-security work as soon as she started working." He said his other two sons were jobless alcoholics who sat around drinking Chibuku, a locally brewed beer.

Sethunya was very ill and had lost much weight. She cried daily from intense pain, but there was little I could give to alleviate her condition. Existing pain medications were inadequate and at that time morphine was not readily available. All Sethunya's mother could do was massage her thin, weak limbs.

I remember once when I helped her parents shift her from her bed, my two hands overlapped from thumb to index finger while gripping her thigh, and I don't have the hands of a basketball player. What was once plump, shining chocolate-colored skin had been replaced by wizened, wrinkled skin-and-bones.

One day when leaving after a home visit, her six-year-old son who was playing quietly in the sand looked up and gently asked, "Is Mama going to leave me like Tebogo's mother?" Tebogo was a child next door whose mother recently died from AIDS.

Looking at those large, innocent eyes, I could only pat his head. The lump in my throat prevented me from talking. I could only walk away to avoid embarrassing myself because our culture has no place for a man's tears.

Sethunya passed away in pain one week later. Death had snuffed out another candle.

We accept death as an inevitable phase, but not with so much pain! With such a high number of AIDS patients, how many more of my people will die in such a painful way? How many children will suffer? How many more battles must we fight?

As a young physician, I came to the Delta region to "make a bigger difference." It became increasingly obvious to me that being a physician was more than just wearing a white coat, carrying a stethoscope and prescribing medication. Caring for Sethunya and her family was personally frustrating because her condition had no cure and she had no access to anti-retroviral medication. I also knew it was possible to die with dignity, to die without much suffering and pain.

I did not have much experience, so I probed and asked for help, but the responses I received were not useful. A few shared my concerns but had resigned themselves to the world of AIDS and wanted to focus on aspects of work that gave them more satisfaction. Some were indignant and felt that I was "too forward" and inexperienced. I faced many challenges. "Don't you know that opioids are dangerous and may kill patients faster or make them addicted?" one of my senior colleagues blurted out when I suggested using opioids for AIDS patients. Many of my colleagues resigned themselves to the situation. Our experience of opioid use was limited to mostly short term trauma and post-

surgical use. Some of my patients had AIDS and some were battling cancer, but their protests of pain were regarded as the complaints of a dying patient.

I saw Sethunya in many other patients who were also dying in pain. At that time, Botswana had one of the highest rates of HIV/AIDS, yet we had minimal medical research facilities and no medical schools. I wanted to make a difference. *Have I? Will I? Can I?*

I suddenly realized that I had a lot to learn and did not know as much as I thought. I had been trained to cure, but I was in unfamiliar territory!

One thing was obvious: this was not my dream. I wanted to be able to make a difference in my patients' lives -- where I could have some control and not be held back by bureaucracy. I took a decision to complete my three-year contract and move on to a level of independence -- a level where I could make change happen. Real, satisfying change.

I opened up a private practice. I was able to arrange medication for my patients from neighboring South Africa. I was also able to arrange for anti-retrovirals for patients who could afford them, but ARVs were expensive and limited in choice. When I look back now, I must highly commend the Botswana government for making resources available to ensure that free antiretrovirals are now readily accessible to Botswana patients who need them.

However, because my services were restricted to out-patient care and home calls, I missed providing the in-patient care I had so enjoyed. In time, a group of us set up a small hospital providing in-patient care in rural north-west Botswana. It was the first private hospital in northern Botswana. This was a challenge because such a hospital could not survive financially without focusing on acute care and surgical procedures. There were no donors, nationally or internationally, to realize my dream of a designated palliative care section in the hospital. I had no formal training in palliative care, and not much experience in sourcing funds other than from local banks that charge very high interest rates. We were already feeling the effect of the interest we were paying to build and run this small hospital.

I decided to introduce what I called the *Hospice-Home Project*. This was an advanced form of home visit where hospital services were delivered to the patient's home. I was accompanied by an ambulance and an assisting nurse, which allowed me to provide I-V fluids and other symptom controls. This service was designed mainly for chronically ill or terminal patients who could not afford in-patient private care. I still had no formal training in palliative care, as I was unaware of such training in Africa.

My need for formal training in patient-focused care and palliative care increased after my involvement in a terrible road traffic accident in South Africa.

What happened?

I was a front-seat passenger in a car driven by a colleague. We were on our way to a medical conference when the driver lost control, smashed on the embankment and rolled three times. My side of the car took the full impact and was badly smashed.

Everything became a blur of motion and sound which seemed to last an eternity. I must have drifted in and out of consciousness. My left humerus was fractured in six places, with torn flesh and tendons turning my left upper limb, into a grotesque twisted appendage of flesh and bones. My scalp had

been viciously ripped open on the left side, leaving my frontal right skull exposed. My right upper eyelid was torn off.

I spent two weeks in intensive care and endured some 16 surgical procedures before being discharged a month later. The surgery was remarkable: tendon transplant, nerve transplant, skin graft, and physiotherapy to learn to use my fingers again. This experience forced me to see life from a patient's perspective. Gradually I recovered physically, but my fears and the psycho-social impact of my injuries were not addressed. While in hospital, I sometimes I felt I was just a number or a research specimen. If I, as a doctor, felt this way then how would my patients have felt?

It became more apparent to me that medical training focuses on the curative: we feel we have failed when we are unable to cure.

My one-month stay in hospital allowed me to reflect on my work as a young medical doctor. Despite my interest in palliative care, I remember with shame how many times as a young doctor I would prefer to let an older ward sister deliver the news of a patient's death to the relatives.

It was more convenient on such occasions to play the 'culture card' and hide behind the belief that such information is better passed on by elders. Of course, we made sure we were in the ward sister's good books. We were ill-equipped in managing bad news. There was usually a sense of failure. We had been trained to cure, to bring news of life, not death!

After discharge, I learned about a postgraduate palliative medicine course at University of Cape Town, and I was grateful to be accepted. This course was invaluable in making me a better, more patient-focused palliative medicine practitioner. I am indebted to my mentor, Dr. Liz Gwyther, Head of Palliative Care, University of Cape Town and Chief Executive Officer, Hospice and Palliative Care Association of South Africa. Liz is one of the most gentle and patient people I ever met. She is a wonderful ambassador of palliative care and has trained many palliative care practitioners in Africa and beyond.

It was at the palliative care training in Cape Town, that I met another palliative care champion, Dr. Joe O'Neill from the USA. He directed the Ryan White CARE Act Program that provides some \$2 billion a year in support for people living with AIDS, in the United States and Territories. In addition, he for some time coordinated the Department of Health and Human Services' HIV/AIDS programs (CDC, NIH, SAMHSA, HRSA, and FDA) and later served as director of the White House's Office of National AIDS Policy – a position popularly called the national "AIDS Czar". In this role, Dr. O'Neill was the prime architect of the \$15 billion Emergency Plan for AIDS Relief (PEPFAR), now the largest global public health undertaking against a single disease in history. He then served as Deputy Global AIDS Coordinator and Medical Director in the U.S. Department of State during the first two years of PEPFAR implementation. He initiated and provided support for numerous projects in Africa, and has done a lot for palliative care in Africa.

Dr. O'Neill knew of my challenges in Botswana and suggested I apply for the Leadership Development Initiative (LDI) at the Institute for Palliative Medicine at San Diego Hospice in California. I applied and was one of twenty-two palliative care doctors selected globally for the pioneering cohort of this initiative. LDI is made possible through funding from the Open Society Institute, Princess Diana of Wales Memorial Fund, and the National Cancer Institute. These funders have greatly supported Palliative Care in different parts of the world, especially in Africa. We are grateful for their assistance.

The government of Botswana has made great strides in the management of HIV/AIDS. It has since made antiretroviral medication freely available for all citizens that qualify for treatment. It was the first country in Africa to take that initiative.

The LDI training program requires participants to develop individual development plans (IDPs). It is my hope that through these projects I can contribute to laying the foundation for palliative care in Botswana. I feel fortunate to be in a situation where I can play a role in pioneering health changes in Botswana.

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a roaring flame will arise!**