

## CHAPTER ONE

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# MY BEGINNING

### A YOUNG WITNESS TO SUFFERING

I was born in the Democratic Republic of the Congo (DRC), at that time known as Zaïre. The second largest country in Africa, the DRC has an extensive tropical rainforest, rivers, and parks with diverse and abundant wildlife. I was born in Bukavu, one of the major cities in South Kivu province, and returned there as an adolescent. I spent my early childhood in Isiro, a small city in the province of Haut-Uele. The city was best known for Sister Anuarite Nengapeta, a Congolese Roman Catholic nun who was murdered by Simba-Mulele rebels in the 1960s because she refused to become the wife of their leader. Sister Anuarite became a hero in this city.

In the early grades, I was driven to school, but when I turned eight years old my father told me I could walk to school alone. The city was small and safe, and my journey was fifteen minutes on the main road, so there was no risk that I would get lost. Every day I passed a roadside memorial to Sister Anuarite Nengapeta in the center of Isiro. I read the inscription on the stone marker, written in French.

*“C’est ici qu’est morte la Sœur Anuarite Nengapeta, sœur de la congrégation de la sainte famille, assassinée par Simba Mulele à cause de sa foi Chrétienne.”*

“It is here that Sister Anuarite Nengapeta, sister of the Congregation of the Holy Family, died, murdered by Simba Mulele because of her Christian faith.”

Above the French inscription was an image of Sister Anuarite, dressed in a white nun’s habit against a blue background. I looked for more information about Sister Anuarite in my school library, where I found a small, illustrated book—like a comic book—about her heroism. Sister Anuarite was imprisoned, beaten, and killed for her principles, and I remember this as the first time I learned about suffering. Although this incident was painful to imagine, I was impressed by her conviction. Though I was not Catholic, I reflected on how I might stand up for my own beliefs.

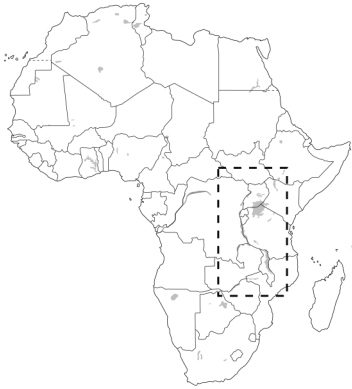
I tried to discuss Sister Anuarite with my parents to understand why this had happened to her. But they didn’t recall the civil wars of the 1960s, they couldn’t comprehend why this terrible incident had occurred, and it was difficult for them to explain such violence to a curious eight-year-old boy. My mother was occupied with my sister and brothers, and my father was busy with his work. Still, I felt my heart was transformed as I imagined Sister Anuarite’s story.

My family subsequently moved to Goma, the major city of North Kivu province, part of the Great Lakes region and close to the Rwandan border (Figure 1.1). My father established his own business and we lived there until my teen years.

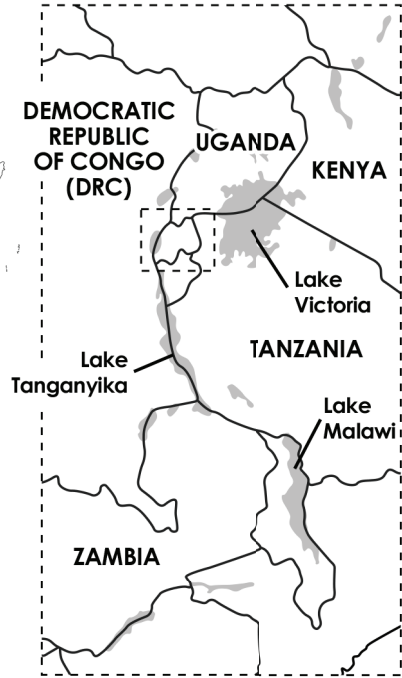
Compared to little Isiro, Goma was a busy city where people seemed more worldly. The large Rwandan community in Goma helped me to connect with my family’s culture. I learned the history of the Rwandan community in Zaïre, as well as our mother language, Kinyarwanda. We were considered outsiders in Zaïre, and I was stigmatized and bullied at school for being Rwandan.

I was in secondary school when the genocide against the Tutsi began on April 7, 1994. We first witnessed the horror on local and international television stations. By July, the former Rwandan government had collapsed, and a million refugees had fled to

**Figure 1.1. Africa**



**Figure 1.2. Africa  
Great Lakes Region**



**Figure 1.3 Detail  
(Locations Approximate)**



neighboring countries. Almost overnight, the peaceful life in Goma was disrupted, and the formerly clean and orderly avenues were full of refugees. Many had walked more than 200 kilometers from Kigali, the Rwandan capital. They carried mattresses and machetes, camped in the streets, and chopped down Goma's beautiful trees for cooking fuel. With unpredictable chaos, criminality, disease, and pervasive danger, it became unsafe to leave our house. My parents decided to move to Gisenyi in Rwanda. Despite the aftermath of the genocide against the Tutsi, it was safer than Goma.

When my family crossed the border in August 1994, I knew that nothing would be the same. Gisenyi seemed empty of people yet filled with the destruction of war, including dead bodies in the streets. My parents helped us feel safe despite the challenges. For the first time, no one told me I did not belong. In fact, I felt welcome as there was no bullying, and no curse words were directed at me for being an outsider.

As school had not yet started, my new friends and I spent our time exploring the devastated city as curious teenagers. When we came upon Gisenyi Hospital, it was an appalling sight. The hospital building was overwhelmed with patients, and sick and injured people slept outside as they waited for care. Witnessing their horrendous wounds and deep suffering, I was reminded of Sister Anuarite Nengapeta. I heard a voice in my head say, "This is what you have to do." I would become a physician to help people and to help my country.

## **CHOOSING MEDICINE**

After graduating from high school in Gisenyi, I attended the National University of Rwanda (now the University of Rwanda) with medicine as my course of study. I expected to graduate in six years and practice in Rwanda. To make a long story short, my studies took more than twice that time. But I never gave up, and in February 2008, I graduated from medical school and prepared to

fulfill the two-year national service requirement for new medical graduates. I planned to pursue a residency in general surgery after my service period.

When I received my appointment letter from the Rwanda Minister of Health to work at a district hospital in Kigali, I was both excited and anxious. I learned that Ubuntu District Hospital had been built by the Government of Rwanda to serve the population around the City of Kigali. The hospital served more than fifty percent of the capital city's population, and its catchment area included urban, suburban, and rural areas. I knew working in Kigali would be demanding due to the high volume of patients.

On my first day of work, I rose at five am, dressed carefully, and took a taxi to make sure I arrived in plenty of time. The hospital campus was lovely, with a long driveway, manicured gardens, and handsome buildings constructed of local red Ruliba bricks. In the early morning light, I followed a path flanked by greenery to a signpost written in French, with arrows pointing in every direction, indicating the departments of the hospital.

I walked slowly to the administration area, presented my letter of appointment, and was introduced to the hospital's director general. All district hospitals in Rwanda are managed by physicians, who might be general practitioners (GPs) or specialists. The director general oversees the administration of the hospital, outpatient health centers, and all health programs in the district. New medical graduates were assigned to a particular department, such as Surgery, Obstetrics and Gynecology, Pediatrics, or Internal Medicine, but provided support for the other departments when they were short-staffed. As I planned to pursue a residency program in General Surgery after my two years of GP service, I requested to work in the Surgery Department.

I started work that same day, April 9, 2008. Most of the time, I assisted the senior surgeon, who, in a district hospital, was usually a senior GP with surgical experience, not a residency-trained

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specialist in surgery. We performed operations, consultations, and minor surgical procedures, and made ward rounds. During rounds, a physician and a nurse reviewed each patient's case, spoke with and examined the patient, talked with the caregivers, and developed a plan of care for the day. In addition, everyone pitched in wherever help was needed.

On a fateful day in late October 2008, one of my colleagues from Internal Medicine was sick, so I helped with rounds in that ward. I noted that a particular room was a source of frustration for the staff. It held ten to twelve beds for patients who had been discharged but remained in the hospital because of financial difficulties, social issues, or limited life expectancy.

Some staff members referred to that room as *Mu rutoki*, local jargon for “banana plantation,” referring to the area behind a rural house where garbage is composted to fertilize banana trees. The *Mu rutoki* patients were, for the most part, poor rural people who were dying. While I understood the cynical metaphor, I refused to allow the stigma attached to these patients and their families to interfere with my responsibility for their care.

I was almost finished in the Internal Medicine ward when a nurse asked me to see a new patient who was in distress. I followed her into a private patient room, where I witnessed a degree of suffering I had never seen. Rafiki was twenty-four years old but looked much younger. His red Chicago Bulls T-shirt and black trousers stood out against the white bed sheet, and his writhing had cast aside a simple gray blanket.

The nurse told me that Rafiki had been referred from Amahoro Hospital, a tertiary public hospital in Kigali. Diagnosed with advanced hepatocellular carcinoma, a type of liver cancer, his transfer summary concluded, “The patient needs palliative care.” As I was unfamiliar with that term, the nurse explained. “They sent him here to die.”

Despite his terminal diagnosis and his agony, he had been prescribed only paracetamol (a simple analgesic), ibuprofen (an anti-inflammatory mild analgesic), and a single dose of meperidine (a short-acting opioid). I was familiar with pain from my work in surgery, but Rafiki's abject suffering was beyond anything I had witnessed. As I observed this young man—his suffering so full of emotion and grief—I felt as though my own bones were twisting and ready to break. Reviewing his chart, I recognized that he had already received the maximum pain medication allowed by hospital protocol. There was nothing more I could do.

Rafiki's family members, who could not bear to see his suffering, waited in the hall. As the nurse and I exited, his mother knelt before me. She appeared to be in her early sixties, dressed in traditional Rwandan cloth with a vivid yellow and black pattern, like rivers running through dark earth. Unspeakable pain and fatigue were etched on her face.

"Please, please, Doctor, give him something to let him sleep and wake no more. Please. Please. *Muganga, mbabarira, mbabarira,*" she begged in Kinyarwanda. "Doctor, I beg you, I beg you," she cried.

I tried to help her up, begging her not to kneel before me. She refused to rise until I promised to do something for her son. I bent over to assist her to her feet, promising to do my best to help. At last, she got up and hugged me so strongly that I thought my ribs would break.

"*Urakoze mwana wanje, urakoze,*" she said. "Thank you, my son, thank you."

But I had no idea what more I could do. Meperidine had been given to the patient eighteen hours earlier. The district hospital protocol governing narcotic drugs would not allow us to administer more. Although opioids such as morphine, pethidine, and meperidine were available to be administered intravenously, they were kept double-locked in the operating rooms (ORs) or nursing office and required a prescription from a physician and approval by a member

of the senior staff. A prescription for morphine had to be written in red ink and signed by three authorities: the clinical director, an anesthesiologist, and a pharmacist.

I felt despondent, hopeless, and ashamed of my double failure. First, I was failing as a physician because I couldn't relieve Rafiki's pain. Worse, I had failed as a Rwandan because, in our culture, an older person should never kneel before a younger person. I caused this mother to humiliate herself, to beg me to bring comfort to her son and reduce his suffering. To fulfill my obligation as a physician.

I recalled Sister Anuarite's conviction and my determination to stand up for my beliefs. Breaking hospital protocol, I ordered another dose of meperidine. The nurse refused to administer it until I signed a form assuming all responsibility if the patient was harmed. In medical school, I had been taught that opioids cause addiction and could hasten death. Like the nurse, I was afraid the patient might die because of the second dose. I was willing to help, but I was afraid I might go to prison. Was I ready to take that risk?

I signed the form.

Rafiki became calm after receiving the injection. His mother thanked the nurse and me. After the nurse and I spoke with the rest of the family members, I went back to finish rounds and complete my reports. Three hours later, I was told that Rafiki's pain had returned and was even more severe. I had to explain to his family that it would be impossible to administer another dose of meperidine.

I left the ward without planning any further treatment for Rafiki or support for his family. I didn't think to call the clinical director for direction, perhaps request to transfer Rafiki back to Amahoro Hospital, or even order more meperidine at my own risk. But I could not stop thinking about what I had witnessed.

Tormented, I shared the experience with a colleague when he arrived for the night shift. His advice: "Stop thinking about it or find another career."



I did not sleep that night, as my mind was restless. I questioned the hospital's opioid protocol. I wondered what more I could have done. What if I had called the clinical director, the anesthesiologist, and the pharmacist to prescribe morphine to relieve the agony of this dying young man? What if they refused? What if, what if, what if . . . ?

In medical school, I learned that maintaining life at all costs was the goal of our profession. The goal of treating physical pain should not be to remove it one hundred percent, a professor said.

“You cannot relieve pain completely, or you will not know if your patient is alive. Pain is the best signal that your patient is alive—in pain, but alive!”

But nothing would change the fact that this young man was dying.

At the hospital the next morning, I was told Rafiki had died in agony during the night, “screaming almost until the end.” As I received this report, a stretcher covered by a white sheet passed by me on its way to the morgue, followed by a wake of Rafiki's family members. I remember their faces, filled with sadness, anger, and accusation. I felt his mother's eyes on me.

Shaken and heartsick, I returned to the Surgery Department wishing I could disappear. Why had I spent years to become a physician if I could not relieve this young man's pain? Was it not my role to bring comfort? I had hoped to become a surgeon, but now I felt I must leave after my obligatory service and find another career.

### **A TURNING POINT**

In 2009, six months after Rafiki's tragic death, the Rwanda Ministry of Health organized palliative care training for five district hospitals. The primary focus was on patients with late-stage HIV and its complications. I attended the training with two nurses, a social worker, a physical therapist, and an anesthesiologist from Ubuntu Hospital.

Although I went with no expectations, in those ten days, I received the most important education of my life. As we explored the meaning of life, death, and dying, I discovered new dimensions of treating and caring for patients. I had been trained to focus on physical illness, but I learned that holistic care addresses the four dimensions of human beings: physical, psychological, social, and spiritual. I realized that although I could treat the disease without treating the person, I could not treat the whole person without treating the disease as well.

Rafiki's death was much on my mind, as were the many surgery patients in pain who were simply told to stop complaining. In Kinyarwanda, the word *Kwihangana*, which means "patience" and "resilience," reflects a philosophy of African stoicism. This concept is conveyed in the following Rwandan proverbs:

*Agahinda si uguhora urira.*

(Having sorrow is not crying all the time.)

*Amalira y'umugabo atemba ajya mu nda.*

(A man's tears flow internally.)

While *Kwihangana* is important in many aspects of life, it shouldn't apply when someone has physical pain. I realized that some of my medical indoctrination kept me from responding to patients as human beings. Why shouldn't we treat physical pain as an emergency, just as we treat fever, respiratory distress, and high blood pressure? At the conference, I was trained in evidence-based pain assessment and treatment, including the safe use of morphine. By the end of the course, I was inspired to bring palliative care to all patients with life-limiting illnesses. I knew palliative care was my calling.

As Ubuntu Hospital was already operating at full capacity, I doubted we would have time to provide palliative care. But our whole group of conference attendees was inspired and willing to

help, and our plan for palliative care was well received by the hospital leadership, especially as it was endorsed by the Rwanda Ministry of Health.

There were skeptics, of course. After presenting the hospital's new palliative care plans at a medical staff meeting, some of my colleagues awarded me the nickname "Gravedigger." They said, "You see the patients five minutes before they die. The gravedigger sees them five minutes afterward. Not a big difference."

But "Gravedigger" was about much more than me, so I did not take it personally. As the Ministry of Health had recognized, we needed a paradigm shift in the Rwandan system of care, from being disease-centered to community-centered, from seeing a "patient" to considering a fellow human being and the environment.

Thus, day by day, my fellow trainees and I quietly developed a small palliative care program. We did this on top of our usual workload, and the hospital administration did their best to support the initiative, despite the challenges of limited resources.

### **A NEW ROLE**

A few months later, the telephone rang in the OR as I was performing minor surgery. An administrator in the director's office said there was a special letter for me. I finished the procedure and went directly to the office. I opened the envelope and got the shock of my life.

*Dear Dr. Christian Ntizimira,*

*With pleasure, you have been appointed as the Acting Director General of Ubuntu Hospital, effective immediately. You are requested to take the position after receiving your appointment letter.*

*Sincerely,*

*Ministry of Health*

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I couldn't believe it.

My heart raced, my stomach was in knots, and I was short of breath. Why me? I did not have enough experience to lead the hospital! I had never in my life dreamed of being in a leadership position. Where would I start?

I took the letter and headed back to the empty OR, where I sat alone and tried to process this development. I consoled myself that perhaps the Ministry of Health saw something in me I couldn't see in myself. On one hand, I felt overwhelmed by the future responsibility; on the other, I thought that I could make the palliative care program a top priority. After reflecting for an hour, I left to find that the news of my nomination had spread around the hospital like wildfire.

The very next day I began managing the hospital administration, the strategic health plan of the district, and many other health programs. For the next three months, I was purely a hospital administrator, attending meetings, workshops, and symposia, implementing health programs, and discussing hospital interests with local and international partners. Once I had built a strong administrative team, I decided to divide my time between administrative duties and patient care. I felt it was imperative for me to provide direct palliative care services to lead our program. I hoped to make the hospital a center of excellence and integrate palliative care programs throughout the district.

In a major transformation, we developed education programs in pain management and updated the opioid protocol to make it accessible to all patients with moderate to severe pain. We changed the culture from fearing morphine to prescribing it appropriately and safely. As the program developed, we implemented education for non-medical staff, such as ambulance drivers, cashiers, hospital housekeepers, administration, and maintenance staff, with the motto, "Palliative care is everyone's business." We recognized that every staff member could play a role in helping patients and families navigate the hospital, thus participating in patient care and

reducing family stress.

As the hospital became well known for its palliative care program, increasing numbers of patients were referred. It became imperative to expand our services, connecting the hospital to the community to allow patients to receive palliative care at home.

With support from an American nonprofit hospice, we found a solution for the patients in the *Mu rutoki* room. The American hospice signed a Memorandum of Understanding with the Rwanda Ministry of Health to provide oral morphine tablets to Ubuntu Hospital. As physical pain was the most common reason the *Mu rutoki* patients remained in the hospital, prescribing morphine tablets allowed seventy percent of them to return to their communities to live in comfort and dignity through the end of life. We converted the *Mu rutoki* room into an office for patient files.

In 2011, to enhance my skills and knowledge in palliative medicine and leadership, I attended Harvard Medical School's Palliative Care Education and Practice course in the United States, planning to apply the lessons to our program in Rwanda. Participants spent two sessions at Harvard Medical School in Boston, Massachusetts, using the six months in between to develop projects at home with the support of Harvard mentors. At Harvard, I met Dr. Susan Block, the late Dr. Andrew Billings, and other leaders in the field.

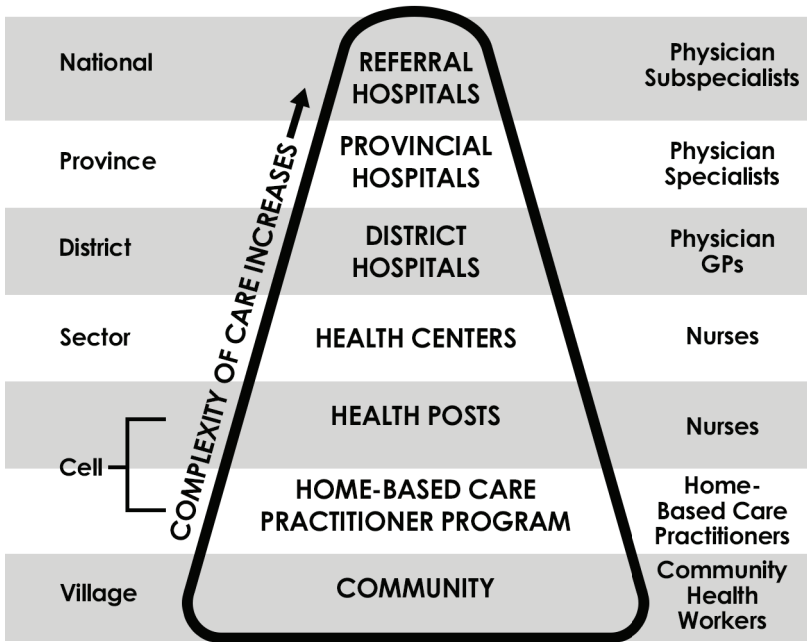
Back in Rwanda, I came to appreciate that what I had learned in Boston had to be respectfully adapted to Rwandan society and culture. I had to be careful not to simply transfer methodology and metrics from one place to another without consideration of Rwandan values, such as the centrality of family and community. I needed a new strategy.

### **COMMITTING TO PALLIATIVE CARE**

As our program grew, palliative care seemed to demand all my attention. I continued as the hospital director general, but spent my free time exploring opportunities to practice palliative care full-time. One event catalyzed my decision to make a change.

In 2011, the Ministry of Health launched the Rwanda National Palliative Care Policy to integrate palliative care throughout the public health system. The Rwanda public health system is well-structured, from rural villages to academic referral hospitals (Figure 1.2). The first step in implementation was training multidisciplinary teams in palliative care principles at selected hospitals.

**Figure 1.2. Rwanda Health Structure**



As part of the Rwanda National Palliative Care Policy launch, the Ministry of Health invited various local and international partners to meet and summarize the global status of palliative care. After the conference, I knew exactly what I wanted to do: become the voice of the voiceless, advocating for patients and families.

In 2013, after six years at Ubuntu Hospital, I left my administrative position for fellowship training in Hospice and Palliative Medicine. I was accepted at the International Fellowship Program

in Palliative Medicine in Columbus, Ohio, USA. I was able to participate part-time in Columbus and part-time in Kigali, enabling me to continue my clinical practice and research in Rwanda. The Ohio program provided training and mentoring, as well as an unexpected breakthrough in my thinking.

The fellowship program was based at Kobacker House in Columbus, a beautiful hospice residence that combined the comforts of a home with the staff and equipment of a hospital. It was a pleasant work environment for the physicians, nurses, social workers, and chaplains, and each private patient room was equipped with an electric bed, a large sofa, and a television. The rich setting contrasted dramatically with a Rwandan district hospital, but it struck me that something was missing. Most of the patients I visited were surrounded by framed photos of joyful occasions with many smiling people. But they were alone.

I realized I had observed the same thing in Boston hospitals. After some weeks in Columbus, I was comfortable posing a question to Jude, the hospice supervisor, about the absence of family and friends.

“Most of them live in different parts of the country,” Jude replied. “And they are busy, which makes it difficult for them to visit.”

“I understand,” I said. “But if they were happy together in the photos, why wouldn’t they be with the patient now, at this difficult moment? Was the happiness in the picture fake?”

“I don’t believe the happiness was fake,” Jude replied. “But the context is different, and people are busy.”

“In Rwanda,” I observed, “when someone is sick and family members live in the USA or Europe, they take a leave from work, travel across the world, and stay with the patient for months. Here in the USA, you have many airlines crossing the country. If someone is important to you, why can’t you find time to visit?”

With a deep breath, Jude replied, “I don’t know, Christian. I don’t know.”

I left the room with many questions on my mind. I couldn't understand why most of the patients I visited in Boston and Columbus died alone. I wondered if patients used photos to create a virtual family or an illusion of family presence to reflect what was in their minds and hearts. In Rwanda, I had always seen patients surrounded by families and communities. There were no photos in patient rooms because the people themselves were right there.

The images of solitary patients in Columbus and Boston haunted me. I returned home sensitized to the critical roles families and communities play in Rwanda to support patients. There are sociocultural reasons for this, including trust, interdependence, and collective decision-making. And there are practical factors: families bring the comforts of home (including food and bedding) to the hospital, provide transportation, and purchase medications. They pay medical bills and attend to practical affairs.

Both the 2002 World Health Organization and the 2011 Rwandan National Palliative Care Policy formalized the longtime hospice axiom, "The family is the unit of care." But even in Rwanda, the central role of family members could be perceived negatively by healthcare providers, especially physicians, as interfering with the plan of care or undermining patient autonomy. I wanted to develop a practical strategy to allow families and communities to collaborate with medical teams in shared plans of care with patients at the center.

As I divided my time between Rwanda and the USA, my goal became to develop a Rwandan model of palliative care based on Rwandan resources, priorities, and values. One young patient, in particular, helped me realize the important role of Rwandan culture in patient and family management.

## **THE STORY OF JOSIANE**

I was asked by the Ubuntu Hospital palliative care team during my fieldwork in Rwanda to see Josiane, a teenager with advanced-



stage osteosarcoma. A star basketball player at her Kigali boarding school, she had fallen onto her left knee during the local championship game. Several days later, Josiane could walk and attend classes, but her knee remained swollen. A month later, her knee was still swollen, and the school advised Josiane's parents to take her to the district hospital. Ultimately, at Amahoro Hospital, a biopsy revealed osteosarcoma, and an above-the-knee amputation was recommended.

The news was devastating to her mom and stepfather. It was not shared with Josiane. The family was referred to a cancer center, where, despite palliative chemotherapy, her malignancy progressed, metastasizing to her lungs. The family returned to Amahoro Hospital where an above-the-left-knee amputation was performed because of Josiane's severe pain from the large tumor. Postoperatively, the family was referred to Ubuntu Hospital for palliative care services.

Outside the hospital ward, I met with Josiane's Aunt Theresa in the company of Honorine, the palliative care team's social worker. It became clear that the family had been transferred from one hospital to another without a clear explanation of the severity of Josiane's medical condition.

I entered the ward to meet Josiane, a tall, slim fifteen-year-old girl listening to music through headphones. Despite her grim medical reports, she appeared to be in good condition. Nicknamed "Miss Rwanda" by the staff because of her beautiful features and frequent smile, at that moment she appeared to be quite sad.

I introduced myself and asked Josiane how she was feeling.

"I'm okay," she replied. She reported no pain and seemed comfortable thanks to a regular regimen of morphine syrup.

Josiane looked me in the eyes. "I know I have cancer, even if my family doesn't want to tell me. Am I going to die?"

I felt as though a sword had pierced my heart. I didn't know how to reply with sincerity, so I looked at her patient chart, avoid-

ing eye contact.

When I inquired further, Josiane told me she was sad because her mom had stopped visiting her after she learned of her cancer. I told her I would see how we could help.

Outside the room, Aunt Theresa explained that she had become Josiane's healthcare proxy because her sister Rosalia, Josiane's mother, had given up. She shared the family's story.

During the 1994 genocide against the Tutsi, Rosalia's husband, two sons, and daughter were murdered. Rosalia survived, but grief and bereavement became her daily bread. Three years later, she remarried and restarted her life with hope for the future. Instead, her husband became an abusive alcoholic who beat her nightly for the next ten years. During that time, she had three more children: Josiane, another daughter, and a son.

Rosalia's husband died of alcoholism, leaving the family with almost nothing. Rosalia continued to live for her children. She eventually married a good man named Francis who was devoted to the family and supported them through Josiane's illness. But Rosalia, believing cancer was a death sentence, told Theresa she would rather die than visit Josiane at the hospital. She preferred to stay away, waiting for the news that Josiane had died. It seemed that Rosalia could not bear to witness another loss, so she avoided any evidence of it, even the sight of her beloved daughter.

I thanked Theresa for the information, and I promised to do my best to help Josiane. I thought it was important to organize a meeting with the family. But when I met again with social worker Honorine, she reported that a member of our team had telephoned Rosalia many times, but she refused to visit the hospital. Aware that Josiane's life expectancy was short, we were distressed by the emotional pain caused by her mother's absence. We agreed that finding a way to bring them together was a priority.

The next day, I met with the palliative care team at the hospital. After painstakingly retracing the history of Josiane's illness and

Rosalia's trauma, we brainstormed strategies. We decided to try a new approach grounded in tradition and culture, hoping it would be better accepted by Rosalia.

In Rwanda, social tasks are differentiated by gender, with some addressed by women and some by men, according to traditional roles. Women bring harmony to care, in contrast to masculine stoicism. For example, a new mother and baby are supported for three months by women from the family and community. Honorine suggested that a group of women visit Rosalia at her home. The group would include Aunt Theresa, Honorine, and two female nurses. They would deliberately exclude a male presence.

After the visit, Honorine gave me a report. Rosalia told the women she had been "surrounded by death" since April 1994. Unable to face this latest tragedy with her daughter, she had avoided going to the hospital. Their visit, Honorine told me, touched Rosalia deeply. Once Rosalia felt respected and cared for as a woman, she understood the importance of being with her daughter and moving forward.

I continued to meet with the team to discuss Josiane's management. Within a few weeks, Honorine called to say Josiane was worse, requiring oxygen for shortness of breath. When I got to her room, I saw Josiane lying on the lap of a woman I'd never seen before. I greeted her and introduced myself. With a smile, the woman said she was Rosalia, Josiane's mom.

I asked if we could speak outside the room, and Rosalia agreed. She told me that Josiane's nurse, Clementine, who had visited Rosalia's home with the team, had explained that Josiane was dying. Clementine and I assured her that our team would be there until the end. Rosalia thanked us for all we had done, and she returned to her daughter's room.

A week later, Josiane—free of pain, surrounded by her family—died at the hospital. When I saw her body on the way to the morgue, with all her family members united around her, I thought

to myself, “Goodbye, Miss Rwanda, until we meet again.”

That image, in stark contrast to Rafiki a few years before, caused me to compare the two experiences. Josiane had died while receiving excellent palliative care, even though it started late in her illness journey. I felt satisfaction and accomplishment despite my sadness. In the case of Rafiki, who died without appropriate care, I had felt guilt, fear, and failure.

The parallels were striking. Two young people unfairly condemned by terrible diseases. Two mothers overwhelmed by suffering and grief. I still hear Rafiki’s agonizing cries, his distraught mother kneeling before me, an inexperienced physician. We were caught in a death-avoiding medical culture whose opioid policies were characterized by inadequate education, restricted availability, punitive laws, and chilling sanctions.

Then, six months after Rafiki’s death, I was chosen—by chance or by destiny—for palliative care training. I became the hospital’s director general, built an interdisciplinary palliative care team, updated the opioid protocol, and implemented medical staff education. Rwanda instituted opioid medication reform and inaugurated a National Palliative Care Policy. When Josiane was referred to our hospital for treatment, she received not only compassionate pain management but whole-person care that extended to her mother Rosalia. Our team, in essence, knelt before Josiane’s mother, humbly offering cultural understanding and care.

I recognized yet another feeling: redemption.

The death of Josiane liberated me from the death of Rafiki, for whom I still carried a heavy burden in my heart. Only then was I able to forgive myself for my failure. A month later, I received a call from Rosalia. She asked me to remember Josiane whenever I speak about palliative care, and I promised I would continue to tell her story.

My experience with Josiane and her family opened my eyes to the importance of incorporating local culture and traditions into

the palliative care process. By changing our perspective, we were able to give Josiane and her mother a loving transition. This deepened my understanding of the role of family dynamics in a patient's management. I became determined to develop comprehensive communication with patients and families so their culture and traditions, history and traumas, could inform our management.

### **EMBRACING FAMILIES**

When we started the palliative care program in the hospital, I suggested to the team that we incorporate family meetings at the beginning of each case. But my colleagues were skeptical because of the complexity.

First, they said that families were too often unpredictable and would interfere with decision-making. Families may bring unresolved conflicts into the hospital, making it difficult to understand their dynamics or identify the best advocate for the patient. One of the nurses said, "Families think they know everything about their patients, and the meeting will just rub salt into their wounds."

Second, we were unprepared for the sheer number of family members involved. In a traditional African system, a family is composed of parents and siblings; grandparents, aunts, uncles, and cousins on both sides; friends, neighbors, and community members. Many people visit patients daily, as everyone feels connected to the person. It is common for one or two family caregivers to stay with the patient around the clock, providing food, assistance with eating, bathing, dressing, and giving support, with additional relatives and friends coming and going during visiting hours. But our small hospital rooms were not designed for family-centered care. Family socializing and visit length interfered with ward rounds, and physicians often had to ask visitors to leave and allow the patients to rest. The hospital administration regularly posted notices on patients' doors limiting the frequency of visits and the number of visitors. Families would be fined if limits were not observed.

Regardless, family members were very much engaged in the care of their loved ones. If we had ignored the families in the past, we had no excuse to do so after our palliative care training. I wanted to stop seeing family members as barriers and embrace them as a channel to support our patients. But how?

It was obvious that families were suffering as well as the patients. I wished to give them a voice. I also hoped to sustain our hospital team in its stressful and emotionally demanding mission. I needed to create a new communication strategy to help us understand family suffering, one that would incorporate local cultures and traditions. Even though I hadn't learned it in medical school, I wanted to incorporate a sociocultural approach. I realized that Rwandan society itself had proven to be a good teacher.

## **EMBRACING LOCAL CULTURE**

The palliative care training I received, both in the United Kingdom and in the USA, emphasized sensitivity to patients as individuals. But it did not describe how cultural sensitivity could be integrated into the care of diverse populations. While the principles of palliative care remain the same, there can be variations in culture within continents, countries, regions, and even neighborhoods. In addition, the daily practice of palliative care in Rwanda had taught me that social and emotional pain could be even worse than physical pain, as it extends beyond the patient to affect the family and the community. We have tools to assess physical pain, but social and emotional pain are more complex because they are grounded in identity. Moreover, social and emotional pain are often invisible, silent, and profound because they go unrecognized by healthcare providers.

My thirst for knowledge about culture and its role in medicine motivated me to explore Rwandan literature and enter discussions with anthropologists, historians, and palliative care colleagues. I came to understand that beliefs and values are essential to patient

identity, determining the quality of clinician–patient relationships, the effectiveness of communication, and the success of decision-making processes. Incorporating local historical and sociocultural contexts into palliative care programs and policies can reduce challenges and avoid unnecessary conflicts.

In the example of Rwanda, the 1994 genocide against the Tutsi is not confined to history; its consequences live on, as I learned from Rosalia in the story of her daughter Josiane. Families and communities are still affected, decades later, by trauma and losses. It can be seen in family hierarchies, in which the role of family leader has been adapted based on circumstance—perhaps led by a single woman or a younger man or woman because the lives of more traditional leaders were cut short. Palliative care in a post-genocide society must consider the history of violence, the severity of trauma, and the context of refugees as well as individual and collective losses.

For most patients and families, culture is the foundation of identity, dignity, well-being, humanity, and connection. Understanding a patient’s culture will help caregivers deliver a respectful and comprehensive care plan adapted specifically to the individual’s needs.

Looking back, I recognize that my approach was unsophisticated and simplistic. But my motivation, despite my ignorance and limited resources, led to creative thinking and innovation.

I point this out to encourage my front-line colleagues to value their own experiences and trust their intuitions. As they are experts in their cultures, they can be confident and dare to bring change using existing local resources. Simply transplanting a model of care from one part of the world to another misses the opportunity for best practice, and it is unlikely to be successful or sustainable. It is important to *adopt* existing values before *adapting* solutions to the context.