



Marion with her dying father.

Courageous struggle for survival in AIDS-ravaged Uganda

Eight-year-old Nkwasiwe Marion crouches by her dying father's bedside. She peers anxiously into her father's eyes and gently takes his outstretched hand. Tenderly, she grasps the soiled, cotton bed sheet and wool blanket that are keeping her father warm and begins to pull them over his emaciated body.

But sensing he has a visitor, Katula Charles interrupts her. He struggles to steady himself on one elbow and moans, a series of agonizing groans that sound as if they are emanating from deep within his abdomen. He gasps for air and grimaces in pain as he props up on his thin foam mattress. His ribs protrude sharply from his gaunt, desiccated abdomen.

Although he is only 42 years old, he looks to be almost twice that age. The merciless disease, commonly known in Uganda as “slim” because of the wasting effect it has on the body, is visibly destroying him.

He coughs violently; his hands shake as he labours to dab the spittle from his lips with his sheet. He slowly turns to see the stranger who has entered his tiny mud and grass thatched home, weakly shakes the hand that has been extended to him and nods his head in acknowledgment.

But his eyes are hollow and vacant; he says nothing. He is too weak to utter even a single word.

Drawing down savings, selling off assets

Katula Charles discovered he had AIDS three years ago when his second wife died from the disease. He sold his livestock and most of

his land to cover the costs to travel several kilometres once a week to the local health clinic.

There, he received treatment and medication, free of charge, for opportunistic diseases that are known to exploit bodies with weakened immune systems such as pneumonia, tuberculosis, bacterial and fungal infections.

He pleaded with his health care workers to allow him to reduce the frequency of his visits to the clinic to every two weeks to cut down on his transportation bill. But when his funds eventually dried up, there was nothing he could do but remain at home and his condition deteriorated rapidly.

He couldn't afford to pay the fee for antiretroviral drugs, which have dramatically reduced AIDS and AIDS-related deaths in rich countries like Canada. But even if he'd had access to the costly medication, it might not have helped him.

Some medical experts contend antiretroviral treatment (ART) cannot be effectively prescribed for people whose primary health and nutritional needs are not being met. To put it another way, if ART is to be effective in prolonging the lives of people living with AIDS in Uganda and the rest of Africa, significant reductions in poverty are needed, as are improvements to nutrition, food security and access to basic health care, argue some of the experts.

On the dirt floor beside Katula Charles's bed are remnants of a meal of watery rice in a blue plastic cup. A filthy discarded salad dressing container serves as a makeshift water jug. Now bedridden, Katula Charles is completely dependent on his young children for his care. His oldest child, Nkwasiwe Marion, has become the de facto head of the household.

Relentless struggle to survive

Outside, seven-year-old Sentongo Abel has lit a fire and carefully deposited what appears to be no more than a hundred or so grains of rice into a pot to prepare another meal of rice for his father while his older sister carves up a single mango.

The children used to cook their food on a flame inside their home, but fearing their father would suffocate from the smoke, they decided to move the fire pit outside.

Once their father's needs are taken care of, the children will feast on a bunch of green bananas that were given to them by a local farmer who took pity on them. The bananas are considered unfit for eating by most local, who prefer to brew them into wine.

But that doesn't seem to bother the children. They are happy to have even one meal to eat today.

Nkwasiwe Marion, Sentongo Abel and Muhezi Fransis are clearly devoted to their father and they are committed to doing what they can to relieve his suffering.

In addition to the trauma of watching their parents die, they bear the brunt of meeting their basic needs. Still, they enthusiastically demonstrate the chores they each must do in order for their family to survive.

Nkwasiwe Marion plops a yellow jerry can on her head to show how she fetches water. She makes the four-hour trip almost every day to a community water source that is shared with free-range livestock.

Sentongo Abel jumps on the trunk of one of the family's papaya trees and shimmies up and down to show how he picks the fruit.

Little Muhezi Fransis wields a hoe and skillfully removes weeds to demonstrate how he tends to the family garden.

During the rainy season, the children often endure sleepless nights because water pours in on them through the holes in their grass-thatched roof.

As their father is confined to the family's only mattress and he uses all of the family's bedding, the children must gather coarse, dried banana leaves from their garden to sleep on each night and they have only the clothes on their backs for warmth.

Although they do their best to cultivate their small plot of land, they lack the manpower required to reap a substantial yield from the unproductive land. Their stunted growth, reedthin limbs and swollen bellies disclose malnutrition and chronic worm and parasitic infections.

Caring for their dying father keeps the children out of school but an education is also a luxury they cannot afford for they lack the money to purchase school uniforms and supplies such as pens, pencils, notebooks, textbooks and mathematical sets.

Loss of schooling has profound implications for the children's futures. Without an education, Nkwasiwe Marion, Sentongo Abel, and Muhezi Fransis will have a difficult time securing work when they grow up and for Marion there is an increased risk she'll be forced into the sex trade to survive.

Bleak futures

Their blank, stoic expressions conceal a lifetime of hopelessness, helplessness and despair, a relentless and perpetual preoccupation with immediate survival needs—a wretched existence devoid of even the most basic human joys.

“I feel so burdened. I have no hope. Dad is dying and I can do nothing to save his life,” says Nkwasiwe Marion, wiping tears from her eyes.

She and her brothers have been denied the basic closeness of family life. They've been denied the sort of love, attention and affection that children with healthy parents take for granted.

"Ever since my mother died, I have never been happy like other children with parents who love and care for them. I only feel pain and hunger," says Sentongo Abel.

Their paternal aunt checks in on the family every now and then, but she is an impoverished single mother who is struggling to care for her own children. Besides emotional support and periodic palliative care for her brother, she can offer nothing more to the family.

Nowhere in the world has the HIV/AIDS pandemic been more ravaging and disastrous than Rakai district, located in southern Uganda, where Katula Charles and his family live. It is estimated that the virus has left over 40,000 children in the district orphans.

Traditionally, orphans were perceived to be the most vulnerable members of society and were either appointed a surrogate parent, cared for by siblings of the deceased or their grandparents, usually on the paternal side. But the unprecedented increase in the number of orphans in Rakai district is overwhelming traditional cultural support mechanisms. Children who were once protected are now left to fend for themselves.

Thus far, funds from donors governments and nongovernmental organizations have been funneled into HIV awareness and prevention programs and overburdened health care services. The needs of children affected by AIDS, the so-called “orphan generation,” remain largely hidden and go largely unmet.

Katula Charles is acutely aware that his children face an uncertain and bleak future. He pleads with a field worker from a local community-based organization who has dropped in on the family: “Please, please ... I’m dying. My children. Help my children,” he says before collapsing on his bed.

His desperate deathbed appeal has left him completely spent.

(This column was posted to the Canadian Broadcasting Corporation’s website, CBC.ca, in 2006.)

A 'bad experience' of horror and brutality in Uganda

It is as if my idealistic, white, privileged Canadian brain lacks the software to process what is being said. My new Ugandan friend, "Paul," is recalling his "bad experience" on the way to Gulu town several months ago. I am utterly ill prepared for what I'm hearing.

Even as Paul describes the most unthinkable, horrific and violent story I've ever been told, I cannot comprehend it. His words simply will not compute.

He and his uncle are on their way to see Paul's father, a doctor in the northern Ugandan district of Gulu, where civil war has raged for close to two decades. Rebels from the Lord's Resistance Army (LRA) have barricaded the road with tires, making it impossible for traffic to pass through.

The armed rebels force Paul's bus off the road then order everyone off. They instruct the "fat" ones to line up in a row in front of the other passengers. They trust a machete in Paul's hands and command him, at gunpoint, to "cut up" his uncle.

I assume Paul means he only had to wound, not butcher, his own flesh and blood. But when the incomprehensible horror story continues I realize how naïve I am and how much I'd failed to appreciate just how evil war is—that there are some people in this world who don't mess around when it comes to barbarism.

After hacking his uncle into pieces, Paul and the other passengers-turned-butchers are ordered to place the body parts of their victims into a pot, boil them up and eat them.

Paul holds his head in his hands and weeps in despair as he recalls having to consume his uncle. "I had to do it," he sobs, "they had a gun pointed to my head." When he finishes his story of unimaginable brutality, he politely thanks me for listening.

It strikes me as bizarre that he has the civility to express gratitude after revealed to me the most bloody, inhumane thing I've ever heard.

I wonder, how does the soul recover after such an experience? How does one continue to have faith in humanity? What is the appropriate response to this story, which apparently is what passes for a "bad experience" in Africa?

After all, when Canadians speak of a "bad experience," they recount a fender bender, a heated argument with a stranger, poor service at a restaurant, or something equally banal.

I'm not sure if Paul ever received any sort of counseling after his ordeal. He seems to be doing OK. He is a social sciences student at Makerere University in Uganda's capital city, Kampala. He volunteers at an orphanage that cares for children who've lost their parents in the war. He says he'll continue working there for free because, tragically, he knows only too well the effect the conflict is having on victims.

Since the war began 19 years ago, LRA rebels have become experts in the psychology of fear, committing countless atrocities such as the one Paul described to me, but mostly on their own people. Terror is a tactic that has served them quite well in their war against the Ugandan government and the traumatized war-weary people of the north.

The LRA has never clearly articulated its demands in the conflict beyond wanting to liberate northern Uganda's Acholi tribe, yet is the Acholi they prey on more than anyone else. Close to 1.6 million Acholis have been cheated out of a future, forced into squalid camps for fear of being murdered, tortured or abducted by the rebels.

The LRA has abducted an estimated 20,000 children who have been coerced into serving as soldiers or sex slaves. Ugandan President Yoweri Museveni insists the war is either "finished" or "being finished." But the violence against civilians in the north persists.

This year, rebels have intensified their attacks on remote displaced communities along the Ugandan border with southern Sudan. Late in May 14 people were shot, hacked and beaten to death in Kitgum district, their bloodied bodies discarded on a dirt road for aid workers to find.

As a student of peacebuilding and human security, I had read news and government reports about attacks on civilians in northern Uganda. Like most everyone else in the world, it was easy to remain detached, to forget about the war, holed up in my safe, comfortable Canadian study.

But being here in Uganda, hearing firsthand testimonials from people like Paul, makes it very difficult to continue to callously disregard this war, which has received scant world attention compared to the crisis in Darfur, the East Asian tsunami and the war in Iraq.

No longer is this war happening to some obscure people in some obscure part of the world; rather, it is an assault on fellow world citizens. Detachment is no longer an option.

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Southern Sudan struggles to achieve its icon's vision

It's his birthday, but my Sudanese-Canadian friend and classmate, Sam Lole, doesn't feel much like celebrating. A look of sober contemplative consternation has replaced his customary expansive, cheerful grin.

A gregarious guy, who lives by the mantra to sublimely "take it kool," Sam is deeply troubled, still reeling from the devastating news of the death of Dr. John Garang. The Sudanese vice president perished with 12 others late in July in a helicopter crash in a mountainous region near the Sudan-Uganda border.

The death of the iconic Garang, who for 21 years led southern Sudan's struggle for equality, self-determination, and social and economic justice, has made Sam feel physically ill, he confesses. Like many others of southern Sudanese descent, Sam had an unwavering confidence in the ability of the Sudan Peoples Liberation Army/Movement (SPLA/M) leader to free the "black African" southern Sudanese from the shackles of the repressive and often ruthless rule of northern Sudanese Arab regimes.

Garang was one of the chief architects of a comprehensive peace accord that in January brought an end to one of Africa's bloodiest and most protracted civil wars. In accordance with a political power-sharing agreement stipulated in the peace deal, Garang was sworn in as vice president of Sudan, realizing a lifelong aspiration to metamorphose from freedom fighter to national leader. But in a cruel twist of fate, he was in the post just three weeks before his death.

Sam has been a staunch SPLA/M supporter ever since the mid-1980s when he moved to the Sudanese capital of Khartoum from his southern Sudanese hometown of Juba to attend high school. He was appalled by what he encountered, drawing a parallel between the status quo and white supremacy during the height of apartheid in South Africa.

At the time, most southern Sudanese lived in shantytowns on the outskirts of the capital. Many has escaped the war in the south and moved to the city in search of a better life only to be denied opportunities simply because they were "black Christians," says Sam.

In 1991, he took to the streets in protest against the Sudanese government's imposition of a law requiring all post-secondary instruction to be in Arabic. Arrested and incarcerated for three months, Sam was dismissed from school after his release from jail, forcing him to move to South Africa to resume his university studies.

Several months before completing his Bachelor of Arts degree in developmental studies and sociology, Sam was in a quandary. His South African student visa was due to expire and as a card-carrying member of the SPLA, he would not be permitted to return to northern Sudan. It was too dangerous to go back to his home in the south, where civil war raged.

He applied to the United States, Australia and Canada to become a permanent resident and seven months later Sam was handed a plane ticket and given only two days to prepare for his move to Edmonton. As far as he knows, Canada was the only country to respond to his request.

Sam managed to return to his hometown in southern Sudan in 2001 to attend his father's funeral because the SPLA/M had wrestled control over the region from the government. Today, he's back in southern Sudan, where the SPLA/M still maintains control. He's volunteering with an African nongovernmental organization that aims to provide people of southern Sudan with the skills they need to prevent conflict.

Even though they still do not have a functioning state, people who have ancestral roots in southern Sudan are positively joyful these days, says Sam. The peace agreement that their revered, dearly departed Garang helped broker has liberated them psychologically and they no longer feel like second-class citizens to the Arab population in the north.

But although he has yet to venture into a government-controlled area, Sam would argue conditions have only worsened for most of the black southern Sudanese who live in the north.

A few years after Sam left Khartoum the Islamic government evicted many of the southern Sudanese who lived in the shantytowns. Their homes were demolished and essentially they were "dumped" into the desert area of Jabl El Aulia over 30 km from the capital. The land they had previously occupied was redistributed to the Arab and Muslim population in the north.

This forced relocation was particularly humiliating and degrading for the southern Sudanese, who struggled to live under the blazing desert sun without any of the basic services people in the West take for granted, such as water, health care and roads, says Sam.

One of the most successful programs Sam has worked on to date has been the transition of former SPLA soldiers into a new police force. He has been impressed with the resiliency of the people and how eager ex-combatants, tribal chiefs and civil administration authorities are to assume new roles in society in an effort to rebuild southern Sudan. Actually, it isn't really a matter of "rebuilding," insists Sam.

Rather, a more accurate description would be the "construction" of southern Sudan, which has long been neglected by the central Sudanese government. "We're starting from zero," he says, adding that about 90 percent of the infrastructure in southern Sudan dates back to colonial times and is upwards of 70 years old.

Running water is rare and it often takes hours to travel very few kilometers by road. Outside of Juba there are neither paved roads nor electricity.

At the moment, however, it seems unlikely the southern Sudanese will have much of a hand in the "construction" of their nation unless training programs are immediately put in place to provide them with skills such as carpentry, brick making, pipefitting and mechanics, which are essential to building basic infrastructure.

Still, Sam is convinced that Garang's death will galvanize the southern Sudanese and strengthen their resolve to work even harder and more cohesively to achieve his vision for southern Sudan.

In fact, the death of the SPLA/M leader easily could have had a destabilizing impact on an already precarious situation. Instead, as one East African newspaper columnist put it,

the southern Sudanese “maintained a stoic dignity and restrained their anger in the face of the tragic end of the man who fought fiercely and loyally for their own place in the sun.”

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Sad lessons of a Ugandan ‘housegirl’

“Ahhh,” exclaims Doris enthusiastically, smiling broadly as she dumps the towels she is carrying in from the clothesline in a heap on the floor.

The source of her abrupt distraction is the unexpected arrival of a guest, who has just arrived in Kampala after a long journey. Doris rushes out to extend her warmest welcome to the wife of our gatekeeper and the couple’s youngest son.

Unlike Canada, where the tempo of modern day demands are pushing aside formal manners, in Uganda such greetings are a serious matter warranting one’s immediate, undivided attention. Actually, it’s considered extremely rude to pass by an acquaintance or to launch into conversation without greeting first. Doris executes this social grace as if it is an art, a verbal and non-verbal ballet masterfully and beautifully performed.

In Uganda, Doris is referred to as a “housegirl,” but I loathe the word and wince at the sound of it. There is power to language and it’s difficult to imagine a grown woman feeling particularly empowered by such a patronizing label, which must be a linguistic relic from colonial time.

She cleans toilets, mops floors, bathes the dog and hand washes and iron the laundry of upward of eight people at a time, depending on the number of ex-patriots who happen to be sharing the house we rent together. She works six days a week and earns a paltry 100,000 Ugandan shillings or roughly \$83 Canadian per month.

Some foreigners here insist Doris is “lucky” to have such a “good job.” But that seems absurd, akin to persuading a woman where wife battery is still tolerated that her husband is “good” if he doesn’t beat her.

Doris is a perfect case study in the need to ramp up programs that hasten women’s emancipation in Uganda—not only as a right but also as a prerequisite to development and growth. Indeed, she earns 40 percent less than our gatekeeper, who, in addition to his pay, is provided with living quarters that includes a flush toilet and electricity.

Just 28, Doris is already a widow. Her husband died a few years ago in a traffic accident, leaving her a single parent of four children. She married when she was just 15. She had few choices other than getting married at such a tender age, she says. She had to drop out of primary school because her parents couldn’t afford to pay her school fees. She has the Canadian equivalent of a Grade 5 education and taught herself to speak English working at the house.

But Doris has other plans for her own children, whom she proudly describes as “very clever.” She doesn’t want her three daughters or son to marry so young.

In an effort to prevent that from happening, she is determined to provide them with a good education and what’s more she’s determined to do it on her own. “I don’t want another man. Sometimes you can get AIDS and I already have enough children,” she says as if there could be no possible reason for marriage other than procreation.

Still, such lofty aspirations will be a challenge for Doris to carry out—and she knows it. School fees for her two oldest children are the equivalent of three months’ salary. Forty

percent of what she earns goes to rent—a squalid one-room mud home that lacks running water and electricity in an overcrowded neighbourhood that most Canadians would describe as a slum. Doris is eager to find a second job to carry out her dreams for her children.

She may not be the best housekeeper in the world, but Doris has mastered the skill of prioritizing. She knows that the laundry can wait a few moments while she greets an old friend and that investing in her children now will help create a brighter future.

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