Epilogue

In Memoriam

Most every Tuesday, somewhere around 1 or 2 p.m., after staff consumed a fast lunch of local food, fish, and groundnut sauce, we piled into the examination and intake room of the Lymphoma Treatment Center (LTC). A wooden table surrounded by hardback chairs dominated the room. A filing cabinet stood in a corner. The social worker, counselor, and I usually assembled on the slightly ragged examination bench with legs dangling. An old sterilizer sat in the corner, donated sometime in the early 1990s by a Christian NGO. Occasionally one of the nursing staff would come in during ward rounds and fire it up, sterilizing piles of cotton gauze that would be used for cleaning up veins after blood draws.

Dr. Joyce Balagadde Kambugu, the head pediatric oncologist at the Uganda Cancer Institute (UCI), would usually rush into the room, apologizing for being late. She would sit down at the seat reserved for her in the middle of the table, surrounded by nursing and laboratory staff, and voluminous piles of pink, manila, blue, and green patient records. Some of the files were so thick they were nearly falling apart. Others were slender, containing only a face sheet and a referral note that had been filled out that very morning. Kambugu would slip a wad of Ugandan shillings to Sister N, the elderly Muganda nurse who had been working on the wards of the UCI since the 1970s. Sister N would come back several minutes later with black *caverras* (plastic bags) of sodas. Coke, Fanta, and Stoney ginger beer would be distributed along with straws to the fifteen or so in attendance, the ward round officially commencing to the sound of bottles being cracked open and the discussion of "very, very sick children."

Quite soon upon returning from a year of training in South Africa, Kambugu, who was running a ward with twenty-four beds and thirty-four to forty more inpatients sleeping outside on the verandah at any given time, decided to initiate comprehensive "sit down" ward rounds in the privacy of the doctor's examination room rather than "standing" ward rounds. Part of this was done to reduce the amount of time spent on one's feet, shuffling from one bed to the next with an entourage in tight quarters. But there was also the question of privacy. "They listen to what you are saying about them," Kambugu says. "They are watching, wondering if you are going to give up on them or if it's game over." "Game over" was the phrase Kambugu invoked time and again for residential cases at the UCI who were for all intents and purposes salvage chemotherapy patients. In a setting that was so public—twenty-four beds jammed on top of one another along with family members and additional kids and relatives coming in to say hello—creating a space for private and frank discussion changed the tenor of the ward round. Given the volume of patients and shortages of space, the long-term goal of admitting a patient—the Luganda phrase *olmuwadde mu'wadde ekitanda* literally means "giving a bed"—was often to discharge that patient as soon as medically and humanely possible. Discharge can come after the side effects of chemotherapy have dissipated, or once the infection from a feeding tube has been abated. Patients who were discharged sometimes come back days later with terrible fevers from immunosuppression, bad headaches, and nausea. Or they might come back two years later with a recurring, newly festering mass. Being discharged and told to come back for follow-up is but one way to leave the UCI. There are other methods—running away, departing in a coffin, or being given a verdict that it is "game over."

On many of these sit-down rounds, we began the day with Baby Winnie. Baby Winnie, an eighteen-month-old who suffered from bladder cancer, was a permanent fixture at the UCI along with her mother for most of 2012. Mama Winnie, a peasant farmer from the central region whose main source of income was selling maize and beans, realized that there was something wrong with her daughter in November 2011 while winnowing beans in her compound. Her child was sitting in a pool of blood. The baby was first taken to elders, who diagnosed the child with a prolapsed uterus, and in "the village style, everyone said they knew the treatment and we started using the local herbs." The child's belly became more and more swollen, and so the child was then taken first to Gombe Hospital, then Nkozi Hospital, and finally Mulago. Mama Winnie recalled:

> When we came to Mulago, the child was so swollen. The swelling was so big and oozing pus and very offensive. We started from the Acute ward where we spent 1 month. We were then sent to ward 2A in New Mulago where she was operated on and a biopsy was done. We spent 2 months in that ward. The biopsy was sent to Wandegeya and the results revealed the child had cancer. After two months, we were sent to the Cancer Institute. When we arrived at the UCI, I found the beds were full. Then I slept outside for two days but since the mosquitoes were so many, I moved in to sleep in the corridors. I stayed there for four days and I was offered a bed in the adult ward. When an adult was admitted, I was requested to leave the bed and waited until I got a bed in the children's ward.[1]

Mama Winnie hung on to her designated bed in the children's ward of the LTC with extreme tenacity throughout 2012, weathering her child's difficult surgery, a feeding tube, and oscillations from chemotherapy cycles, all the while refusing the Institute's attempts to push the family to go home whenever Baby Winnie would stabilize. Away from earning her income from maize and beans, she also became a regular charge of the Uganda Children's Cancer Foundation, which subsidized some of the more expensive tests for Baby Winnie. As Baby Winnie improved over the course of the year, the LTC staff increasingly tried to turn Baby Winnie into an outpatient, to free up the bed, and to have Mama and Baby Winnie come back only for treatment cycles. Mama Winnie refused in stubbornly subtle ways. She would claim that transport money was not available. When transport money was made available, Mama Winnie still refused to leave, preferring to stay on the verandah until the possibility of readmission. The LTC became home.

Next in the stack was Patience and Mama Patience, who lived on the wards of the LTC off and on in 2011 and 2012. Patience suffered from intestinal cancer and was a long-term resident at the UCI for chemotherapy. She was also incontinent from a botched surgery performed for nearly free by a charity hospital located on Entebbe Road. Patience came first to the UCI after several months of searching for a diagnosis. Her story of coming to the UCI captures some of the deep familial conflicts, often about money, regarding how to chart a course of treatment for a patient. These conflicts often emerge over the protracted process of taking biopsies, traveling to referral hospitals, and losing time on the wards. Here is the story relayed by Mama Patience:

> My child fell sick from February 5, 2011. I took her to a clinic but the nurse requested me to go to a main hospital. It started with a swelling from the urethra and would occasionally bleed. I was then referred to Kitovu Hospital, where we were admitted for one week before an operation and a biopsy was taken. We were discharged and told to return after one month for the results. When I went back I did not find him on several occasions. After two weeks, we went back and the growth had grown back, found the doctor who indicated that he had got the results but misplaced them, but they found that the child has cancer. He then asked me to allow him a week to look for them, which I did, and on return he said they were completely lost and we needed to have another biopsy done. This took us another week. There was no transport but the father was still caring and requested the biopsy and brought her to Wandegeya in Kampala.
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> Meanwhile the child became worse and started oozing pus and had a lot of pain but we kept getting treatment. We then got the results and they said she has cancer and we continued on for two weeks. We were then referred to Mulago but the father decided to take us back home now that the doctor had indicated that there was no hope.
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> I had cultivated my groundnuts but because I spent a long time in the hospital they were not attended to very well. At this point it was around three months since identifying the problem. I sold my groundnuts for 120,000 [Ugandan shillings, about US$46.50] and by this time my child was bedridden. So with this money, I decided to bring my child to Mulago, where the doctor had advised us to come. So we came in June 2011 and we started from there until now.
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> I did not inform my husband about my plan as he indicated that he does not have any more money for this case.[2]

Making a cancer diagnosis after the onset of obvious illness can take months or upwards of a year in Uganda. Murky differential diagnoses are one thing, but paperwork is another. At the UCI in 2012, a referral note and a biopsy result must be in hand (or, at the very least, pending) in order for a patient to be admitted to the wards of the UCI. In the 1960s and early 1970s, centralized pathology services at Mulago, which would cooperate with referral hospitals throughout the country and correspond via the post office, ensured that the project of remote diagnosis would take about a week.[3] When the UCI was under serious duress, this referral structure helped to conserve scarce resources from being spent on "hopeless cases," or patients without diagnoses. It was a triage mechanism at the UCI during the 1980s, 1990s, and 2000s, when there were only ten staff members. In 2012, a lost biopsy result could often mean salvage chemotherapy.

By far the largest most complicated file on ward rounds was the file of Baby Angel. For nearly the entirety of 2012, Baby Angel resided in crib number twenty-four, right at the entrance of the pediatric side of the LTC. Her crib was surrounded by a big blue mosquito net, stuffed animals, and a puffy-cheeked doll that mirrored her own cheeks, which were puffed up from steroids. Sponsors and passersby doted on Baby Angel, who had been abandoned by her mother in early 2012. Baby Angel had been left in the care of her father, a peasant farmer from outside of Lira who grew sesame, sorghum, and soya beans. He knew much about the vagaries of rains and planting seasons but less, at least initially, about how to cook or attend to domestic chores. But Tata Angel was a dedicated caretaker. After his wife left for the north, he spent weeks tediously weaning Angel on starchy muffins, tea, and porridge. He would strap Baby Angel to his back and make his way to the market to buy food for cooking at night. Still in contact with his own family members, he would receive weekly shipments of *sim sim* (sesame paste), via bus to be cooked up with sorghum porridge. In the central region, where the diet is based on a starchy banana known as *matooke* and peanut sauce, these packets of sim sim paste offered a taste of home.

Tata Angel was also the "ward chairman" of the LTC. In Uganda, the chairman is a common figure. Chairmen preside over anything requiring meetings or social organization, from boda boda (motorcycle taxi) driver cooperatives to routine UCI general purpose meetings and to National Resistance Movement district government cells. At the LTC, the ward chairman is designated as a point person who welcomes newcomers to the ward, maintains social order and ensures that people and their property are secure, takes grievances to the staff, and oversees hygienic routines like cleaning out the showers and scrubbing the toilets.

In September 2012, Baby Angel was discharged from the LTC permanently. There was no salvage chemotherapy combination left. It was time to go back to their village just outside of Lira. It was "game over." Fieldnotes from that day capture the heaviness:

> We are sitting in silence. He wears dark-green trousers and a pale-colored short-sleeved shirt with a slightly frayed collar. He has grooved lines on his forehead and crow's feet around his eyes, which are expectant and resigned at the same time. I put my hand on his shoulder and he begins: "They have discharged us, me and Angel. We are going home. They say that the drugs aren't working anymore, that it is time to go home, but I will go home and show the family the changes in the body."
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> "I am going to the market to buy food. I have food but I do not feel like cooking today. I will buy some fish, maybe," said Tata Angel as we continued to sit. I listened on. "You see my hands—all of this washing. I have been doing so much washing." Tata Angel's hands were cracked and chafed at the nail beds. For weeks, Baby Angel had suffered from terrible, explosive, bloody diarrhea. Her clothes and her bedding needed to be washed constantly.
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> Tata Angel was tired of cooking, tired of washing, tired of being away from home. He packed their possessions from hospice, home, and donations into several large cheap plastic zipper bags and slept out on the verandah for a night.
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> Anxiety among the LTC staff ran high—would he abandon the child here on the ward to die or would he take her back to Lira? Would he wait around on the verandah after being discharged to meet his local "sponsors" from the Uganda Children's Cancer Foundation who had given money and gifts? "If the sponsors don't have a chance to meet the person they've been sponsoring then they will feel little incentive to sponsor someone else in the future," Dr. R noted. I was headed up to Gulu myself—would it make sense to drive them home to their village if it meant that Angel would actually safely reach home?
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> Tata Angel made the decision to go home via the Gisenyi Bus Park on a Saturday morning in September, less than 48 hours after being discharged from the LTC. They had two motorcycles worth of possessions to take to the bus park. A week later, Angel died at home.
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> At the LTC, even though her bed was quickly taken over by another patient, the crib seemed empty. A few sticker stars were

> still plastered onto the wall, but there was no bright blue mosquito net, no chubby cheeked baby splayed out for a nap with her hand resting on a tiny bible, no Tata Angel donning workman's protective gear to clean out the toilets in the afternoon or to partition jackfruit at night.[4]

Only a handful will remember the day in September 2012 that Kirabo's parents found out it was "game over" for their sweet, cherubic little girl. Kirabo had lived off and on at the LTC for months, receiving treatments for her leukemia. Kirabo's mother often wore a blue *gomesi* (a popular floor-length dress style) the color of the noonday Kampala sky, hair wrapped in a flowing white head scarf, usually carrying the new baby on her back. Kirabo's father, who stayed outside of Kampala toward Lugazi, was often at the Institute over the weekend, checking in on his daughter and her progress. Everyone agreed they were a wonderful family. But acute refractory leukemia "in our setting" is not something that can be easily treated. You would need access to bone marrow transplant technologies to even have a fighting chance, and that's just not publicly available in Uganda. On ward rounds that day there was a long discussion about how to slowly and gently break the news to Kirabo's family that it was finally "game over." Kambugu said (and I'm paraphrasing here), "We'll call in hospice to help break the news, send them home with some small juice boxes, some oral morphine, some antibiotics, and what? Anything that can make them more comfortable. It's too bad that we didn't bring in hospice sooner. With them coming in now it just seems like it's game over. It's such a shame. She is the sweetest, most beautiful girl you've ever seen. She doesn't deserve this. Her family doesn't deserve this. But with acute refractory leukemia like this we are out of options without transplantation."[5] Kambugu made a final point to the medical students who were on her service for the next few weeks and were doing master's programs in pediatrics. "Please don't say anything to the family while we are at the bed. We need to be able to break the news."[6] The next day, I saw that the news had been broken. Mama Kirabo was standing next to a hospice vehicle and chatting with them. Kirabo played with some of my arm bracelets and was giggling and wearing her mother's white headscarf like a pirate. She was still cherubic and in high spirits. Even her hair was growing back after the latest round of chemo. And then she was gone.

I remember the departure of Kirabo particularly well only because it was my last day of major ward rounding and I was hoping for some sort of optimistic closure. But for most of the afternoon, a simple wooden coffin sat open and waiting for the deceased on the adult side of the LTC. One of the patient's relatives let out a wail of universal grief when the coffin was finally loaded onto the minibus and driven down the hill. Mama Patience looked slightly exhausted, wearing her faded but formal black suit, walking back and forth between the bathrooms and the ward with a bright-blue bucket to contain the retching. Patience's hair was again shaved close, as she started another intense round of chemo that made her violently retch. Stevie, an adolescent boy being treated for leukemia, was out playing on a seesaw with a friend. "What are you doing, Stevie?"

"We are playing." I could see that.

At the end of the sit-down ward round for the pediatric patients, little Nakkazi from Wobulenzi walked in, sobbing intensely. "Nakkazi, what's *wrong?*" asked Kambugu. In between her eruptions of grief, she said, "I want to go home. I want to go home. I want to go home."[7]

Seeing Kirabo and her family leave with their oral morphine, juice boxes, and instructions for when to go to the hospital for blood, we were all a bit shattered. As I got into my car I asked a colleague, "When on earth will we ever get bone marrow transplant services here in Uganda?" He was hilarious and frank: "Marissa, asking me when we'll get bone marrow transplant services in Uganda is like asking me when I'll be eating chicken every day. There are so many factors—we need infection managers, we need hematologists, we need *everything*. . . . We might as well open a poultry farm. These are things that we might want. But they are just really hard to attain without going slowly by slowly."[8]

During 2012, colleagues shaped systems of care and triage at the LTC through trial, error, the limitations of staffing and resources, and the realities of trying to offer cancer care to patients and families for whom shifting back and forth between the ward and the village was simply too much. As Kambugu worked to build these systems, she did so within a ward space that had been designed largely as a Burkitt's lymphoma research and care facility by Dr. John Ziegler and colleagues in 1967. The old building was nothing special. But it was designed in such a way that the wards had decent cross-ventilation, the verandahs and grassy spaces allowed for play and decompression after ward rounds. There was also a large cooking and washing area in the back. There was a dedicated space for doing bone marrow aspirates and lumbar punctures. In subtle ways, these innovative designs made it easier for staff to do their work and allowed families to camp out at the Institute for weeks or months at a time. The entire time Kambugu and her colleagues worked at the LTC in 2012, they did so with the knowledge that this historical structure was slated for demolition to make way for the new UCI–Fred Hutch Cancer Research Center.

At multiple points in the history of cancer care and research in Uganda, it has been the children—whether deformed by Burkitt's lymphoma or playing with blown-up latex gloves in between chemo cycles—that have given the Institute its international appeal. In October 2011, political dignitaries and international health moguls came to the Institute to celebrate the groundbreaking ceremony for the UCI–Fred Hutch Cancer Research Center that would displace the LTC. And it was the LTC that held the most appeal for the visitors. When I attended the event as a historian-ethnographer, handing out my business cards to American oncologists for follow-up interviews and joking with nurses in Luganda, I remember feeling a sense of horror when I realized that the cancer patients and their family caretakers would not be joining us for the buffet, as they would be expected to at any celebratory Ugandan function such as a wedding or funeral. Instead, patients watched us from the verandah of the LTC. After the ceremony, the visiting oncologists went off for ward rounds to look at exotic cancers. They also saw how oncology is practiced within the LTC, with its outmoded procedures room, children's ward with twenty-five beds, and cribs jammed neatly along walls. "Now I understand why they don't use chemo ports," one of the Americans noted to me after the tour, as patients would be septic in a matter of hours. Another said that it's a shame that survival outcomes for curable cancers remain low, when compared to survival outcomes at the UCI in the 1970s. It was then that I could not help saying, "Well, in the 1970s researchers were paying for transport and buying patients food." The answer was that we should look into building a Ronald McDonald House, as "the kids are just so appealing."[9]

Even after it was slated for demolition, the LTC remained the showpiece of the Institute, used in part to try to marshal further support and donations to furnish the new inpatient cancer hospital. On one such occasion, a prince from a Middle Eastern country announced he was making a visit to the UCI to see the important work being done on noncommunicable diseases in the country. The staff had approximately twenty-four hours to make preparations for his tour of the facilities. Tents needed to be rented. Dancers well versed in "traditional" performances spanning from Kabale to Kitgum were hired to perform hospitality. Box lunches of chicken, samosas, and sodas were ordered. The public relations officer found an imam at the last minute to offer the opening prayer. There was hope that the Middle Eastern country would make a contribution toward

$4 million worth of medical equipment needed to furnish the not-yet-open five-story Ministry of Health–sponsored cancer inpatient facility at the Institute.

That Saturday morning in June 2012, patients and their caretakers were up and out of the LTC before dawn, just as the call to prayer from Mulago National Referral Hospital's mosque started to reverberate up the hill. The floors were scrubbed until they shined. Bleach replaced the smell of vomit and other sicknesses. Beds were made with square hospital corners. Pediatric patients dressed in their best and cleanest outfits. Medical records were stacked neatly on the reception area table, which was cleared of all traces of its usual purpose as a chemotherapy reconstitution lab bench. Overflowing sharps containers were taken down to the incinerator. Rarely used suction machines and blood pressure monitors were wheeled out into prominent view. That morning, the ward sparkled, painted in that unmistakable industrial seafoam green so characteristic of hospitals in East Africa and beyond. The undersea mural of starfish, sea horses, and bobbing fish looked cheerful rather than dreary. All traces of residential life—the cook stoves, cardboard shelters, mats, bedrolls, suitcases, crutches, buckets, and donated stuffed animals clearly loved to death—were erased from the public space of the verandah and the wards and shoved back behind the LTC for the day. Nurses in freshly pressed white government uniforms came to start the morning ward round early, around eight o'clock, ensuring they would finish before the "VIPs" arrived at eleven.

I arrived at the UCI at around 10 a.m. with my camera and notebook to find plenty of police forces standing around in blue security uniforms, but I slipped in easily through the main gate without being searched. There were two tents set up across from one another in the main parking lot, much like they would be at a *kwanjula* (a Baganda introduction ceremony), with ribbons of purple and yellow festively tied to the stakes. The dancers and drummers performed in full force and attracted an audience of patients and caretakers who were watching the scene from the LTC lawn directly outside of the building's main entrance. I walked inside to extend my morning greetings and to check in on a few of the pediatric patients, marveling at how the sparkling walls and tidied supply closets made the space feel less overwhelming, even if there were still a few patients sleeping on the floor.

In particular, I wanted to check on Oliver, an eight-year-old with acute myelogenous leukemia who, upon our first meeting, was a cheerful kid scrawling out his name repeatedly in an exercise booklet and reading from a few donated books to keep up with his schooling while away from his home in Luweero. Tata Oliver, often sporting a Hawaiian shirt, was a maize and beans farmer as well as a blacksmith. He and his wife had seven children, including a new baby. He had put crops and metalwork on hold to care for his favorite son. It was not going well. Months into treatment, the outlook was not good. The treatments had puffed Oliver's face to the point of being barely recognizable. His belly was distended and his arms and legs emaciated. He was only comfortable sleeping in the fetal position and had taken to scratching and biting at his father out of frustration and disorientation. In the United States, Oliver's leukemia would have been a prime candidate for bone marrow transplantation. Here, in Uganda, the oncologists had been working through all lines of salvage therapy. Oliver was very hypertensive, losing weight, and up vomiting morning, noon, and night.

"*Oli otya, mukwano?*" (How are you my friend?) I tried to get a smile.

"He is not fine," said Tata Oliver.

"And how are you doing?" I asked.

"I am not okay," said Tata Oliver. "When he eats, he vomits. When he drinks porridge, he vomits. When he takes water, he vomits. The only thing he can take is tea." Dr. M deftly took Oliver's blood pressure as Tata Oliver continued. "I am not okay. We were told this muzungu is visiting today and that we must put on clean clothes and make the bed. I am happy he is visiting, but"—and here Tata Oliver began to get angrier, louder, and more animated—"I *clean*. I keep my child clean. I make the bed with clean sheets!" he said as he gestured to the perfectly folded corners on the bed. "What is this muzungu bringing me? I have nothing. We have nothing. The doctors said to clean this place. But what are they doing for me? I am not good. I am not fine." I would find out from staff in the next week that in the cleaning frenzy to welcome the prince, someone had thrown out all of Oliver's clothing that had been left to dry on the lawn, leaving them with nothing.

I took my leave to sit down in the tent next to an American colleague who was visiting from Seattle. "What do you think it would take to get a bone marrow transplant unit here?" I asked, filling him in on the scene that had just unfolded.

"It's a strange thing, isn't it?" he said. "There's dancing. And there's dying. I think the only way to make sense of this is to put this into a five-year perspective. If this prince comes, and if the beds are made and clean, perhaps he'll give money. Maybe there will be more second-line drugs. Maybe, someday, the infrastructure for bone marrow transplants."[10]

And so we waited. Then we waited some more. A Ministry of Health vehicle drove up to the gate. An official stepped out and went to talk to the UCI's director. The prince was stuck in traffic across town and would not be coming. He had an afternoon flight to catch out of Entebbe. The imam opened the ceremony with a prayer. We stood for the Ugandan National Anthem. The UCI's director stood with poise and delivered a succinct speech. Kitchen staff distributed warm sodas. The master of ceremonies announced that we were closing the ceremony, and we stood again for the anthem. Patients and staff mingled under the tents and ate the box lunches; among those present was Tata Oliver, who cajoled his son to take another sip of Fanta. I took my leave and told a Ugandan colleague I was very sorry that they had gone to all of this last-minute expense and planning, only to be thwarted by the traffic. "As long as there is money coming," the colleague noted, "it is okay that the prince did not come." To the best of my knowledge, the money never came.[11]

More than a year later, it only took half a day to bulldoze the LTC. It came down easily. The bricks and the plaster and the dreary mural depicting cartoon seahorses swimming in the sea and anthropomorphic starfish crumbled into fine powdery dust. The windows, the doors, and the iron gates were salvaged and piled up behind the Institute's generator. Staff were kindly reminded in internal memos taped on the wall that they were not allowed to re-use these old materials for their own construction needs. Nurses quietly cried and took photographs of their decrepit but beloved LTC. "The heart and soul of the Institute," said Sister A. From their newly improvised temporary space, the Lymphoma Treatment Center II (LTC II), patients and their caretakers watched the building crumble. It was a refurbished tuberculosis outpatient facility with three airless rooms with about seven full-sized beds and a few floor cases apiece, and there was a hallway which had been hastily enclosed to accommodate pediatric cribs. The reception table, which also doubled as a chemotherapy constitution bench in the old LTC, was repurposed outside of the corridors as a place for patients to lean against and store their bedrolls, washing bins, and buckets. This was the temporary fix in 2013. Patients would move into the Ugandan government's newly completed cancer hospital at the top of Mulago Hill as soon as the building was furnished.[12]

When I returned to Uganda the following year in 2014, I was thrilled to be back and fielded inevitable questions like "When are you having a child?" "When are you finishing the book?" "Where are my chocolates?" And I asked my own questions: "Is Oliver still alive?" "How are your chemotherapy supplies these days?" "When did you get married?" "When are you moving up to the new hospital?" "Do you miss the old LTC?" "Tell me what it's like to work in the new LTC?" "How does this new temporary setup shape your day-to-day work?" I filled my notebooks with words. And I share them here with you, not to undermine the efforts to transform the Institute but to offer a fuller historical record of some of the costs of breaking the UCI's original experimental infrastructure.

> From the first day I set foot on the wards of the Uganda Cancer Institute in 2010, I was struck by the social intimacy of the place. It seemed to me that the UCI was a lot like a small village, complete with council meetings, weddings, funerals, and a constant procession of increasingly pregnant nurses whose swelling bellies marked the passing of time. Patient families lying out on mats and plaiting one another's hair or preparing a morning meal on tiny cook stoves, the MTN mobile money shacks, the laughter of children, and the rogue goat lunching on the lawn all cemented a sense of village life. Nursing sisters took long and rabble-rousing tea breaks. Mr. K would read the *New Vision* for at least a half hour every morning before he distributed X-ray reports to patients snoozing on benches. Boda bodas would blast into the parking lot, dropping off patients and supplies. Quotidian Kampala pastoral at its best.
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> Beyond the appearance of village life, there were also complicated kinship networks and intergenerational relations. Some of the older nurses who worked on the wards for three or four decades were much like sisters to one another. The newly trained medical oncology fellows had tended to nighttime emergencies as resident student health officers and were beloved by their surviving patients, many of whom continued to come for follow-up appointments years later and check in as one would do with a relative. Personal histories of staff were often woven into the daily sociality of the Institute, either through intergenerational family ties, personal tragedies, or romance. Mr. S, who was responsible for running orders for blood and platelets back and forth between the UCI and Nakasero Blood Bank had grown up at the Institute. His mother had worked as a cleaner in the X-ray department for

years. She had died of colon cancer herself a few years before and had been a patient on the wards.

That summer, scarcely more than a month into fieldwork and energized by this easy analogy, I remarked to a physician colleague that the Institute seemed to resemble a village. He paused for a moment and then looked at me with great seriousness and said, “This isn’t a village, Marissa. This is a camp,” gesturing to the scene in front of us. It was a revelation. I looked at the bedrolls, the washing basins, and one young patient with debilitating Kaposi’s eating away his foot. He had been living on a piece of cardboard outside of the Solid Tumor Center for over three months. It did not take a great leap of imagination to see that my colleague had a point.

I think about this description of the UCI as a camp often as I witness the aftermath of the demolition of the LTC. Forty-five years of carefully planned practices bulldozed for chemotherapy clinical trials that will happen at some point in the future. In the meantime, you have to walk through the toilets to get to the X-ray department or weave through cooking stoves. I expect to see relief tents and multiple hand-washing stations and an army of crisis workers. Where is Doctors without Borders when you need it? Why is there only one water spigot for a hundred-plus people and a cooking area that is a huge accident waiting to happen? This shit stinks—you can literally smell it wafting up from the gutter that separates the LTC II from the construction site while chatting with Mr. K at the X-ray department.

Comments about this tough situation by colleagues spill out over tea and casual conversation. “How do you practice medicine without an examination table?” “I know that the air circulation is poor in that room.” “The environment is not good.” “We had a flood in February. A flood of patients. They were sleeping and staying on every part of the landing.” “There is no space.” “We know it’s not good that patients are sleeping on the floors.” “There have been no pediatric bone marrow needles since October.”

Is any of this surprising? This is the sausage-making part of shiny global health initiatives that nobody wants to see or talk about. My Ugandan colleagues aren’t happy with it, but *bibaawo:* that’s life, what can we do? And my American colleagues who have drawn a strategic line between themselves as researchers

> and the realities of clinical care at the site are saying, “Well, our new building will be awesome.” At the same time, colleagues at the Fred Hutch significantly delayed the construction of the new UCI–Fred Hutch Cancer Center to account for the fact that the LTC patients had nowhere to go and also contributed significant funds to the refurbishment of the temporary LTC II.
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> Both my colleagues at the UCI and the Fred Hutchinson Cancer Research Center know full well that this temporary ward—hastily made to provide care for lymphoma and leukemia to children and adults while they wait to move into the new building—is far from an ideal situation.[13] They are realistic. They are frustrated. The Institute staff come early to work, and they stay late taking care of patients, running up and down to get chemotherapy drips started and blood transfusions administered. They circumvent the toilets and the cooking stoves as they work. They keep disgust in check in the airless adolescent ward room that smells like bile and wounds. And, in many ways, the Institute sounds and looks much as it did in 2012.
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> There are silver linings. In the past two years, Kambugu has built a pediatric oncology service that works in “our setting.” There are more antibiotics on the wards to prevent infections. There are now standardized treatment protocols for all of the common pediatric cancers. Dr. G, who started on the wards in 2012, has all of the makings of a dedicated pediatric oncologist. Kambugu spends less time in the clinic and more time looking for resources and cultivating partnerships, thanks to Dr. G’s dedication and engagement. The six nurses on staff are fully committed to the children. Patients are surviving. Nobody is starving and everyone is getting something warm in their bellies three times a day.
>
> I am keeping my cool and taking notes and trying to gauge the sentiments of my colleagues. I know I’m not in a position to do anything but finish up my work and that the politics of this will speak for itself.[14]

I could easily flip the narrative here and tell an optimistic story of an institution that has defied all odds and miraculously pressured the Ugandan government to take cancer seriously. It has. One could argue that the past decade’s investment both from the international community and the national government in oncology goods in Uganda is unprecedented, historical, and miraculous. It is. And these dramatic improvements can be attributed largely to the visionary leadership of Dr. Jackson Orem and his team, who provide care and engage in the political work of making cancer visible. In the years since the LTC was bulldozed, the landscape of cancer care in Uganda transformed dramatically. Referral centers have opened at regional hospitals, new buildings have become equipped and operational, patients have come to the clinic through cancer screening programs, and Ugandan oncology experts have published their research. The temporary LTC II is no more. The LTC is now in its third iteration in the new UCI hospital building, and pediatric patients have a floor of their own. The plans Olweny and colleagues drafted in the early 1980s to rehabilitate the Institute and continue Africanizing oncology are, as I finish this book, coming to full fruition.

And there are surprising moments of survival. In June 2014, while reeling from the changes at the Institute one hot afternoon, I encountered a little boy spinning Ugandan shilling coins like a game of tops on the floor of the verandah space at the new temporary LTC II. He was giggling to himself and wearing shorts and an oversized pinstripe black suit jacket. I only figured out who this cheerful kid was when I made eye contact with Tata Oliver. He sat at the reception bench, and we exploded into smiles, laughter, relief, and joy. "Greet the muzungu!" said Tata Oliver, pulling him away from his coins and up to his feet. We bumped our fists together and had a wonderful laugh. Who knows what will happen next? Dr. G says he has residual disease in his central nervous system. He is one of the last of the leukemia patients I recognize from 2012. Most of the others have "passed."

Notes

PRELUDE

1. Republic of Uganda, *National Population and Housing Census 2014* (Kampala: Uganda Bureau of Statistics, 2014), http://www.ubos.org/onlinefiles/uploads/ubos/NPHC/NPHC%202014%20PROVISIONAL%20RESULTS%20REPORT.pdf.
2. That is, if there is blood available in the country. For more on chronic blood supply shortages in Uganda, see "Major Hospitals Still Lack Blood," *New Vision*, June 5, 2013, http://www.newvision.co.ug/news/643579-major-hospitals-still-lack-blood.html.
3. Fieldnotes, July 2012.

INTRODUCTION

1. Helen Tilley, *Africa as a Living Laboratory* (Chicago: University of Chicago Press, 2011).
2. *Uganda Cancer Institute Annual Report, 1970–1971*, Uganda Cancer Institute Archives.
3. M. S. R. Hutt and D. Burkitt, "Geographical Distribution of Cancer in East Africa: A New Clinicopathological Approach," *British Medical Journal* 2, no. 5464 (September 25, 1965): 719–22.
4. Idi Amin's disastrous effects on Uganda are well known. See David Martin, *General Amin* (London: Faber and Faber, 1974) and A. B. K. Kasozi, Nakanyike Musisi, and James Mukooza Sejjengo, *The Social Origins of Violence in Uganda, 1964–1985* (Montreal: McGill-Queen's University Press, 1994). For a reconsideration of Amin and Ugandan life in the 1970s, see in particular Alicia Decker, *In Idi Amin's Shadow: Women, Gender, and Militarism in Uganda* (Athens: Ohio University Press, 2014); and Derek R. Peterson and Edgar C. Taylor, "Rethinking the State in Idi Amin's Uganda: The Politics of Exhortation," *Journal of Eastern African Studies* 7 (2013): 58–82.
5. While this book is the first full-length monograph on the history of the UCI, others have generated thoughtful accounts of the Institute's history. See, for example, Charles Olweny, "The Uganda Cancer Institute,"