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Africanizing Oncology

Creativity, Crisis, and Cancer in Uganda

Marissa Mika

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For Aram and Shauna

“I know that the ones who love us will miss us.”

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Acknowledgments

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This book is a bit road weary. It traveled first to London in the middle of Brexiting Britain and then to a new experiment in global health in rural Rwanda and then back to California in the middle of a global pandemic.

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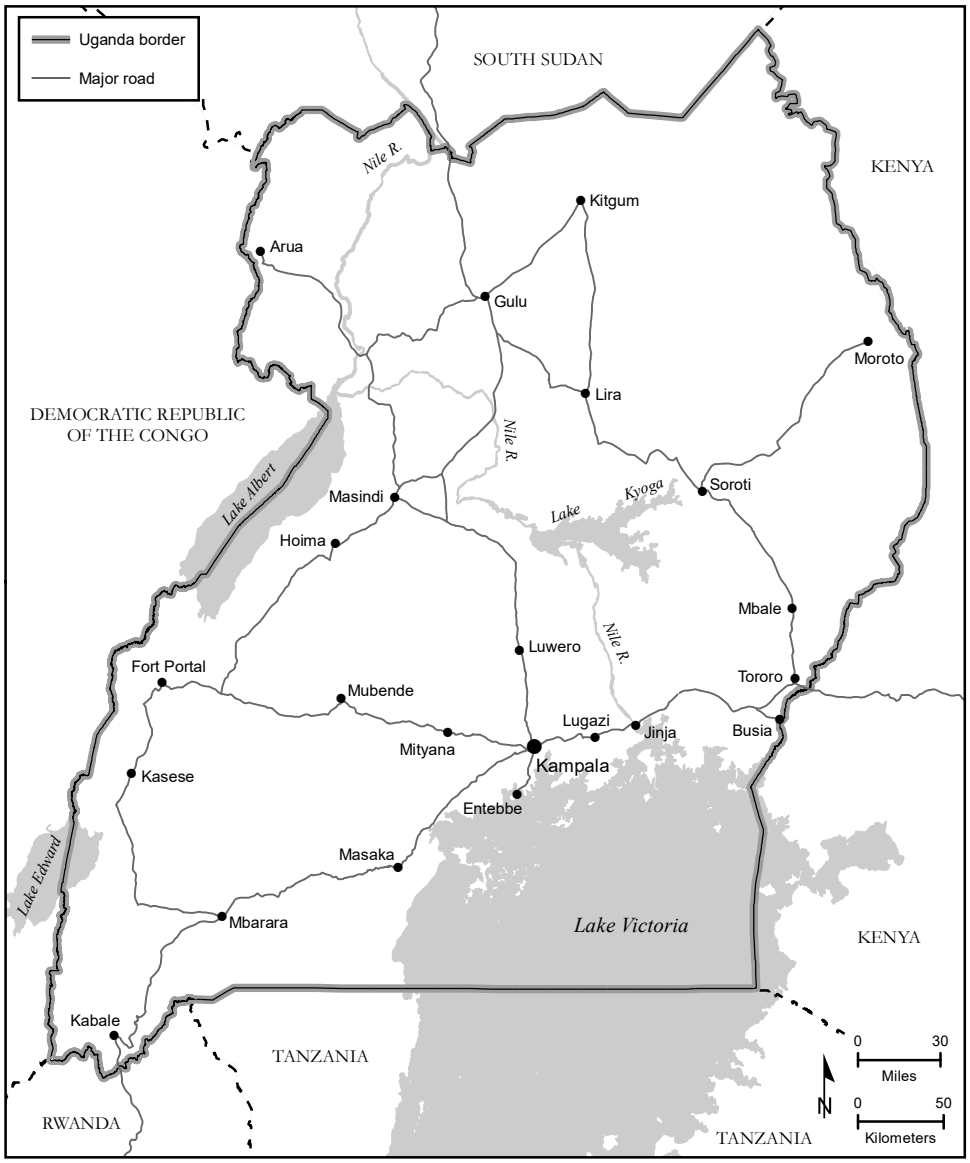
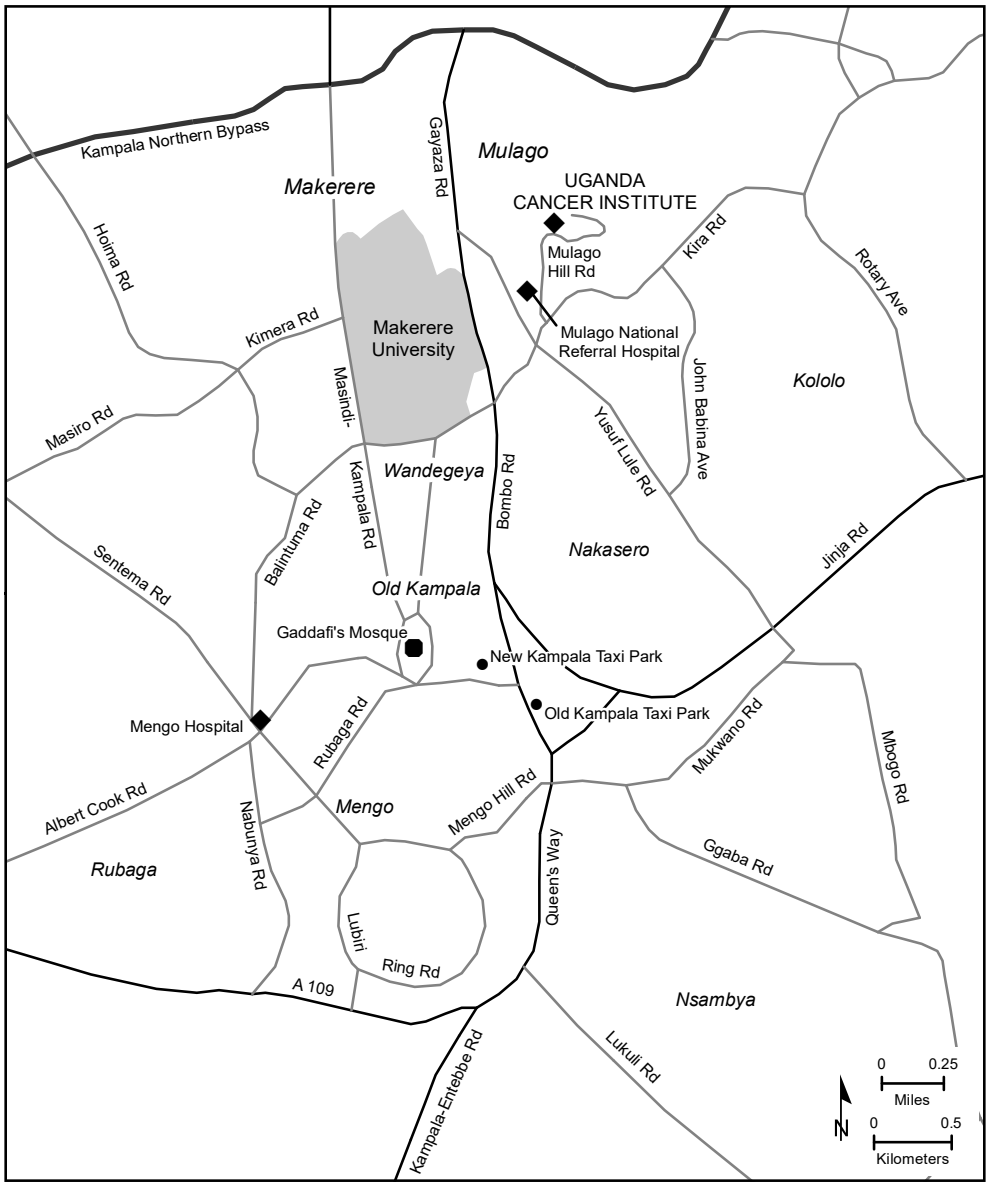
Abbreviations

FHCRC	Fred Hutchinson Cancer Research Center (also Fred Hutch)
IAEA	International Atomic Energy Agency
LTC	Lymphoma Treatment Center
NCI	National Cancer Institute
STC	Solid Tumor Center
UCI	Uganda Cancer Institute (also the Institute)



MAP 1. Uganda. Map drawn by Brian Balsley.



MAP 2. Kampala. Map drawn by Brian Balsley.

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 minibus 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 Kambugu, 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.

Introduction

The Uganda Cancer Institute (UCI) has served as "Africa's living laboratory" for producing knowledge about cancer in sub-Saharan Africa for over fifty years.[1] It began in 1967 as a joint venture between the American National Cancer Institute (NCI), the Makerere Department of Surgery, and the British Empire Cancer Campaign.[2] Established in one of Old Mulago Hospital's abandoned maternity wards and surgical theaters, the two original wards of the Institute, the Lymphoma Treatment Center (LTC) and Solid Tumor Center (STC), provided the infrastructure for chemotherapy clinical trials on cancers that were highly common in East Africa but rare in the United States, such as Burkitt's lymphoma and Kaposi's sarcoma.[3] When Idi Amin assumed power in Uganda in a military coup in 1971, the American staff left and put a Ugandan oncologist, Professor Charles Olweny, in charge of the facility.[4] Despite a decade of economic instability and political precarity, Ugandans continued to run clinical trials and remain embedded in international cancer research collaborations.

Olweny left the Institute in the early 1980s for personal safety reasons. The Institute could have closed, but again Ugandans decided to keep this site going. Throughout the 1980s, 1990s, and 2000s, Dr. Edward Katongole-Mbidde worked as the Institute's director and sole oncologist in the country, providing oncology services in a severely underfunded context.[5] Over the course of the HIV/AIDS epidemic, the Institute served in part as a palliative care facility for those living with HIV and cancer.[6] At the same time, Mbidde maintained high standards and expanded the Institute's research

mission largely by focusing on HIV and the treatment of Kaposi's sarcoma, working with numerous international research partners.[7]

In the past decade, under the directorship of Dr. Jackson Orem, the UCI experienced a profound renaissance as well as a remarkable enlargement of scale and expansion of purpose. It shifted from a place where you were "sent to die" to a site where cancer services are provided as a public health good backed with funding from the Ministry of Health. The combination of more ministers of Parliament getting cancer and the visibility of a long-term partnership between the UCI and the Fred Hutchinson Cancer Research Center (FHCRC or the Fred Hutch) expanded oncology services at the Institute. Thanks to collaborations and newfound institutional autonomy from Mulago Hospital in 2009, drug stocks are more plentiful, more nurses are on the wards, and the number of Ugandan oncologists has increased from one in the year 2000 to twenty in the year 2020. The number of patients, everyone agrees, has also increased dramatically, crowding the two original wards—the LTC and the STC—which were never designed to provide comprehensive cancer care for Uganda's entire population. As a response, the Ugandan government recently completed a five-story inpatient cancer hospital.[8] A new research and outpatient treatment facility stands on the site of the LTC, built through a long-standing partnership with the Fred Hutch in Seattle. These investments in public oncology and cancer research infrastructure in Africa are distinctive. There are few other sites on the continent with the depth or breadth of publicly available cancer services.[9] The UCI now serves a population catchment of approximately forty million residents in the Great Lakes region of Africa.[10]

It is tempting to read the current investments by Americans at the UCI as a new scramble for African research subjects in the global health industry.[11] However, cancer is not a new epidemic in Uganda. It is a long-standing health dilemma that has been under the gaze of biomedical researchers intermittently for the past century. Furthermore, Ugandans at the UCI have long used collaborative medical research as a resource for expanding and consolidating cancer services for a broader public. Many international partners, starting with the British Empire Cancer Campaign and the NCI, have come to Uganda since the 1950s to study and treat cancers. But international collaborators come and go. It was and is ultimately Ugandans who keep experiments going and freezers operating. They provide care to patients on the wards of the UCI long after international colleagues leave, research results are published, and funding cycles end. A collective commitment to keeping things going explains the remarkable durability of this institution

over the past fifty years. Rather than a case of unilateral extraction, cancer research in Uganda was and continues to be generative for creating and supporting long-lasting cancer care infrastructures for Ugandan publics.

The UCI's current slogan is "Research Is Our Resource." And to be sure, this slogan reflects the current terrain of biomedical care in Uganda, where global research projects on HIV and AIDS bring vital funding for buildings, health workers, and therapeutics. But it also speaks to the UCI's necessity, since its inception, to develop context-specific knowledge and knowledge workers. Research on the specific epidemiology of cancers in Uganda, such as their prevalence and survivability, is vital for national health-care planning and resource allocation. The pronounced synergies between infectious diseases and cancers in Burkitt's lymphoma, Kaposi's sarcoma, and liver cancer have long shaped research questions and collaborations. Over the fifty years of the Institute's history, research partnerships have brought resources for cancer care to Uganda. And in turn, research at the Uganda Cancer Institute generated vital knowledge about cancer relevant to both the African context and beyond.[12] Some examples: research at the UCI generated knowledge about the curability of cancer with cytotoxic agents alone in the 1960s and 1970s. In the 1980s and 1990s, large numbers of patients with HIV-related Kaposi's sarcoma provided an indispensable source of clinical material on neoplastic disease and AIDS. In the 2000s, with newfound interests in the relationship between infections and cancers, the Institute is once again an attractive site for cancer research.

Africanizing Oncology argues that Ugandans use research as a powerful resource for mobilizing and extending care, even if they do so in a highly unequal world. This historical-ethnography tells the story of how the UCI transformed from a small experimental chemotherapy clinical trials unit in the 1960s into a site of oncological excellence in present-day Uganda. The book examines the ways in which physician-researchers, especially Ugandans, refashioned the resources and oncological technologies brought through transnational cancer research partnerships to meet the needs of Ugandan cancer patients and their caretakers. The book ahead tells the stories of physicians, nurses, laboratory technicians, administrators, patients, families, visiting scientists, and even the occasional politician who have lived and died on the wards of the UCI over four generations from the 1950s onward. These four generations map roughly onto distinct periods in Uganda's history—colonial developmentalism (1940s–1950s), Ugandanization and independence (1960s), Idi Amin's dictatorship (1970s), civil

war (early 1980s), structural adjustment (1980s–1990s), the HIV epidemic (1980s–present), and Museveni's National Resistance Movement government (1986–present). I show how physician-researchers exercise creativity in crisis, be it straddling the demands of treating late-stage tumors and remaining viable to the international oncology research complex, or negotiating with Idi Amin's state police. The first four chapters of the book discuss the history of cancer research and care in Uganda, beginning with colonial medical research on cancer. They trace the founding of the UCI in 1967 and the ways in which the Institute survived Idi Amin, civil war, and austerity. The last two chapters of the book consider the ways in which international partnerships and research initiatives, coupled with the increasing visibility of cancer in Uganda as a public health problem, are remaking this fifty-year-old site into something new.

Drawing from insights in science and technology studies, medical anthropology, and works on everyday life in contemporary Africa, *Africanizing Oncology* makes three core contributions to African health histories. The first core contribution focuses on the long history of how research, including its social and material technologies, shaped oncology services in Uganda. Many of oncology's treatment technologies originally came to Uganda through international research partnerships or as gifts. Cancer research and experiments have shaped the built and social infrastructure for public cancer care in Uganda over the past fifty years. Practitioners and patients harnessed and transformed these international research collaborations to serve Ugandan publics. I use the term *experimental infrastructure* to describe the constellation of physical facilities, research questions, care practices, data collection procedures, and human labor that makes research and care function on a day-to-day basis at the Uganda Cancer Institute. Efforts to maintain, repair, and transform these traveling oncological technologies can teach us much about what it means to keep biomedical care going in contemporary Uganda. The histories of how oncology traveled to Uganda and the development of the UCI's experimental infrastructure further our understanding of the dynamics between research, resources, and the role of experiments in shaping health care in East Africa.

While the UCI's cancer research is well cited in the biomedical literature, especially on Burkitt's lymphoma and Kaposi's sarcoma, East African oncological expertise remains largely invisible in the historiography of biomedicine in Africa and more popular general histories of cancer. *Africanizing Oncology* amplifies the critical contributions East Africans

(and Ugandans in particular) made to understandings of the etiology of viruses and cancers, the curative potential of chemotherapy, and the necessity of palliative care for cancers associated with HIV. The UCI's history offers a necessary and long-overdue opportunity to situate Africans at the center rather than the periphery of biomedical knowledge production as researchers, physicians, administrators, patients, caretakers, and laboratory technicians. Rather than focusing on the ways in which the substances of African bodies and lives are turned into scientific research commodities or data points on a survival curve, *Africanizing Oncology* highlights the political, moral, and medical ambiguities African knowledge producers face.

Finally, by combining historical and anthropological approaches in telling stories about biomedicine in Africa (and beyond), this book makes a methodological argument for further integration of these disciplines in writing contemporary histories.[13] Hospital ethnographies offer an intimate look at these spaces of care as social worlds unto themselves, liminal places with deep existential concerns about the end of life, and complicated relationships between the public and the state. Historicizing the hospital allows for tracing the impact of political, economic, and scientific events on everyday life as they play out in a microcosm of the state. Oscillations of fortune, waxing and waning resources, and epidemics have all impacted the scale, quality, and scope of biomedical care in Uganda. But there are also powerful continuities, particularly at Mulago Hospital, Makerere Medical School, and the UCI, which have long been sites of biomedical research, medical professionalization, and specialist care. Combining history and ethnography allows us to take a longer view of the material stakes, creative practice, and lived experience of biomedicine in East Africa over the past fifty years.

THE BIOMEDICAL TURN IN AFRICAN HEALTH HISTORIES

The idea for this book began in 2006 during an interview with a South African epidemiologist. Commenting on the rise of global health interventions and researchers on the continent, he said, "We're carving up Africa again! But this time it's for HIV and AIDS research. If you want to study something interesting, study that!" This conversation ignited many questions regarding how histories of biomedical research in East Africa shaped the provision of biomedical care. In a context where accessing biomedicine was (and still is) often tethered to colonial experimentation and the extraction of bodily materials and knowledge, how did African health workers and physician-researchers in newly independent countries such as Uganda, working at a hospital like Mulago and a medical school like

Makerere, think about their work in the context of these complex inheritances? What were and continue to be the legacies of tethering experimentation and research to the provision of care?

In retrospect, the epidemiologist's comment was astute and prophetic, anticipating a biomedical turn in histories and ethnographies of health and healing in Africa over the past decade. In the 1970s, 1980s, and 1990s, historians and anthropologists turned their attention to the "social basis of health and healing in Africa" and created a rich corpus on a variety of topics, including therapeutic and healing traditions, illnesses of God and man, missionary medicine, colonialism and development's impact on environmental health, and the political economy of disease.[14] As Nancy Rose Hunt notes, the emergence of the HIV epidemic dramatically changed the conversation about health and healing in Africa in the late 1980s and into the 1990s.[15] The epidemic's impact on demography, gender relations, and livelihoods, as well as the rise of the antiretroviral techno-fix and its attendant disparities dramatically shaped the preoccupations of the field.[16] Furthermore, the West African Ebola epidemic between 2013 and 2015 put issues of global health securitization into relief.[17]

Newer scholarship written largely at academic institutions in the Global North on African health and healing engages with these emerging therapeutics, epidemics, and global health infrastructures by closely examining how biomedicine works in a variety of local contexts. New histories explore the complexities of biomedical professionalization, medical and scientific experimentation, and the legacies of colonialism in postcolonial medical practice.[18] These works join a growing number of ethnographies of global health in contemporary African contexts and beyond, many of which consider how experiments, humanitarian emergency, and epidemics shape access to biomedical care.[19] This scholarship highlights what African scholars, physicians, epidemiologists, public health professionals, nurses, data analysts, and policymakers have known for years—that biomedicine, experimentation, and extraction often go together.[20]

A recent trend in the anthropology of health in Africa is to examine the repercussions of structural adjustment and neoliberal reform on the provision of biomedicine in spaces that Paul Farmer would witheringly call "clinical deserts." A rich conceptual vocabulary, including "capacity," "African science," "improvisation," "triage," and "normal emergency," has emerged to describe what it means for health-care workers to provide meaningful (biomedical) care in postcolonial spaces that appear to be largely defined by absence and scarcity.[21] Building on critical conversations about

imperial debris, work on the fate of postcolonial "African science" after independence emphasizes the material remains, colonial medical detritus, laboratories in a state of ruin, and the discarded stuff of biomedical and scientific research on the continent.[22] The approach is both aesthetically pleasing and a critical theoretical intervention to track the afterlives of colonial medical initiatives and their objects in Africa after independence.[23] But the emphasis on the remains of the past can also inadvertently reinforce a narrative of state failure, Afro-pessimism, and inevitable decline, mirroring Fred Cooper's argument that opportunities were profoundly foreclosed in the decades following African independence.[24] How might we move beyond accounts of failure, exploitation, technocratic bumbling, and untimely death in contemporary African health settings?

Nolwazi Mkhwanazi has argued that there is a "single story" that dominates much of the contemporary medical anthropology literature on Africa produced by scholars based largely in the Global North. Through careful reading, Mkhwanazi shows us that "stories that are not about the state's inadequacy in health provision, suspicion, and distrust, or thwarted local agency, are rare in medical anthropological studies of Africa."[25] I fully agree, and the approach that I offer here follows Mkhwanazi's lead in more deeply historicizing local knowledge and experience. By focusing on the creativity of Ugandan health and knowledge workers over periods of stability and moments of crisis, *Africanizing Oncology* moves beyond a thick description of coping with scarcity to tracking how scarcity itself ebbs and flow over time.[26]

WHEN ONCOLOGY TRAVELS

One of the core concerns of this book is how oncology became part of biomedical practice in Uganda. That is, how did Ugandans Africanize oncology? To answer this question, I draw from theoretical tools in the history of technology and theories of infrastructure. I argue that cancer research projects were and continue to be key means of transferring oncological tools to Uganda.[27] Oncology came to Uganda in such forms as technology transfer, gifts, international research collaborations, technocratic solutions, and pharmaceutical collaborations.[28] Nevertheless, Ugandan medical practitioners and cancer patients remade these oncological technologies to suit the local context, and they continue to do so today.[29] For example, when the UCI was founded in the 1960s, the American National Cancer Institute staff brought boxes of gloves, stockpiles of syringes, vials of cyclophosphamide, and massive amounts of gauze to set up their

"hospital built from scratch."[30] But these material goods were not the only things they brought. They also brought a set of practices from their training in medical oncology from US hospitals—ward rounding, specific ways of writing up a chart, protocols for doing complete blood workups before deeming it safe to administer chemotherapy. Almost immediately, Ugandan patients and practitioners started to change these systems of care. Ugandans pushed expatriate oncologists to expand their definition of supportive care and to take travel, food, farming, and shelter seriously.[31] The fact that patients and families stayed at the wards for months at a time demanded that Americans rethink who counted as a patient. Within six months, the UCI was treating entire families (not just individual cancer patients) for malaria and parasites. They ensured that there was a big scoop of pungent, nutrient-rich greens on plates of local food for pediatric patients. They hired a schoolteacher for village children who would be missing school. They adapted the resources of research to accommodate the needs of childhood cancer care in the vernacular.[32]

Anthropologists Margaret Lock and Vinh-Kim Nguyen have argued that biomedicine is best understood as a constellation of technologies. They define technology broadly, accounting for both objects and practices: "No doubt what springs most readily to mind when thinking about biomedical technologies are machines such as mechanical ventilators, imaging technologies including X-ray machines and CT scans, as well as devices such as prosthetic limbs, cardiac pacemakers, tooth implants, and so on. However, our lives are filled with far more mundane biomedical devices and technologies including the basic physical examination, patient history-taking (including self-examination and self-history taking), administration of injections, and the prescription of medications."[33] Oncology, as an arena of biomedicine, can be thought of similarly as a constellation of technologies embedded in a broader system of care. In contemporary America, everything from cancer screening to pathology laboratory reagents and breast cancer awareness campaigns—and to pharmaceutical companies conducting cancer clinical trials—comprise oncology's technologies, regimes of research and care, and infrastructure. Løchlann Jain calls this tangle of markets, medical practitioners, politics, and patients *the cancer-corporate care nexus*.[34] In comparison to the United States, Europe, or indeed other parts of the Global South, oncological treatment and care infrastructure is relatively shallow and tethered to experiment and biomedical research. The UCI was not established with the intention of providing comprehensive oncology services

to the Ugandan masses, even when the population was less than ten million.[35] It was originally an enclave established to do research on African bodies.[36] This history partially explains why, until the mid-2000s, the Uganda Cancer Institute was largely a chemotherapy experimentation and treatment facility rooted in the socio-technical practices of oncology as they were in the 1960s and 1970s. It also helps to explain why there was only one Ugandan oncologist, one Ugandan radiotherapy machine, and one central place for receiving cancer care in the country for much of the 1980s, 1990s, and early 2000s.

Throughout this book I use the concept of *experimental infrastructure* to describe the Uganda Cancer Institute. The materiality and practices of oncology, the built environment of the UCI, and the movement of patients, drugs, biopsies, and knowledge are all components of experimental infrastructure. Infrastructure allows for the largely uninhibited movement of stuff, or ideas, or people, or services both across spaces and across time. In the 1990s, scholars such as Susan Leigh Star focused their attention on infrastructures situated in the United States and Europe.[37] Classic examples of twentieth- and twenty-first-century infrastructure include roads, electricity grids, aviation, water and sewage, and the internet.[38] Coordinated social action, standardization, repair, maintenance, long-sighted planning, and technocratic expertise are all vital to keep infrastructures humming in the background of daily life. Paul Edwards says that "this notion of infrastructure as an invisible, smooth-functioning background 'works' only in the developed world. In the Global South (for lack of a better term), norms for infrastructure can be considerably different. Electric power and telephone services routine fail, often on a daily basis; highways may be clogged beyond utility or may not exist; computer networks operate (when they do) at a crawl."[39] Edwards notes, however, that living with an infrastructure constantly in the foreground and highly visible due to its unreliability is "equally modern" and a feature of everyday life in the Global South.[40] More recent works in the anthropology of infrastructure consider the ways in which chronic economic or political instability, the atrophy of expertise, the systematic cutting of financial resources for maintenance, and the impact and aftermath of disasters can all cripple infrastructure or render its problems sharply visible.[41]

In Uganda, many infrastructural investments such as roads and railways, electricity grids, telecommunication systems, education systems, and indeed biomedicine have historical roots in colonial conquest and later colonial development initiatives.[42] There is a thinness and a lack

of redundancy (i.e., backup systems or engineering fail-safes) to many of these old colonial infrastructures—think of the lone highway that stretches from Mombasa to Kampala, the singular tertiary national referral hospital in Mulago, the first university on Makerere Hill. And there is a legacy of resource extraction knit into many colonial-era infrastructures—think of the routes of mobility that slaves conscripted during the ivory trade endured in East Africa, the grotesquely inadequate housing infrastructure that was built to facilitate mining in southern Africa, or indeed the bureaucratic systems established for the trade of coffee and cotton in Uganda.[43]

The development of biomedical infrastructure in much of sub-Saharan Africa was inextricably tied to colonial conquest and later on, development aid. From quinine to venereal disease treatments, early colonial health programs in much of sub-Saharan Africa involved experimentation on African bodies in small enclaves and catchments, akin to sites of global health treatment interventions today.[44] Over the past century, biomedical services for the Ugandan population were offered at Mulago Hill often via experiments and research on issues such as venereal disease, yaws, malnutrition, tropical maladies, and "diseases of civilization" such as heart disease and cancer.[45] One of the long-term legacies of the development of colonial medical infrastructure in East and Central Africa is that many public biomedical care infrastructures have not been seriously "modernized" since they were established in the 1960s. Particularly since structural adjustment and financial austerity were imposed on African countries as a condition of debt relief, medical services on the continent have atrophied.[46] Some would go as far as to say that there is no meaningful medical care in some sites on the continent.[47] This infrastructural atrophy poses real dilemmas for the contemporary, booming biomedical research enterprise and HIV treatment complex in eastern and southern Africa. Drugs can be imported, staff can be trained, and computers can be hooked up to speedy internet connections for a price. But the physical spaces where potential and often poor research subjects congregate for care are often worse for the wear. The political and logistical work of international medical research on human subjects often consists of creating new infrastructures for care that operate alongside crisis-ridden government health services. This is certainly the case at the Uganda Cancer Institute, where major investments from international partners and the Ugandan government alike over the past decade have led to an expansion of oncology infrastructure not seen in the country since the late 1960s and early 1970s.

CANCER IN AFRICA

Originally, I did not set out to write about cancer. But serendipity shifted the focus from the history of HIV/AIDS research in Uganda to the history of cancer research in Uganda. I first learned about the UCI while going through the papers of an American scientist at an archive in Philadelphia. I found a copy of the Institute's annual report from 1971, which documented a series of chemotherapy clinical trials underway in Idi Amin's Uganda. It was too interesting to ignore, and I began to look for traces of the UCI's past in historical and popular works on cancer in the United States, United Kingdom, and Uganda. In the 1960s and 1970s, the UCI made major contributions to global understandings of the power of chemotherapy drugs in treating pediatric cancers. In Siddhartha Mukherjee's biography of cancer, *The Emperor of All Maladies*, which focuses extensively on the history of pediatric chemotherapy research, these contributions of the UCI to the promises of chemotherapy were relegated to a footnote. It reads, "Many of these NCI-sponsored trials were carried out in Uganda, where Burkitt's lymphoma is endemic in children."[48] Thinking that the UCI's contributions would be more visible to historians of medicine in Africa, I looked to John Iliffe's *East African Doctors*, where the critical research conducted on cancer in Uganda in the 1960s and the contributions of Olweny and Professor Sebastian Kyalwazi were briefly highlighted. Based on these thin accounts, I expected the UCI to be a thing of the past. Instead, arriving at the top of Mulago Hill at the Institute for the first time in 2010, I found not a ruin but a bustling hospital.

Over the past decade of working on this book, cancer itself has emerged as a more politically and epidemiologically visible phenomenon to African public health authorities and global health specialists alike.[49] Publicly funded cancer wards are opening across the continent from Botswana to Kenya to Rwanda.[50] As Megan Vaughan, Julie Livingston, and Emily Mendenhall, among others, highlight, epidemics of noncommunicable chronic disease are reshaping African health futures.[51] This cancer burden occurs alongside a host of chronic ailments, including hypertension, heart disease, stroke, renal disease, kidney failure, diabetes, liver disease, and mental health issues. These chronic conditions join a high burden of infectious diseases, and epidemics of violence and injuries, creating a "quadruple disease burden" or a crisis of "syndemics."[52] While threads of causation have yet to be fully pulled apart, public health experts and lay observers agree that increasing urbanization, consumption, and affluence are rapidly contributing to the growing burden of noncommunicable diseases in the Global South.[53]

Growing attention to a cancer crisis in Africa operates alongside a growing "global oncology" research agenda in the Global North.[54] New tools for studying oncogenes and vaccine development have reanimated research on the causal relationships between viral infections and cancers. Infectious diseases are a necessary link in the causal chain for cancers such as Burkitt's lymphoma, which is associated with Epstein-Barr virus, Kaposi's sarcoma, which is caused by human herpes virus 8, certain kinds of liver cancer from long-term hepatitis B and C infections, and cervical cancer, which is linked to human papillomavirus.[55] The synergies between HIV/AIDS and cancers are particularly pronounced in southern and eastern Africa. As HIV-positive patients on antiretroviral therapy live longer, they are more vulnerable to developing infection-related cancers, particularly cervical cancer.[56] In Uganda, data from the Kampala Cancer Registry suggests that in the twenty-five years between 1991 and 2015, most cancer incidence rates increased in Uganda. Incidence rates of prostate cancer, breast cancer, and cervical cancer were all higher in 2010–2015 when compared to 1991–1995. Cases of Kaposi's sarcoma and non-Hodgkin's lymphoma, both cancers associated with HIV/AIDS, were on the rise in the 1990s and then declined in the late 2000s. According to colleagues at the Kampala Cancer Registry, these trends "reflect the changing lifestyles of this urban African population, as well as the consequences of the epidemic of HIV/AIDS and the availability of treatment with antiretroviral drugs. At the same time, it highlights the fact that the decreases in cancer of the cervix observed in high and upper-middle income countries are not a consequence of changes in lifestyle, but demand active intervention through screening (and, in the longer term, vaccination)."[57]

Academic monographs on cancer in Africa and elsewhere in the Global South generally remain scarce. The notable exceptions are Benson Mulemi's moving work on cancer in Kenya and Julie Livingston's portrait of the emerging cancer crisis in southern Africa. Livingston viscerally draws us into the human stakes of cancer treatments in a stripped-down setting where analgesics are few and oncologists are even fewer. Published in 2012, *Improvising Medicine* made the emerging cancer epidemic in Africa strikingly visible. But cancer is neither a single disease nor is the situation in Botswana generalizable to the diverse experiences of cancer and practices of oncology on the continent. The cancer ward of Princess Marina Hospital (PMH), which opened in 2001, offered a window into the emerging infection-related cancer epidemic in southern Africa where malignancies often present "without oncology."[58] The bodily experiences

of cancer care at PMH, including the pain epidemic, botched surgeries, exploding tumors, and riotous vomiting, are certainly present on the wards of the UCI. But the UCI is a space where cancer research and care have long coexisted.

Oncology in Uganda grows out of a long-standing biomedical research culture, which began at Mengo Hospital and soon after at Mulago Hospital in the early 1900s. Research at these sites shaped much of the knowledge about the prevalence and treatment of cancer in East and Central Africa over the twentieth century. The Uganda Cancer Institute consists of multiple sedimentary layers of infrastructure, research legacies, and a culture of oncological practices that go back to the 1950s. Furthermore, those who practice oncology as specialist physicians in Uganda are, at this point, Ugandans. This has been the case since the 1970s. They are not expatriates like Dr. P fleeing the economic and political atrophy of Zimbabwe or South African specialists escaping the grind of Johannesburg. The physicians who practice oncology at the UCI are, for the most part, Ugandans who grew up in Uganda. Some cared for relatives at the height of the HIV epidemic and now pay the school fees of children whose parents did not survive. These Ugandan physicians could be practicing oncology anywhere, but they choose to remain in Uganda not only because they are deeply invested in furthering the well-being of the Ugandan public but also because it is home.

NEW DIRECTIONS IN UGANDAN HISTORIES

The research for this book occurred during a period of increased national reflection about Uganda's past. Since Uganda celebrated independence on October 9, 1962, with the lowering of the Union Jack at midnight, political struggles, prolonged periods of economic crisis, mercurial state-sponsored violence, and the challenges posed by the HIV/AIDS epidemic have all profoundly shaped political, social, and economic lives and livelihoods of Ugandans. The National Resistance Movement (NRM), which has been in power since 1986, brought relative economic prosperity and political stability to Uganda. NRM leaders in particular use this narrative about the transition from apocalyptic chaos to prosperity and growth as a justification for remaining in power in what Aili Tripp has dubbed a "hybrid regime."[59]

The celebration of fifty years of independence—the Golden Jubilee—created a public space for national discussions about the country's past and future. This was particularly evident in the news media. Starting on January 1, 2012, for example, both the *New Vision* and *Daily*

Monitor newspapers started a Golden Jubilee countdown, with every issue including a short history lesson starting from the 1700s and working its way up to the present. These stories highlighted the biographies of important Ugandan intellectuals, key moments in the history of precolonial kings and kingdoms, African land agreements with European colonial officials, stories of escaping police in the times of Idi Amin, and much more. The flurry of public storytelling was a marked departure in a context where there are few sites of public commemoration for Uganda as a nation. With the milestone of fifty years of independence, and nearly thirty years of NRM governance, Ugandan citizens are beginning to ask what is beyond the seemingly impenetrable smoky cloud of violence that obscured much of Uganda's past between 1962 and 1986, and more generally about the politics of erasure and memory in modern Ugandan history.[60] Historians of Uganda's past are benefitting from this turn to national reflection, thanks in part to an unprecedented transformation in the availability of documentary sources in the country.[61]

Africanizing Oncology joins this new wave of contemporary histories of Uganda. But rather than using ethnicity or high politics or a single disease like HIV/AIDS to reconstruct the history of Uganda since independence, this book focuses on the history of the cancer hospital. Over the years, staff and patients alike at the UCI felt the reverberations of critical political, social, and economic events in Uganda.[62] The Institute itself was founded shortly after Milton Obote consolidated power by abolishing the historic kingdom of Buganda, among others, and declaring himself president in 1966.[63] While situated in central Uganda and the heart of Buganda, the UCI's mandate was national in scope and the patients it recruited for research trials and treated came from all over the country.[64] It is not insignificant that the UCI became a place where Obote's wife routinely took visitors and dignitaries to see the fine scientific work that Ugandans as well as Americans were conducting on cancer.[65] Amin's declaration of the expulsion of the Asian population in 1972 severely disrupted the everyday workings of the Institute as most expatriate staff left.[66] The violent punctuation of the Tanzanian War of Liberation in 1979 turned Mulago Hospital into a war hospital.[67] Institute staff dodged bullets to attend to night emergencies.[68] In Museveni's Uganda, the current renaissance at the UCI is in part a reflection of a broader culture of public-private partnerships, which dominate development initiatives in the country today. The UCI offers a unique vantage point for understanding how Ugandan health workers in particular navigate shifting relationships between politics and science.

ON METHODS AND AUDIENCE

This book draws upon research conducted in archives and institutions across three continents and combines historical and ethnographic methods. In summer 2010, I met with Dr. Jackson Orem for the first time and asked him if he would be interested in allowing a doctoral student to reconstruct the history of the Uganda Cancer Institute. I started shadowing work in the LTC's wards shortly thereafter. I returned to Uganda in summer 2011, worked as a historian-ethnographer in the country from January to October 2012, and made yearly shorter return trips of one to eight weeks from 2013 to 2020. Methodologically, I drew a great deal of inspiration from the turn toward "hospital ethnography," wherein a hospital or medical ward is used as a primary field site.[69] My original intention in triangulating ethnography with archival research and oral history was to inform a baseline of comparison for interviews with actors about the past. By understanding how chemotherapy was, for example, administered on the wards in 2012, I could provide a point of comparison in interviews with nurses about practices of working with cytotoxic agents in the 1960s, 1970s, and 1980s. The ethnographic research in and of itself wound up creating a vivid yet only partial account of a place that no longer exists. I treat these fieldnotes as an additional archive and as a collection of personal papers, observations, and photo snapshots from the UCI as it was in 2012. Both the places and the people depicted in these fieldnotes, and indeed Kampala itself, have changed dramatically in the space of just a few short years, and the differences have only become more pronounced as this book goes to press.

In addition to ethnographic fieldwork, I conducted approximately forty formal oral histories with prominent people in the history of cancer in Uganda, and about twenty interviews with patient caretakers to get a sense of some of their experiences of life on the wards. Interviews were conducted by me and Irene Nassozi with patient caretakers in June, July, and August 2012 in Luganda. I accompanied and listened to the interviews and asked follow-up questions in English, which were then translated. Irene Nassozi then wrote translations of the interviews verbatim in English. These interviews followed five months of intensive participant observation on the wards of the UCI, and most of the patient caretakers interviewed already knew me relatively well. We followed an informed-consent procedure approved by both a Ugandan university institutional review board (IRB) and an American university IRB.

Blending history and ethnography shaped decisions regarding identification and anonymization. The individuals and institutions named and

identified in this book are already well established in the public historical record. Wherever possible I've used the public record as a point of reference in identifying individuals and institutions. If it was not already on the public record, or if it was not said to me specifically on the record, I erred on the side of caution and used my best judgment. In the consenting process for oral histories, individuals were given the option to remain anonymous or be publicly identified. Pseudonyms, in the form of a title followed by an initial, are used for contemporary medical staff. All names of patients are pseudonyms. Despite the use of anonymization and pseudonyms, some medical staff, patients, and patient caretakers may still be recognizable to those who know the UCI well.

Research in Uganda was complemented by archival research conducted in the United Kingdom and the United States, as well as interviews in Seattle with colleagues at the Fred Hutch. I worked extensively from the UCI's archives. This included patient records from the 1960s to the present, as well as old personnel files, logbooks marking the events of a night's shift on the wards, and old oncology journals, and home visit reports from epidemiology studies in the 1960s. There were also patient records written out on student exercise notebook paper in the 1980s and assembled with tiny strips of gauze—a signal of just how scarce materials were during Uganda's civil war in the early 1980s. The archive was in remarkably good shape given the years behind a padlock. As Dr. John Ziegler, the founding director of the UCI, said in email correspondence about these materials, "Uganda is extraordinary in that nothing is discarded. Offices are like museums."[70] I am grateful to the director, Dr. Jackson Orem, and deputy director, Dr. Victoria Walusansa, for granting me permission to work with these vital materials. And I am also grateful to the entire staff of the records department for kindly accommodating my work.

This book is but one component of a broader corpus of publicly engaged work at the UCI. Over the years, I have organized history workshops and research-in-progress presentations and also collaborated with the photographers Andrea Stultiens and Rumanzi Canon of History in Progress Uganda to document the changes at the Institute in real time. In 2017, to celebrate the fiftieth anniversary of the UCI's founding, we exhibited some of these images from both past and present at the Afriart Gallery in Kampala for the show and book launch of *Staying Alive: Documenting the Uganda Cancer Institute*.

Readers will engage with this book across multiple time zones, cultural contexts, and professional backgrounds. Many who read this account

will no doubt be thousands of miles away from Kampala. They may never have had the misfortune of a cancer diagnosis or caring for someone with cancer. For other readers, the stories within will hit a deeply personal nerve. And some colleagues, especially in Uganda, may feel that this book dwells too much on broken things, the dark side of oncology and on those who died rather than the survivors. I have found over the years that many who work at the UCI are the first to acknowledge that the Institute can be a tough place. Still, I am well aware that it is a delicate matter when institutional challenges are described by a *muzungu* ("White person," or "the person who wanders") outsider, whether she be a journalist or a historian-ethnographer.[71] Despite my best efforts, there is no doubt some of the research and writing replicates knowledge-production asymmetries of the White expatriate colonial and postcolonial physician-researchers I discuss in this book. During a particularly hard day of fieldwork, an American physician I knew urged, "Write your truth!" I have endeavored to do so in these pages. But truths can only tell part of the story. Charles Olweny's memoirs, oral histories with NCI expatriates such as John Ziegler, Denis Burkitt's autobiography, and countless medical journal articles all offer counterweights to my narrative and interpretations of the past. The book intentionally ends in 2015 with the opening of the UCI–Fred Hutch Cancer Center and the new government-sponsored facilities at the UCI. Much has changed since then, including fully equipping the new UCI hospital, procuring new radiotherapy machines, building new radiotherapy bunkers, and expanding training and research programs at the UCI.

Other readers may decide I dwell too much on the good deeds of Ugandan doctors and too little on the suffering of strangers.[72] I am reluctant to minimize the great bravery (the very definition of heroism) involved in keeping the UCI open in the 1970s, or downplay the choice to come back to war-frayed Uganda after studying in the UK in the 1980s. Nor do I want to discount the bravery of patients to show up for medical appointments and endure harsh treatments, or the courage of a parent to prioritize a child over a marriage that then dissolves. At the same time, I am mindful of Mkhwanazi's critique of "single stories" about African health contexts, especially single stories that are overly celebratory. She says, "Drawing on the narrative of the state's lack of or inadequate involvement in the provision of health care, medical professionals working in Africa are conventionally presented as working tirelessly and selflessly under impossible conditions in the service of humanity."[73] There is plenty of tireless labor at the UCI every day, but I think of the medical professionals in this book

differently. Drawing inspiration from historians of health and healing in Africa who have highlighted the pivotal role of public healers in maintaining social and political order in precolonial Africa and then actively, vocally, powerfully leading resistance against colonial powers, I see the work of Ugandan medical practitioners at the Institute as an example of what we could call "postcolonial public healing."[74] Mitigating malignancies relies on care, political networks, hospitality, and shrewdness. In particular, I see the Ugandan directors of the Institute—Charles Olweny, Edward Katongole-Mbidde, and Jackson Orem—serving the social, moral, and political function of upholding the health of the public by actively navigating Uganda's political scene in a quest for securing oncology goods and engaging in research. They are physician-intellectuals. My attention to the courage and care of Ugandan health workers and knowledge makers is intentional. But my intentions are not whiggish. African histories of medicine and the practice of oncology itself demand holding healing and harming in the same frame.[75] This is not a story of linear progress but one of multiple and overlapping cycles of creativity and crisis, repair and destruction, and hope and despair. And there is so much to learn from how Ugandan physician-intellectuals, fieldworkers savvy in forging friendships, resilient patients, and invested caretakers keep things going: be they buildings, bodies, experiments, kitchens, therapeutics, blood banks, or optimism.