

Prelude

A Week in the Life of the Uganda Cancer Institute

PRESENT-DAY KAMPALA is expanding at a breakneck pace. New buildings are mushrooming across the city on a daily basis. There is a booming middle class, and more cars on the road means punishing traffic. There is occasional tear gas during political protests and slum clearing in the name of beautification. But if you squint hard enough through the pollution and dust that settles on the city in between rainy seasons, you can still see remnants of a colonial garden city. This was a city designed in the 1960s with a maximum of three hundred thousand residents in mind, not the 1.5 million people who today call greater Kampala home.¹ If you see baby goats butting heads on the side of the road or tall stalks of silvery green maize being grown in the middle of town, it's a reminder that Kampala is a city where the pastoral and the urban meet.

Today, if you stand at the top of Makerere Hill, home to the oldest university in East Africa, to the south you would see Kololo Hill and Nakasero Hill, with their posh suburbs and government establishments. Farther to the east, Kamwokya is a rough working-class neighborhood being rapidly gentrified by malls and NGOs alike. If you buy groceries at the new and shiny Nakumatt housed in the Acacia Mall, you will see not only a photo of President Yoweri Museveni at the checkout counter but also a portrait of the current *kabaka* (king of Buganda), Ronald Mutebi, a reminder that Buganda kingdom is still celebrated. Standing at Makerere, if you look toward the east, past the valley of Wandegeya with its

bustling clothing shops, food vendors, and auto repair garages, you will see a sprawling concrete building with a powder-blue roof and smaller, older facilities dotting the hill. This is Mulago Hospital, located on the hill that bears the same name.

Many patients, patient caretakers, physicians, nurses, social workers, and the like arrive at Mulago Hospital every morning via *matatu* (a mini-bus taxi that is also a ubiquitous form of transport in much of East Africa), footing, or increasingly by personal car. Plenty also arrive by *boda boda* (motorcycle taxis), often carrying large plastic bins and bed rolls, meticulously balanced along with an infant or child on the back of the motorcycle. Fewer come to Mulago Hospital via ambulance, although every morning, if timed properly, one can see the morning commute's motorcycle accident victims being taken into the "casualty ward" (what Americans would consider to be an "emergency room"), on the ground floor of Mulago Hospital. Accident victims are unceremoniously pulled by the ankles from dark blue police truck beds, thrust into a wheelchair, then wheeled to the casualty reception area to have their limbs cast back together or to be given blood.² Or in more serious cases, they are delivered to the morgue.³

Mulago National Referral Hospital is the teaching hospital of Makerere University's College of Health Sciences. Founded in 1913 as a small venereal disease treatment facility, the hospital has expanded over the past century to include multiple free-standing wards built between the 1920s and 1950s and a larger "new" Mulago Hospital that was opened in 1962. In its present-day incarnation, Mulago Hospital Complex includes a sprawling public teaching and referral hospital with over a thousand beds, a public health school, and a medical school. As the government's flagship hospital, Mulago receives the difficult cases from the national referral hospital system and also serves the urban poor in the greater Kampala area. It is a site of convergence for people across the country seeking care. For many decades, patients have come to Mulago for relief from mild ailments such as malaria or dysentery. Many have also come to Mulago for relief from less quotidian illnesses and misfortunes, including cancer. These patients are directed to the Uganda Cancer Institute (UCI), which stands at the very top of Mulago Hill.

On Monday mornings at the UCI, by the main entrance to the Lymphoma Treatment Center (LTC), approximately forty to sixty outpatients sit quietly on hard wooden benches, lab request papers crinkling in palms. You can hear the quiet sipping of steaming hot *chai* (tea). The silence is

only periodically broken by Mr. D, the lab technician, wearing his white coat and glasses and a warm smile, calling out for a *mzee* (an elderly gentleman) to get his blood drawn. Mr. D is all business as he says, “Come inside, please. Come inside.” Mr. D used to work down at a laboratory in lower Mulago where he would arrive late to work and leave early. Here at the UCI, he comes to work early and stays late. For him, this daily ritual of drawing blood and then running the vials through the newly acquired complete blood count machine allows him to keep an intimate connection between the samples he tests and the people he serves. He does not want to let the patients down.

After the adults have disbanded from the waiting area, children will line up to have new IV cannula lines inserted into their hands for chemotherapy treatments. Taking a seat on the hard wooden chair in the entry area, which doubles as a procedures room, some feign bravery and others melt into puddles of sobs as the nurse pulls out a latex glove that she will tie around the spindly arm to pull up a vein. Screams, whimpers, and cries of “*Omusawo!*” (meaning “doctor” or “medical person”) fill the space, as do the consoling murmurs of the nursing staff: “Sorry, sorry, sorry.”

Plates, cups, and forks clatter and clang around 1 p.m., and families shuffle outside to the kitchen area to line up for *posho* (a thick porridge, usually made from maize) and beans—the one free meal of the day. Patients and caretakers hum and chatter in various languages—Luganda, Acholi, Ateso, Runyankole, Lugbara, Lusoga, and even a smattering of Swahili swell and amplify in the line-up, eagerly talking in anticipation of eating. And then, an eerie silence falls, a deadly calm as people carry their lunches out to the verandahs and eat without saying a word. All you can hear are the children slurping at their fingers as they tear into the sticky hot posho. By the late afternoon, with chemotherapy finally administered through IV drips on the ward, the chorus of vomiting begins. Some children quietly retch into plastic buckets held out beneath them by their caretakers. Other kids go outside and into the bushes, heaving, choking, and sobbing. At 5 p.m., the buzz of car engines fires up in the parking lot adjacent to the LTC, as doctors and staff drive down the hill to meet the evening’s jam. Wailing sobs sound through the adult ward of the LTC. Someone has just died. Sister H bursts into the nurse’s room, asking loudly where all the death forms went. “I need them *kati kati* (now, now) so I can go home.” Another Monday at the LTC draws to a close.

Tuesdays, the pace of work at the UCI is different. It’s not an outpatient day, so the laboratories and outdoor waiting areas are slightly less

congested. The major management meeting of the week happened on Monday, so you are more likely to hear the voice of a senior doctor outside of the Outpatient Center, politely demanding to know whether or not this patient or that patient has started on treatment now because treatment should have started yesterday. “Why is this patient not on treatment? Where are the biopsy results? This Burkitt’s lymphoma is an *emergency*.” Dr. Joyce Balagadde Kambuğu, the newly appointed pediatric oncologist, intervenes and says, “We are taking care of it. The child is on the Burkitt’s lymphoma project and will get special care and treatment.”

On the wards, the sounds are largely those of teaching—major teaching ward rounds happen on Tuesdays at the UCI. They start anywhere between 9 and 11 a.m., and they can go until five o’clock in the evening, depending on how late they started and how many patients there are to see. On the Solid Tumor Center, which caters mainly to adults with a variety of solid tumors ranging from liver cancer to Kaposi’s sarcoma to breast cancer to prostate cancer to malignant melanomas, patients are packed tightly into every nook and cranny of the space, and beds are jammed against one another and make a perimeter along the wall of the building that used to be an enclosed porch. Here, the cancers are often fetid, florid, fulminating, and the rot stinks. On teaching ward rounds, medical students, a medical officer, the nursing sister, and I all crowd around Dr. Fred Okuku, as we move several inches from bed to bed.

As a student in secondary school, Okuku was fascinated by biology, and his favorite part of class was the frog dissection. He used to carefully dissect frogs and then attempt to stitch them back together, with the hope that he would at some point manage to reanimate them. Nothing fazes Okuku. And the more extreme and advanced the bodily state and cancer stage is, the more important the teaching lesson. An elderly woman’s malignant melanoma engorged with blood and roughly the size of a cantaloupe is carefully shown on ward rounds as an example of a patient coming “late.” Some medical students are engaged and drawn in, others curl their nostrils, barely able to contain their disgust as a woman’s stage-four breast cancer rot wafts up after she exposes her wound to us on the ward. We have joked about how he is, for all intents and purposes, “the late-tumor oncologist.”

Teaching rounds at the UCI are a form of triage, both in terms of engaging with patients who are in bad shape and plotting a course of palliation or salvage, but also in terms of bringing in more medical staff to manage the crowded wards. Medical students clerk, do patient intake,

man the night shift, run down the hill for blood, and read complete blood counts. They do not administer chemotherapy. Two or three are usually “poached” from a ward in any given year and brought in as volunteer medical officers to learn how to do lumbar punctures and manage emergencies. Okuku’s teaching rounds are not horror shows, but they do have the quality of a hazing ritual, as medical teaching rounds are in many other settings.

On any day of the week at the UCI—but especially Wednesdays—there is the sound of laughter. There is the laughter of Paul and Stevie, two adolescent boys who are currently being treated for leukemia and live on the LTC full-time even when they are “not on a bed.” They take turns pushing one another in a shiny red wheelchair (recently donated by a Christian organization) up and down the patch of grass directly outside the ward. They collapse into hysterical giggles every time the chair comes to a complete halt. The “mamas,” the ten or so women who cannot afford to travel between treatment cycles for their patients, congregate in the back kitchen area and erupt in full belly laughs when I kneel down on their sitting mats and greet them in Luganda, Acholi, and Lugbara. Wednesdays are the relaxed days at the UCI. They are days for early research-in-progress meetings in the board room at 8 a.m. They are days for catching up on writing and paperwork, for doing fast “business” ward rounds, and for giving politicians and research scientists tours of the facility. They are a moment of reprieve from the chaos of outpatient Thursdays and cancer-screening Fridays.

Mondays and Thursdays at the UCI are quite similar—patients congregate in the morning for their bloodwork information outside of the LTC, which houses the laboratory, and then proceed to limp, shuffle, walk, or be carried to a camouflage green, open-air army tent directly outside the Outpatient Ward, where they will wait until names are called for chemotherapy. If it is not a day for chemotherapy, but a day to see a senior doctor for evaluation, the patient may congregate inside the ward, waiting for the doctor, be it Dr. J, Dr. F, Dr. A, or Dr. N, to reach his or her name in the thick stack of forty patient files that each of the doctors is expected to power through on an outpatient clinic day.

In the public chemotherapy administration room, a breeze is mercifully blowing up from Lake Victoria this afternoon, as Sister J and her team work methodically to insert, push, and drip chemotherapy into IV hand needles as quickly as humanly possible. Sixty to ninety patients are waiting to receive their treatments so they can go to the bus park before the

night falls—providing cover for pickpockets and thieves—all so they can make the treacherous two-hundred-plus-kilometer night bus ride home. It is hard to say what is worse—vomiting into a Kanga cloth the whole way as the bus races over potholes and dodges goats crossing the highway, the prospect of a head-on collision, or harassment from the state police at a nighttime roadblock as they look for bribes. Like the LTC ward on a chemotherapy afternoon, this administration room, with its six plastic chairs and shared IV poles, endures periods of eruptive retching, whimpers, and silence. About every two hours, one of the cleaners will be called to mop up a new mess of pink sickness heaved onto the white tile floor.

By Friday, the UCI buzzes with the anticipation of the weekend, which for the staff means most likely attending a wedding or wedding introduction ceremony on Saturday, and an all-day extravaganza of ecstatic prayer at church on Sunday, if Pentecostal or Born Again, or a more reserved morning service at Namirembe or Rubaga cathedrals, for the Protestants and Catholics, respectively. And on a Friday, as nurses shed their uniforms and put on their Kampala city outfits of fashionable dresses and suits, some Muslim headscarves appear, beautiful shimmery pinks and yellows, covering well-coiffed heads of cornrows or braids. During Ramadan, the Muslim nursing sisters fast even during the day shift, working without food and occasionally without water.

For the patients and their caretakers who are staying at the UCI for the weekend, a month, or a year, the prospect of wealthier Kampala relatives coming to check in on their extended family members over the weekend, and the good meal of fish or chicken or beef that will most likely accompany that visit, is met with great anticipation. The traffic on an early Friday evening in Kampala is cacophonous, eruptive, and temperamental. Prados packed to the brim with family members are heading out to burials in the villages. Several large Friday markets, particularly in Kamwokya and Nakawa, snarl traffic on Kira and Jinja roads. Traffic police trying to add a few extra shillings to their pockets for the weekend pull over matatus with officious smirks. And as you walk down from the top of the hill at the UCI, the sounds of honking car horns and the smell of corn being grilled on the side of the road greet you, reentering the city.