Research is Our Resource: Surviving Experiments and Politics at an African Cancer institute, 1950 to the Present

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Abstract
This dissertation is a historical-ethnography of the Uganda Cancer Institute. In the 1960s, the Institute was a small chemotherapy clinical trial facility established through a joint partnership between Ugandans and Americans. Today it is the only site of public oncology goods in the Great Lakes region of Africa. 60 beds serve a catchment of 40 million people. New research partnerships to examine HIV and cancer aim to transform this site from a dilapidated research enclave into a “center of excellence”. To understand this transformation, I place African health workers and physician-researchers at the center of this story, and examine their political and medical labor in maintaining an African cancer hospital, decades after initial outside support evaporated. I do this by tracing the ways in which cancer research and care continued throughout several periods of profound transformation—Independence (1960s), Idi Amin’s dictatorship (1970s), civil war (early 1980s), structural adjustment (1980s-1990s), and the HIV epidemic (1980s to now). I argue that throughout these crises, Ugandan physician-researchers creatively secured equipment and drugs to maintain oncology services by making the case that “research is our resource” to the Ugandan government and international scientific community.

The dissertation makes three key contributions. Firstly, I expand our understanding of medical knowledge production in postcolonial Africa. Historians, anthropologists, and sociologists have focused on the scramble for African research subjects and the questionable ethics of extraction from and experimentation on African bodies. Research is Our Resource works to move beyond this framing by examining not just the work of western scientists, but the equally critical work of Ugandan practitioners to create medical knowledge. Secondly, by integrating theory on technology transfer, infrastructure, and socio-technical systems with new approaches in the study of biomedicine as a cluster of technologies, I unpack the long-term repercussions of the transfer of oncology research and care to one corner of the Global South. I use this site of postcolonial knowledge production as a lens to examine how people cope with malignancies and malignant politics. The dissertation is based on over two years of archival and ethnographic research in Uganda, between 2009 and 2015.

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RESEARCH IS OUR RESOURCE: SURVIVING EXPERIMENTS AND POLITICS AT AN AFRICAN CANCER INSTITUTE, 1950 TO THE PRESENT

Marissa Anne Mika

A DISSERTATION

in

History and Sociology of Science

Presented to the Faculties of the University of Pennsylvania

in

Partial Fulfillment of the Requirements for the

Degree of Doctor of Philosophy

2015

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DEDICATION

For Aram and Shauna Mika
ACKNOWLEDGMENTS

My deepest thanks and gratitude extend to the staff, patients, and patient caretakers of the Uganda Cancer Institute who welcomed me as their historian for nearly half a decade. I thank patients and caretakers for generously engaging with an outsider during times of great duress, heartache, and loss that were occasionally peppered with laughter and joys. To protect privacy the names of patients and caretakers are not recorded here, but they are not forgotten. Ngo labye, munange.

In 2010, Dr. Jackson Orem agreed to meet with me after a phone call and a brief letter of introduction. Over the years, he has become a dear friend and mentor. He is also an extraordinary advocate for cancer research and care in Uganda. Thanks to Jackson for everything, especially entrusting me with reconstructing the history of this institution. And many thanks to Irene Nassozi for scheduling meetings and helping me on the ground with neverending paperwork.

The past directors of the Uganda Cancer Institute were astonishingly generous. Dr. John Ziegler, founding director of the UCI, mailed me archives and photographs, spent hours on the phone patiently answering questions, and welcomed me to his homes in California. John’s humility, as well as his deep appreciation and respect for Uganda, helped to shape my own analysis and attempts to write with care. Professor Charles Olweny, the UCI’s director through most of the 1970s and early 1980s shaped this research profoundly, both through his commitment to keeping the doors of the UCI open throughout the Idi Amin era, and
his intellectual and practical generosity in meeting with me several times over the course of this project for interviews and conversation. I thank him for his work as an oncologist, advocate, and historian. Dr. Edward Katongole Mbidde, a fixture at the Institute since 1967 as everything from a Student Health Officer to Olweny’s deputy in the 1970s to the Cancer Institute’s director from the early 1980s up to the mid 2000s, generously took time away from his obligations as the current director of the Uganda Virus Institute to meet with me and to attend the UCI’s first History Symposium in 2014. His singular dedication to the Institute for four decades, and his commitment to the maintenance of high standards in the face of extreme difficulty and scarcity, is nothing less than remarkable. The UCI’s current Deputy Director, Dr. Victoria Walusansa, also deserves special mention for welcoming me to the day-to-day activities of the wards.

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In Seattle, Dr. Corey Casper graciously welcomed me at the Fred Hutchinson Cancer Research Center. I thank him and the rest of his team, especially Erica Sessle,
Jason Barrett, Katie Maggard, and James Farrenberger. Thanks especially to Jen Ashe for dealing with scheduling headache after scheduling headache.

Upon her return from South Africa, Dr. Joyce Balagadde welcomed me onto her service as an observer and a participant as she built pediatric oncology services from scratch at the Uganda Cancer Institute. She, and the entire Lymphoma Treatment staff made large components of the ethnographic research at the UCI happen. I thank them all, particularly Sisters Allen, Susan, Mariam, Rose, Harriet, and Misty, as well as Mr. Collins and the dedicated counselor Primrose. A special thanks to Dr. Geriga, Dr. Nixon Nyonzima, and Dr. Grace for their work in softening the edges of bone marrow aspirates, tending to emergencies, and answering questions from concerned parents and ethnographers alike. The families who pass through the LTC in search of care and relief are lucky to have such dedicated staff on the wards. *Weebale kujanjaba.*

Dr. Fred Okuku spent many hours of casual conversation regaling me with stories of the UCI’s history and the general dilemmas of practicing oncology in east Africa and the United States. Without Fred, this would be a very different dissertation. Late tumor oncologist. Master interpreter. Dedicated teacher. Thank you for all that you do. Dr. Noleb Mugisha understood the contemporary and historical logic of this project immediately. I thank him for his ready willingness to be a sounding board on matters ranging from tracking down past historical actors to purchasing a car in Kampala. Dr. Abrahams Omoding taught me much about HIV
medicine, oncology, and the possibilities of providing comfort at the end of life. Dr. Innocent Mutyaba and Irene Nassozi both made interviews with Burkitt’s lymphoma caretakers possible.

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The local Hutch-Uganda program staff, especially Mariam, Annet, and Andrew Okot, made me feel welcome. I thank Sarah Gerdts for consistent sharing and thoughtfulness regarding the Burkitt’s lymphoma project at the UCI and for her hard work in implementation. Warren Phipps provided deep contextualization on a number of levels, from memories of old buildings to running the fabulous research in progress meetings—the ultimate incentive to get to the UCI by eight in the
morning, jam or rain notwithstanding. Isma was the quintessential fixer. There are, of course, many other people at the Uganda Cancer Institute who helped to shape this work and offered their time, and I extend my warmest thanks to all of them.

Walking down the hill to the main Mulago Hospital and Makerere College of Health Sciences, my deep thanks to Dr. Elly Katabira for offering sage advice and steering me in the right directions. Dr. Alex Coutinho and Dr. David Serwadda both shared their memories of working as medical students and clinical officers at the UCI in the early 1980s. The entire pathology department, especially Professor Henry Wabinga and chief technician Mr. Ssempala filled in important gaps about the history of cancer registration in Uganda. Thanks to the ladies at the Dome Café for coffee, samosas, the space to write field notes, and consistent Luganda lessons.

Esther Nakkazi and I first met at the Uganda House in 2009, and she has been pulling me out of traffic, offering sage advice, and working as an intellectual collaborator and a trusted friend since then. Kampala would not be the same without you, Esther. Thanks for the journeys down Entebbe road, the vibrant discussions over plates of muchomo, and your tireless work on health journalism in Uganda. I’m happy we spent my thirtieth birthday together, and I hope we can spend my fortieth birthday together as well.

Dr. David Kyaddondo and Dr. Herbert Muyinda shared much as scholars and friends. Dr. Asiimwe Godfrey provided intellectual support and freely shared many of the challenges of being an academic in Uganda. I also thank him for his help in
procuring mobility for the year. Waalabyeki Magoba took me on as a student of Luganda and Buganda, and left an indelible mark on this project. Deo Kawalya offered generous language instruction. To all other Ugandan colleagues left unnamed here, I thank you for your hospitality and friendship.

Over the course of the past decade, mentors and colleagues at several academic institutions have shaped me into a historian of Africa. I thank the History and Sociology of Science department at the University of Pennsylvania, as well as colleagues at the University of California, Berkeley, the University of Cape Town, and Johns Hopkins University. My foremost thanks goes to Steven Feierman for taking me on as a student, especially at this time in his own career and life. Thank you, Steve, for such intellectual generosity, for reading every word, for asking the hardest questions, for believing in this project, for coping with the vagaries of long distance advising, and above all for being an exceptional mentor. Many of the issues discussed here in this dissertation about social health, biomedical technology transfer, and care from below came out of long and productive conversations with Steve over the past seven years and his ideas on these issues. I thank Robert Aronowitz for friendship, close reading, and generosity in all things from career advice to how to write about cancer with both empathy and clinical acumen. Adriana Petryna offered wise counsel on occasions too numerous to count, and in particular gave me tools for bringing order to this project started after nearly a year of writing in circles.
At Johns Hopkins, Sara Berry first suggested that the Uganda Cancer Institute would be a perfect place to situate a dissertation. Although she retired, she stayed with this project, offered space for trying out ideas in Africa Seminar, and continues to help me find and refine arguments. Randall Packard encouraged me to pursue a career in African history in 2007, and his urging to go into the long history of HIV/AIDS research in east Africa brought me to Uganda and to cancer. Julie Livingston supported this work with such generosity of spirit, enthusiasm, and questions over many years. I thank her for paving the way in all things. Cori Hayden graciously hosted me at the Center for Science, Technology, Medicine, and Society at UC Berkeley and I thank all at CSTMS for their hospitality. Two seasoned and brilliant scholars of Uganda made this work better. I thank Holly Hanson for her friendship, sharing her time and ideas so generously, and for much needed moral and emotional support in the field. Derek Peterson offered both practical and critical advice regarding archives and tools for thinking about the creative political work of the 1970s in Uganda. Conversations initiated at a conference on Uganda in the 1970s at the University of Michigan continue to inform this work.

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Aram and Shauna Mika taught me early on that the world was far bigger than Santa Barbara, California. I am forever grateful for that lesson, and dedicate this dissertation to them. It is a profound sadness to me that Aram Mika unexpectedly passed away in 2005 and is therefore unable to see how this project unfolded, or that it even began. Shauna Mika has supported work that takes me 6,000 miles away from home on a regular basis with cheer and enthusiasm. I thank her and Rick Callison for their ongoing support. Eric Mika has provided hilarious times in New York en route to and from Kampala too many times to count. He also graciously attended several boring academic events over the years to support this work. Mic Hansen, cancer survivor, read many of the chapters here and also paid a visit to London in 2012 when family time was sorely needed. My in-laws have been phenomenal. Patricia and Wallace Mandell offered encouragement at every juncture. David Mandell urged me to go into public health school and then to come to Penn for African history. The good humor of Joe, Alex, Austin, and Susan Blanks combined with the quietude of East Texas fixed many chapters.
Finally, twelve years ago, Hunter Blanks came into my world and transformed it for the best in every way. Hunter supported this work from afar and endured months of separation and mediocre Skype connections. He also made the time for several trips to Uganda and offered his keen observations about life in the country, which have greatly improved this work. I thank him for being such a generous partner in long distance fieldwork. Thank you, Hunter for welcoming this project into our home, and Uganda into your heart. I am excited for our next adventure together. Tugende!
ABSTRACT

RESEARCH IS OUR RESOURCE:
SURVIVING EXPERIMENTS AND POLITICS AT AN AFRICAN CANCER INSTITUTE,
1950 TO THE PRESENT
Marissa Anne Mika
Steven Feierman

This dissertation is a historical-ethnography of the Uganda Cancer Institute. In the 1960s, the Institute was a small chemotherapy clinical trial facility established through a joint partnership between Ugandans and Americans. Today it is the only site of public oncology goods in the Great Lakes region of Africa. 60 beds serve a catchment of 40 million people. New research partnerships to examine HIV and cancer aim to transform this site from a dilapidated research enclave into a “center of excellence”. To understand this transformation, I place African health workers and physician-researchers at the center of this story, and examine their political and medical labor in maintaining an African cancer hospital, decades after initial outside support evaporated. I do this by tracing the ways in which cancer research and care continued throughout several periods of profound transformation—Independence (1960s), Idi Amin’s dictatorship (1970s), civil war (early 1980s), structural adjustment (1980s-1990s), and the HIV epidemic (1980s to now). I argue that throughout these crises, Ugandan physician-researchers creatively secured equipment and drugs to maintain oncology services by making
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PREFACE: A Week in the Life of the Uganda Cancer Institute

Roughly 8,000 miles separate Kampala and Seattle. In a pressurized aluminum tube, it takes over 24 hours to travel from Entebbe International to Sea-Tac. The dark winters of the chilly Pacific Northwest are a sharp contrast to the equatorial stability of days and nights by Lake Victoria, where the cycle of rainy seasons signal the passing of the years. There is the time difference. As people take their morning coffee and search for an umbrella or all weather jacket to get out the door often by foot or bicycle or bus, Kampala residents are getting into their cars, or onto the backs of motorcyclies, or crowding into minibus taxies to face the long ride home in “the jam” for a dinner of steaming soft bananas and sauce.

In Seattle, Washington, one of the photographs hanging on the wall of a cancer research specialist who has spent much of 2004 to 2015 dividing his time between Seattle and Kampala is a sweeping portrait of Kampala’s Old Taxi Park. This Taxi Park is located in the heart of the city bowl. He keeps the photograph of the taxi park up on his wall as a reminder. It is a reminder that gridlock, chaos, and rainy downpours that can ground the entirety of Kampala’s public transportation networks for hours on end do have an organization unto themselves. Taxi conductors, standard routes, fixed prices, specific minibus taxi stages, and an army of repair men ready to install the best counterfeit Taiwanese versions of genuine Japanese spare parts all make the taxi system in the capital city work on a day to day basis. For this American researcher, the logic of the taxi park is analogous to the
logic of the way the Uganda Cancer Institute works—there is a system, largely invisible to outsiders, that makes things work. At the Uganda Cancer Institute in 2012, domestic rituals—washing, cooking, cleaning—and medical rituals—ward rounding, drug administration, emptying beds—merge to create a daily and weekly temporal rhythm, an order of operations that staff and patients can fall back on in the midst of either medical emergencies or the boredom of waiting.

This is a dissertation about how and in what ways Ugandans adapted medical research initiatives on cancer in the country over the past fifty years to meet the needs of patients and caretakers. It is also a story about the work of Ugandans and international researchers to make two very different worlds commensurable. Before telling this story in detail, I offer this small interlude as an effort to close that distance between you, the reader, and Kampala, by introducing you a week in the life of the Uganda Cancer Institute, as I encountered it in 2012.

On Monday mornings, by the main entrance to the Lymphoma Treatment Center, approximately 40 to 60 outpatients sit quietly on hard wooden benches, lab request papers crinkling in palms, and you can hear the quiet sipping of steaming hot chai tea. The silence is only periodically broken by the lab technician, wearing his white coat and glasses and a warm smile, calling out for Mzee to get his blood drawn. D is all business as he says, “Come inside, please. Come inside.” 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 (CBC) machine allows him to keep an intimate connection between the samples he is testing and the people he is serving. He does not want to let the patients down.

Later in the morning, 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 in Luganda) fill the space, as do the consoling murmurs of the nursing staff, “sorry, sorry, sorry.”

Plates, cups, and forks clatter and clang around one pm, and families shuffle outside to the kitchen area to line up for posho and beans—the one free meal of the day. Patients and caretakers hum and chatter in various languages—Luganda, Acholi, Itesot, Runyankole, Lugbara, Lusoga, and even a smattering of Swahili\(^1\) swell and amplify in the line up, eagerly talking in anticipation of eating. And then, an eerie quiet falls, a deadly calm as people take 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.

---

\(^1\) Swahili is a *highly stigmatized* language in Uganda, particularly in central Uganda.
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 5pm, a chorus of car engines fire up in the parking lot adjacent to the Lymphoma Treatment Center, 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 BL is an EMERGENCY.” Dr. J, the newly appointed pediatric oncologist, intervenes and says “We are taking care of it. The child is on the BL 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 9am and 11am, and can go until 5pm in the evening, depending on how late they started and
depending on 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, beds 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. F, as we move several inches from bed to bed.

As a student in secondary school, Dr. F was fascinated by biology and his
favorite part of class was the frog dissection. He used to carefully dissect frogs apart
and then attempt to stitch them back together, with the hope that he would at some
point manage to reanimate them. Nothing fazes Dr. F. 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 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 where they learn how to do lumbar punctures and manage emergencies. Dr. F’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 Wednesdays, but really on any day of the week at the UCI, 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,” taking turns pushing one another in a smart red wheelchair recently donated by a Christian organization up and down the patch of grass directly outside of the ward. They collapse into hysterical giggles every time the chair comes to a complete halt. The “Mamas,” the ten or so ladies who cannot afford to travel between treatment cycles for their patients congregate in the back kitchen area and laugh 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 8am. They are days for catching up on writing and paperwork, for doing fast “business” ward rounds, 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 Lymphoma Treatment Center 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 Outpatient ward, waiting for the doctor, be it Dr. J or Dr. F or Dr. A or Dr. N, to reach his or her name in the thick stack of 40 patient files that each of the doctors are expected to power through on an outpatient clinic day.

In the public chemotherapy administration room, thankfully a breeze is 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 and provides cover for pickpockets and thieves at the bus parks, all so they can make the treacherous 200 plus kilometer night bus ride home. It is hard to say what is worse--vomiting into a Katanga cloth the whole way as the bus races over potholes and dodges goats crossing the highway, or the prospect of a head on collision, or harassment from the state police at a nighttime road-block as they look for bribes. Like the Lymphoma Treatment Center ward on a chemotherapy afternoon, this administration room, with its six plastic chairs and shared IV poles, goes through 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 staid morning service at Namirembe or
Rubaga cathedrals, for the Protestants and Catholics, respectively. And on a Friday,
as some of the nurses shed their uniforms and put on their Kampala clothing worthy
for the streets, some Muslim headscarves appear, beautiful shimmery pinks and
yellows, covering well coiffed heads of cornrows or braids, as they get ready for the
loud and long call to prayer of Fridays. During Ramadan, the Muslim nursing sisters
fast even during the day shift, feeling “so holy” as they do their work without water
or food.

For the patients and their caretakers who are staying at the UCI for the
weekend or for a month or for 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 horns and the smell of corn being grilled on the side of the road greet you, reentering the city.
INTRODUCTION: Surviving Experiments and Politics

The Freezer Graveyard

The Uganda Cancer Institute stands at the top of the hill at Mulago National Referral Hospital in Kampala. The Institute itself was founded in 1967 through a joint venture with the American National Cancer Institute, 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 and Solid Tumor Center, were designed to provide space for clinical trials of chemotherapy 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

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\(^2\) “Uganda Cancer Institute Annual Report, 1970-1971,” Uganda Cancer Institute Archives. Over the course of 2012, I was granted unrestricted access to the Uganda Cancer Institute’s institutional archives and patient records dating back to the 1960s. 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 am grateful to the entire staff of the Records department for kindly accommodating my work. The Uganda Cancer Institute’s archive has no formal cataloging system. These records are housed in a dusty room full of bundles tied up in twine. The only organizational system I was able to structure for this archive was my own, through photographs and digital time stamps. Photographs of the archive are in my possession, and the possession of the Uganda Cancer Institute.

Uganda in a military coup in 1971, the American staff left, but put a Ugandan oncologist, Professor Charles Olweny, in charge of the facility. Ugandans continued to do serious cancer research during a decade of profound economic instability and mercurial violence. 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. Over the course of the HIV/AIDS epidemic, the Institute developed a reputation as “the place where you were sent to die.” At the same time, Mbidde maintained 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.

In 2004, the Uganda Cancer Institute’s director, Dr. Mbidde, welcomed a new

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6 Interviews conducted with various Uganda Cancer Institute Staff, 2012.

7 One of these key collaborations was with colleagues at the University of California, San Francisco. See, for example, Susan Desmond Hellmann and Edward Katongole Mbidde, “Kaposi’s sarcoma: recent developments,” AIDS 5 (1991): s135-s142.
visiting American researcher interested in the possibility of collaboration. This researcher, an infectious disease expert, was interested in starting a collaborative project at the Institute focusing on the role of viral infections in causing cancers. This researcher knew from data generated by the Kampala Cancer Registry, which was established in Uganda in the 1950s, that the Institute saw many patients with Kaposi’s sarcoma, cervical cancer, Burkitt’s lymphoma, and liver cancer. All are cancers associated with infections and particularly prevalent in patients with HIV/AIDS.\(^8\)

The last stop on the tour was the Institute’s outpatient facility, a former dental surgery unit. At the time, it had no running water or electricity, but it did have plenty of plump, Kampala-sized rats.\(^9\) Behind one of the doors of this shell of a building was a room full to the brim with old equipment, freezers, and refrigerators. Someone had painstakingly carved the acronyms of partnerships into these individual pieces of equipment. Some of these freezers dated back to the 1960s, when they were first brought to Kampala by American scientists to store the tissue samples of Ugandan cancer patients before they were shipped to the National


\(^9\) Rats have long elicited disgust and public health eradication efforts in Kampala. See Meghan Vaughan, Curing Their Ills (Palo Alto: Stanford University Press, 1992), 42-43.
Cancer Institute on dry ice. Other refrigerators stored vials of Adriamycin for liver cancer treatment trials conducted at the Institute in the 1970s. In the midst of violence and war in Kampala in the early 1980s, student medical officers kept these freezers and refrigerators running, pouring diesel into generators in between episodes of gunfire exchanged by soldiers and rebels.\textsuperscript{10} This room was a mausoleum for research collaborations past.\textsuperscript{11} After opening the door, the Institute’s director gave his guest a moment to take in the scene, and then asked if he would be leaving another abandoned freezer in a dilapidated building. Would this be the legacy of this proposed research venture between the Uganda Cancer Institute and the Fred Hutchinson Cancer Research Center?\textsuperscript{12}

The visiting researcher took the freezer graveyard seriously. As Corey Casper remembers, “My first thought was, ‘What makes you think you could do anything better?’ My second thought was, ‘What if your legacy in working here was more than just another rusty freezer?’”\textsuperscript{13} Since 2004, the Fred Hutchinson Cancer Research Center in Seattle has poured over $10 million into rehabilitating the infrastructure of the Uganda Cancer Institute and training a new generation of Ugandan

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\textsuperscript{10} This description of the inventory of the freezer graveyard is drawn from fieldnotes from discussions with Corey Casper in 2012, and Interviews: Vicki Mujuzi, March 2012, Alex Coutinho, April 2012.
\textsuperscript{12} This anecdote is drawn from fieldnotes and several conversations with Corey Casper in 2012 and 2013.
\end{flushleft}
oncologists. Ten years ago, there was one Ugandan oncologist. As of 2015, there are eleven Ugandan oncologists practicing in the country. In 2009, the Ugandan Ministry of Health granted the Institute institutional and fiscal autonomy, dramatically increasing its budget chemotherapy drug procurement and staffing. The number of patients has increased from about 500 a year in 2004 to about 40,000 patients a year. Most patients are coming with late stage illness. Most patients die within their first year of treatment. The crowning achievement of the Fred Hutch-UCI collaboration is a new outpatient and cancer research facility, which is designed to see about 20,000 patients a year and opened in May 2015.

The combination of more Ministers of Parliament getting cancer and the visibility of a long-term partnership between the Uganda Cancer Institute and the Fred Hutchinson Cancer Research Center has helped to politicize oncology services. In the past ten years, the UCI has 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 Ugandan government recently completed a five story in-patient cancer hospital, which still needs an injection of about $6 million worth of furniture and medical equipment to be fully operational. These

14 Interviews: Jackson Orem, July 2012. See also Mary Engel, “Building a legacy of hope”.
15 Ibid.
17 Fieldnotes, May 2015.
investments in public oncology and cancer research infrastructure in sub-Saharan Africa are unique. There is no other site on the continent with the depth or breadth of publicly available cancer services, such as they are.\textsuperscript{18} The UCI now serves a population catchment of approximately 40 million residents in the Great Lakes region of Africa.\textsuperscript{19}

For the past fifty years, Uganda served as “Africa’s living laboratory” for producing knowledge about cancer in sub-Saharan Africa.\textsuperscript{20} Many international medical research collaborators, starting with the British Empire Cancer Campaign and the American National Cancer Institute, came to Uganda since the 1950s to study cancers in Africa. But these international collaborators come and international collaborators go. It was and is ultimately Ugandans who keep these experiments going, freezers operating, and provide care to patients with late stage cancers on the wards of the Uganda Cancer Institute long after international colleagues leave and funding ends. In short, there is a fundamental dynamism to medical research and health care infrastructure for cancer in Uganda, a reflection of the broader landscape of healthcare in sub-Saharan Africa in the 20th century.\textsuperscript{21} Focusing on the

\textsuperscript{18} For a discussion of the overall state of cancer services in Africa at roughly the time of this dissertation’s publication, see “Cancer Control in Africa,” \textit{The Lancet Oncology} 14 (2013): 277-e195.
\textsuperscript{19} These estimates come from the Uganda Cancer Institute’s current director, Jackson Orem.
\textsuperscript{20} Helen Tilley, \textit{Africa as a Living Laboratory} (Chicago: University of Chicago Press, 2010).
\textsuperscript{21} There are several recent and excellent edited volumes on the history of medical research and public health infrastructures in Africa. See: Wenzel Geissler, ed. \textit{Para-States and Medical Science: Making African Global Health} (Durham: Duke University
history of the Uganda Cancer Institute, this dissertation traces the history of the
dynamism of health care infrastructures, and focuses on the ways in which Africans
shape these infrastructures. Incorporating insights from science and technology
studies, I argue that oncology’s tools and systems were transferred to Uganda
through practices of medical research and experiments in the 1950s and 1960s.\textsuperscript{22} I
show how global research partnerships create and shape local contexts of
biomedical care long after initial partnerships themselves end. I treat the Uganda
Cancer Institute both as a microcosm of the Ugandan state and as a way to explore
the Africanization of biomedical research in the 20\textsuperscript{th} century.\textsuperscript{23} I focus on how and in
what ways African physicians, patients, caretakers, laboratory technicians, nurses,
and even politicians worked to Africanize cancer research and care. I ask how
international medical research projects shape the provision of care in the Ugandan
context.

\textsuperscript{22} On the history of technology transfer in Africa, see Daniel R. Headrick, The Tools of
their use in everyday life, see David Arnold, Everyday Technology: Machines and the
Making of India’s Modernity (Chicago: University of Chicago Press, 2013); David
\textsuperscript{23} See John Iliffe, East African Doctors (Kampala: Fountain Publishers 2002);
Kenneth Ombongi, “The Historical Interface between the State and Medical Science
in Africa: Kenya’s Case,” in Wenzel Geissler and Catherine Molyneux eds., Evidence,
Ethos and Experiment: The Anthropology and History of Medical Research in Africa
The entanglement of biomedical services and practices of experiment is a longstanding dynamic in the history of the establishment of biomedical institutions throughout sub-Saharan Africa in the 19th and 20th centuries. These entanglements include sleeping sickness treatment camps, sexually transmitted disease camps, missionary medical experimentation, maternal health care, HIV/AIDS care and research, malnutrition research, and of course tuberculosis research and care. Adriana Petryna has demonstrated that the pharmaceutical industry’s hunger for research subjects for clinical trials has led to a proliferation of experimental sites across the globe, where cutting edge biomedical research enclaves are established alongside atrophied or nonexistent public health care facilities. Africanist anthropologists such as Johanna Crane suggest that this is also a contemporary trend across sub-Saharan Africa, where there is a scramble for research subjects for the study of infectious diseases and HIV/AIDS. But this latest “scramble for Africa” and the rise of global health, is part of a much longer history of biomedical research and care on African populations in central Uganda. Over the past century,

biomedical services for the Ugandan population were offered at Mulago Hill often through the practices of experiments and research on issues such as venereal diseases, yaws, malnutrition, tropical maladies, and ‘diseases of civilization’ such as heart disease and cancer.28

In addition, this booming biomedical research enterprise in sub-Saharan Africa poses real dilemmas for the management of the “mileage between hunger and wealth” in “resource poor” settings. 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, often poor, research subjects congregate for care are often dilapidated. In eastern and central Africa, many of these public health care infrastructures have not been seriously “modernized” since they were modern in the 1960s. 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, especially in sub-Saharan Africa. I use the term experimental infrastructure to describe the constellation of physical facilities, research questions, care practices, data collection procedures, and

human labor that make up the biomedical research enterprise. The Uganda Cancer Institute is, in and of itself, an experimental infrastructure. It is unique in that it provides a continuous fifty-year historical case study of precursors to “global health,” the ebb and flow of international research partnerships, and the dynamics of scientific inquiry in sub-Saharan Africa.

While this dissertation is situated at an Institution, the focus is on the creative political and social work of African researcher-physicians themselves. I examine the intellectual work of these Ugandan physicians as they make a case that “research is our resource.” I argue that these actors transform and adapt the tools of oncology initially brought to Uganda for medical research purposes and expand the mandate of this research enclave to provide cancer care. In short, they Africanize oncology. I show how four distinct generations of Ugandan physician-researchers navigate not only cancer in the clinic, but also the malignant politics of the postcolonial state over distinct time periods— independence (1960s), Idi Amin’s dictatorship (1970s), civil war (early 1980s), structural adjustment (1980s-1990s), the HIV epidemic (1980s to now), and Museveni’s NRM government (1986 to now). I argue that these physician-researchers exercise creativity in crisis, be it straddling

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the demands of treating late stage tumors and remaining viable to the international
oncology research complex, or bribing Idi Amin’s state police.

“Research is Our Resource,” is the Uganda Cancer Institute’s current slogan and the title of this dissertation. At the UCI, “Research is Our Resource” is a strategic invocation of the Institute’s long history as a cancer research facility. Most Ugandan government facilities have mottos or slogans. Kampala City Council Authority’s official motto is “To Be a Better City”. “For God and My Country” is the Ugandan state’s slogan, officially commissioned upon independence in 1962. In Uganda, these catch phrases are rarely just words. They are a formality in a national context where virtually every organization and government body has a motto.

“Research is Our Resource” encapsulates institutional pride. This phrase is on signs welcoming visitors and patients to the UCI from lower Mulago Hospital. It is printed in shiny blue brochures along with the organization’s vision: “To be an internationally recognized center of excellence advancing comprehensive cancer management in Africa.”

By framing research as a resource that can be tapped and utilized, Jackson Orem and his colleagues are gesturing to the contemporary landscape of medical

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30 In using Research is Our Resource as the title of this dissertation, I take the multiple meanings ascribed to the slogan by colleagues at the Uganda Cancer Institute seriously and also secured permission from the Institute to use this phrase, under the condition that I explain where the phrase comes from and attribute it to the Institute.
31 Interview: Jackson Orem, July 2012.
Research and development partnerships in the country.\textsuperscript{32} The “public-private partnership model” shapes many investments in infrastructure and services in contemporary Uganda. “Research is Our Resource” is suggestive of a scenario wherein research conducted at the Institute can bring more resources for cancer, as has been the case over the Institute’s fifty-year history. Some examples—research at the Uganda Cancer Institute generated knowledge about the curability of cancer with cytotoxic agents alone in the 1960s and the 1970s. In the 1980s and 1990s, the 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 research.\textsuperscript{33} This message is intended for two audiences. One is the Ugandan government. The data that can be generated from the bodies and cancers treated at this site can shape local cancer control policies. The other key audience this slogan speaks to are internationally based

\textsuperscript{32} They are also gesturing more generally to a common feature of the provision of biomedicine in sub-Saharan Africa today, that by opening field sites and study populations up to international partners, African physician researchers can access therapeutics, technologies, and built infrastructures that cannot be secured through local government channels alone, either due to the issue of prohibitive costs or a more general question of who is responsible for setting the priority agenda. Again, see Johanna Crane, \textit{Scrambling for Africa}; Adriana Petryna, \textit{When Experiments Travel}; Betsey Brada, \textit{Botswana as a Living Experiment}, (PhD Diss. The University of Chicago, 2011).

\textsuperscript{33} These are the institutional highlights often presented in tours of the Institute and celebrations. Mika Fieldnotes, October 2011, February 2012, July 2012, May 2015.
scientific partners looking for attractive sites to conduct research.34

Writing Histories of Uganda

The Institute’s historical legacy as the original site of sustained cancer research in East Africa and indeed, most of sub-Saharan Africa, was an ongoing subject of celebration when I conducted my research. At the same time, during the period I worked at the Uganda Cancer Institute from 2010 to 2015, history was literally being torn down. The Institute’s original building, the Lymphoma Treatment Center, was torn down to accommodate a new “state of the art” outpatient care unit, laboratory, and training facility. Funds from the Fred Hutchinson Cancer Research Center in Seattle, Washington, the United States Agency for International Development, and the Ugandan government made it possible to build this facility and usher in a new era at the Institute. The Ugandan government also built a six-story inpatient cancer hospital. It stands at the very top of Mulago hill, a several hundred-foot walk from the original Institute. These new buildings were the physical manifestations of new investments in both cancer care and research in the country—investments in cancer that have not been seen in

34 Corey Casper, the current co-director of the Fred-Hutch Uganda program is a case in point. He originally came to Uganda in 2004 looking for enough HIV positive Kaposi’s sarcoma patients in order to do research on HHV-8. See Joanne Silberner, “Seattle Doctor Takes Cancer Treatment to Developing World,” KUOW.org May 27, 2015, Accessed August 1, 2015, http://kuow.org/post/seattle-doctor-takes-cancer-treatment-developing-world
Uganda since the late 1960s.\textsuperscript{35}

This dissertation joins both a growing body of scholarship on Uganda in the 20\textsuperscript{th} century. The research and writing between 2009 and 2015 occurred during a period of increased national reflexivity 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, which has been in power since 1986, brought relative economic prosperity and political stability to Uganda. NRM leaders in particular use this simple 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.”\textsuperscript{36}

\textsuperscript{35} Indeed, these are public investments in cancer services and infrastructure that are all too rare in sub-Saharan Africa. For a general overview of the state of contemporary cancer care services in sub-Saharan Africa, the special issue “Cancer control in Africa,” \textit{The Lancet Oncology}, 14 (2013): 277-279, e142-e195. For an astute historical assessment of why cancer resources are so thin on the ground in Africa, see Livingston, “Neoplastic Africa,” in \textit{Improvising Medicine}, 29-51. For an ethnographic account of public oncology services in neighboring Kenya, see Benson Mulemi, \textit{Coping with Cancer and Adversity: Hospital ethnography in Kenya}, (Leiden: Africa Studies Centre, 2012).

This celebration of fifty years of independence—the Golden Jubilee—created a public space for national reflexivity 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, much more.

The flurry of public story telling was a marked departure in a context where there are very few sites of public commemoration for Uganda as a nation. One of the few enduring markers celebrating Uganda’s independence in October 1962 is a concrete statue of a woman hoisting a child high up into the air. The independence monument, designed and executed by the sculptor Gregory Maloba, stands on Nile Avenue, at the top of a flight of steps that back into fence that today marks the grounds of Kampala’s Sheraton Hotel.\footnote{To commemorate the Commonwealth Heads of Government meeting in 2007, a mural of Uganda’s historical past was painted on}
this fence to celebrate. The mural starts in 1900 with the kingdom of Buganda, complete with a depiction of the Kabaka and historic tombs. From Buganda, the mural depicted colonial governance, including what appeared to be signing documents and agreements, World War II, political party struggles in the 1950s and early 1960s, and the raising of the Ugandan flag in 1962 and the lowering of the Union Jack. 1962 to 1986 is just a puff of billowing, grey smoke from fighting and violence, with a soldier stepping on a bleeding, barely clad corpse. The only Ugandan president depicted in the mural is Yoweri Museveni, pictured in army fatigues and reading his inaugural speech in 1986. From there, the mural paints a picture of merry Africa, with Ugandans returning to coffee cultivation, young children going to primary education, a Ugandan businessman striking a real estate agreement with a muzungu (or white person) in sunglasses and a pink suit, and a petrol tanker barreling through customs. The final scene is dancing and drumming outside of a home in a banana garden. The mural ends with the CHOGM 2007 logo of a crested crane in Ugandan colors and the globe.

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38 Buganda refers to a large and historic kingdom that still exists and has a vibrant political life in modern day central Uganda. It is situated at the northwestern and northern shores of Lake Victoria, extending into the interior of the country to towns such as Luweero, Masaka, Rakai, Mpigi, and the like, not to mention the city of Kampala. The kabaka, or king, plays a prominent role both in contemporary Buganda as a figure of the kingdom and moral authority. In the early 1900s, the Baganda (the people of Buganda), offered hospitality to British colonial authorities. Luganda, the language of the Baganda, also has a long and complicated history of use and appropriation. Today the language most frequently used on Kampala streets is Luganda.
The monument was, according to Ugandan radio commentator David Rupiny, “darkened and stained with the vagaries of weather portraying a sorry sight. The CHOGM paintings depicting Uganda’s history are peeling off. The tarmacked ground has developed potholes while the grass around are scanty. People walk past the monument oblivious of its importance as two lonely policemen keep watch.” Just before the Golden Jubilee celebrations of Uganda’s 50 years of independence, the mural behind the independence monument was itself erased, the grey smoke of thirty years of lost history followed by prosperity and rebirth returned to neutral white. It is a shame, because in several hundred feet, this mural summarized a remarkably durable and standardized version of Uganda’s history as told by the National Resistance Movement. Festive Ugandan flags of black, gold, and red were strung up along Nile Avenue instead. With the milestone of fifty years of independence, and nearly 30 years of NRM governance, Ugandan citizens are beginning to ask what’s 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.

39 Independence Monument Refurbishments Starts a Week To Celebrations http://ugandaradionetwork.com/a/story.php?s=46046
Historians of Uganda’s past are benefitting from this turn to national reflexivity, thanks in part to an unprecedented transformation in the availability of documentary sources in the country.\textsuperscript{41} The political and economic realities of Uganda since independence have profoundly shaped the topography of archives and access, the practicalities and safety of conducting prolonged periods of historical and ethnographic fieldwork, and the kinds of research questions one might ask about Uganda in the 19\textsuperscript{th} and 20\textsuperscript{th} century. The overall condition and accessibility of Uganda’s archives, in contrast to other former British colonies such as Kenya, Tanzania, and Ghana, was, for several decades, largely unkempt. Uganda’s national archive, currently located in a basement of a government building in Entebbe, did not have a complete and accessible catalog until 2011. Several initiatives to catalog district archives in Jinja, Hoima, and Kabale are underway.\textsuperscript{42}

The disarray of Uganda’s government archives has shaped the terms of historiography and debate in the country. By far the most developed historiography on Uganda focuses on the kingdom of Buganda, where British colonial archives, the collections and publications of colonial era anthropologists, missionary archives, Ugandan Protectorate documents printed in triplicate, and Makerere University


\textsuperscript{42} Derek Peterson, Personal Correspondence. Peterson and his colleagues at the University of Michigan, colleagues at the Makerere Institute of Social Research, and partners at the Uganda National Archive are the chief architects of this transformation, and they deserve great thanks and appreciation.
library holdings offer a rich documentary landscape for understanding debates about land, politics, and ethnicity. For historians of colonial medicine in Africa, Uganda is a site of considerable interest. It is home to East Africa’s oldest and most important medical school and teaching hospital, Makerere Medical School and Mulago National Referral Hospital. The Church Mission Society and Albert Cook’s Mengo Hospital also offer a window into the practices and anxieties of missionary medical approaches to venereal disease, yaws, and sleeping sickness from 1880 to 1950. Excellent sources from British Colonial Medical Officers located at the Rhodes House, Birmingham’s Church Mission Society archives, and Albert Cook’s medical records in both Uganda and at the Wellcome Library in the United Kingdom have all provided the context for a rich engagement with histories of colonial medical research in Uganda. With the increasing accessibility of new archives and relative political stability, colleagues are now turning their attention to political, economic, social, and cultural life in colonial and postcolonial Uganda in an effort to move beyond the prism of historic kingdoms or popular accounts of life falling apart under Idi Amin.

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44 For a discussion of these sources, see Iliffe, *East African Doctors*.

45 In addition to the published works previously mentioned, there is a remarkable group of graduate students doing their dissertation research on twentieth century
The Hospital as Microcosm of the Ugandan State

*Research is Our Resource* joins this growing body of scholarship on modern Uganda. I use the vantage point of a cancer hospital to understand the lived experiences of Ugandans in the 20\textsuperscript{th} century. Rather than using ethnicity or high politics or a single disease category like HIV/AIDS to reconstruct the history of Uganda since independence, I focus on this institution, the cancer hospital, which allows us to see how national identity, political violence, epidemics, and economic life were entangled with one another.\textsuperscript{46} This approach is possible because of a rich evidence base, which uses patient records, oral histories, private papers from US oncologists, American National Cancer Institute records, British colonial office reports, and even the built architecture of the Institute itself.

The Uganda Cancer Institute’s history maps onto critical political events since Uganda’s independence in 1962. The Institute provides a window for understanding how and in what ways a cadre of Ugandan physician scientists, nurses, laboratory technicians, peasant farmers, and indeed cancer patients navigated the ups and downs of political, economic, and social life in Uganda since independence.\textsuperscript{47} Some examples. The Institute itself was founded shortly after

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\textsuperscript{46} This methodological approach is inspired by classics such as Charles Rosenberg, *The Cholera Years* (Chicago: Chicago University Press, 1962). See also Mark Hunter, *Love in the Time of AIDS* (Bloomington: Indiana University Press, 2010).

\textsuperscript{47} See Veena Das, *Critical Events: An Anthropological Perspective on Contemporary India* (Oxford: Oxford University Press, 1997) and the way historian Lynn Thomas...
Milton Obote consolidated power by abolishing the historic kingdom of Buganda among others, and declaring himself President in 1966. While situated in central Uganda and the heart of Buganda, the Uganda Cancer Institute’s mandate was national in scope and the patients it recruited for research trials and treated came from all over the country. It is not insignificant that the Uganda Cancer Institute 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. Idi 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. The violent punctuation of the Tanzanian war of liberation in 1979 turned

invokes critical events as a way to engage with African history in Politics of the Womb: Women, Reproduction, and the State in Kenya (Berkeley: University of California, 2003): 6-9. I am choosing to refer to the period of Uganda’s history since 1962 as the time since Ugandan independence. This is how colleagues and the popular press alike in Uganda write, speak, and describe the time after the end of British Protectorate rule on October 9, 1962. Describing this period as “postcolonial,” while appropriate in an academic intellectual setting, does not ring true with the vernacular Ugandan English description of Uganda’s recent past. For more on celebrations of Ugandan independence, see James Magara, Uganda Jubilee Handbook 2012: Commemorate. Celebrate. Contemplate. (Kampala: New Life Publishers, 2012).


Interview: Avrum Bluming, February 2015.

Interview: John Ziegler, June 2012. British National Archive File
Mulago hospital into a war hospital. Institute staff dodged bullets to attend to night emergencies. In Museveni’s Uganda, the current renaissance at the Uganda Cancer Institute is in part a reflection of a broader culture of public-private partnerships, which dominate development initiatives in the country today. The stories of living, dying, and caring on the wards of the Uganda Cancer Institute offer a window into everyday life in modern Uganda, and they are more often than not stories of survival—surviving both politics and experiments.

Historians of 20th century Africa are increasingly turning their attention the role of intermediaries, middle figures, and cultural brokers, as well as the politics of Africanizing bureaucracies, institutions, and commerce. This dissertation follows this lead, highlighting the ways in which Ugandan medical officers, administrators,

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52 As Iliffe argues, Uganda in the 1970s was a “disintegrating state,” and this could be seen quite clearly at Mulago, where “Its [Mulago’s] piped water supply broke down in 1974 for a decade. The mortuary’s refrigeration system was out of action from 1975 and sewerage ceased to function at about the same period. [...] At that time [1978] not one of the hospital’s twelve X-ray units was functioning. [...] Yet they kept the hospital functioning,” in Iliffe, East African Doctors, 147.

53 Interview: David Serwadda, July 2012.


physician-researchers, patient caretakers, nurses, laboratory technicians, and others transformed the Uganda Cancer Institute from an experimental research outpost into a site of the provision of public oncology services. I argue that this labor required creatively working within, around, and in spite of the state to continue the work of researching and treating malignancies after international support and sponsorship waned.

Drawing inspiration for historians of health and healing in Africa who have highlighted the pivotal role of public healers in maintaining social and political order in pre-colonial 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.\textsuperscript{56} Mitigating malignancies relies on care, political creativity, 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, in a sense, “physician intellectuals.”\textsuperscript{57}

\begin{footnotes}
\footnote{Ibid.}
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Malignant States: Bodies and Politics

One of the core arguments of the dissertation is that Ugandans at the Institute have all contended not only with malignancies on the wards but “malignant politics.” Years ago, Jean Francois Bayart brought our attention to the “politics of the belly” as a way to understand African politics in the 20th century. Bayart argues that African political order can be understood through the lived reality of hunger and wealth. That is, there is a literal and visceral quality to wealth and power in sub-Saharan Africa—wealth often connotes being well fed. The politics of the belly are also a way of describing the accumulation of wealth by politicians who consume resources, material goods, donor contributions, and people.58 Thinking about political life in Uganda from the vantage point of a cancer ward, where cancer itself greedily consumes bodies and National Medical Stores employees greedily consume bribes to accept substandard cancer drugs, these connections between malignancies in bodies and the malignant tendencies of the state become difficult, if not impossible, to ignore.

The texture and substances of “malignant politics” also changed over time in Uganda. For Charles Olweny, coping with malignant politics meant navigating the

times of Idi Amin, where the state seemed to be literally eating itself from the inside out, on account of corruption, violence, and disintegrating infrastructure. As we will see, in the 1980s, 1990s, and 2000s, Edward Mbidde often found himself in the position of navigating the politics of international research collaborations, particularly who would ultimately benefit from the data produced from Ugandan patients at the Cancer Institute. Today, Jackson Orem works in a context where there appears to be unmitigated, relentless growth—the Ugandan economy is rapidly growing, Kampala city is booming, and it seems that there are more and more Ugandans and East Africans seeking care for their cancers on the wards of the UCI. At the same time, there is a collective national discourse about the problem of corruption as a major force in contemporary Uganda, that greed and a propensity towards graft is eating the promise of a peaceful and prosperous nation from the inside out.\footnote{Godfrey Asiimwe, “Of Extensive and Elusive Corruption in Uganda: Neo-Patronage, Power, and Narrow Interests,” \textit{African Studies Review} 56 (2013): 129-144.}

The malignant politics and conducting scientific research were often entangled at the Institute. As one UCI staff member said, “This was a scientific unit. Not political at all.”\footnote{Interview: A, February 2012.} And yet politics, both within the Parliament of Uganda and within the meeting rooms of the National Cancer Institute in Bethesda, shaped the realities of providing care and conducting science profoundly at the Institute from its inception to the present. Take the story of one of the Uganda Cancer Institute’s
administrators in the 1970s. A was a clinical officer at Mulago Hospital in the 1960s. The Uganda Cancer Institute hired A and several others to do follow up with patients and families who were treated at the Institute, as well as patient recruitment in villages across Uganda. In the early 1970s he worked in the UCI’s administration, where he was often on the front lines of dealing with soldiers, greasing the purchase of food and transportation with small bribes, and even handing over small money in order to have the mail delivered. As he put it, “politics came in forcibly.” In the wake of the raid on Entebbe in 1976, A helped one of the Ugandan physicians who had cared for Dora Bloch at Mulago to flee the country, and it became clear that he would also have to leave Mulago for his safety. In 1977, “Fortunately I moved out of Kampala and deep into the village. Don’t join any political spheres. Don’t go anywhere and just keep quiet. Many people have lived that sort of life in Uganda up to date. And there are many here in that sort of exile. [. . .] Put endeavor into coffee and forget the American life. Almost giving up and forgetting Christianity and staying at home. And survive.”

In this dissertation, I take politics as a broad category. The politics discussed here span from the macro events of coups and cleavages to the micro negotiations between bureaucrats or the in-fighting between scientists. I also want to note that in oral histories with staff at the Institute, the ripples critical political events were

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61 Interview: A, February 2012.
often experienced as secondary or tertiary to the pressing needs of patients and their families on the cancer ward. The realities of working at a cancer research hospital where the extreme oscillations of the conditions of patients both from cancer and the side effects of treatment also shaped the culture and texture of medical labor and scientific research at the Institute. Most often, “politics” sculpted the context of everyday life with regards to scarcity of basic supplies and bodily insecurity, making it all the more challenging to attend to the shattering lows of oncology’s healing and harming arsenal and frightening and fleshy discomfort of late stage tumors. While these connections between politics and tumors are visible and striking, I want to avoid making linkages between cancer and the state that are too facile. Rather, the question here is how the oncologist engages in political as well as medical labor as he (and now she) battle two kinds of malignant states—those found on the cancer ward and those within postcolonial Ugandan governance itself.

By focusing on the creative political work of Africans as they navigate the extreme oscillations of political, economic, and social orders since the 1940s, I aim to complicate the binary of pessimism and optimism that dominates discussions of Africa since independence. On the one hand, there is an overly pessimistic narrative about Africa since 1940. The short argument is that opportunities at independence were quickly foreclosed, and that independent Africa is characterized by limited economic development and state failure in the 1970s, 1980s, and early 1990s.63

63 The literature articulating the failures of the African state since independence is vast, but the language about the foreclosure of promise is taken from Fred Cooper, *Africa Since 1940*, 91-132. I should also note that Cooper’s discussions of Africa since
Others argue that the continent is undergoing a profound renaissance, pointing to economic growth in a neoliberal order and the democratic triumphs of countries like South Africa. The history of the Uganda Cancer Institute helps to collapse this binary, and examine what Patrick Chabal calls “the politics of suffering and smiling.”

**Global Oncology and Global Health**

In addition to providing a fine grained account of the lived realities of politics in twentieth century Uganda, this dissertation also situates the rise of “global oncology” in a much longer history of colonial medicine, international health, and the rise of global health. Over the past decade, scholars have increasingly turned their attention to critically engaging with the rise of “global health,” defined by Paul Farmer as a “collection of problems [...] ranging from epidemics (from AIDS to


polio to noncommunicable diseases) and the development of new technologies
(preventatives, diagnostics, treatments) to the effective delivery of these
technologies to those most in need—[that] all turn on the quest for *equity* [emphasis
original].”

Global health, while still loosely defined more as a set of problems and
concerns than a particular discipline, is framed by some as a departure from
“International health”—efforts in the 19th and 20th centuries aimed at disease
control and eradication schemes often situated in what we would term today as the
Global South or developing world. Upon its founding in the wake of World War II,
the World Health Organization became an arena for defining international health
priorities and working with nation states to implement disease eradication schemes
particularly in the areas of malaria, smallpox, and polio. These “vertical” health care
interventions fell under scrutiny in the 1970s, and there was a general move in
international health to take primary health care more seriously, culminating in the
development of the Alma Ata Declaration in 1978, which emphasized “health for all.”

Primary health care envisioned community driven health programs, essential
medicines, maternal and child health programs, and basic water and sanitation
improvement in order to raise health standards and prevent early mortality and
morbidity. But a few short years after the Alma Ata declaration, most governments

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67 Paul Farmer, Preface to *Reimagining Global Health: An Introduction*, *Reimagining
Global Health: An Introduction*, by Paul Farmer, Jim Yong Kim, Arthur Kleinman, and
from ‘International’ to ‘Global’ Public Health,” *American Journal of Public Health* 96
in sub-Saharan Africa were saddled with catastrophic debts—a fall out of the oil crises of the 1970s—and facing punishing neoliberal economic reforms that made it impossible to expand or maintain expansive primary health care systems.69

It was in this particular socioeconomic and international health policy context that HIV/AIDS emerged across sub-Saharan Africa, severely straining already depleted public health care sectors. In the context of severely strained government sponsored health services, HIV/AIDS was addressed in part through a large movement of caretaking from below, spearheaded by a plurality of actors and organizations including African physicians, families, church organizations, nongovernmental agencies, nurses, hospice teams, private laboratory owners, farming cooperatives, schools, and local businesses.70

In the 1990s and early 2000s, thanks to the advent of highly active antiretroviral therapy, HIV became a pharmaceutically manageable chronic illness


in much of the United States and Europe. With the bulk of the global HIV/AIDS epidemic concentrated in sub-Saharan Africa, the vast disparities in access to life-prolonging pharmaceutical technologies were cast as a humanitarian emergency. These concerns launched a broad based treatment access campaign in countries such as South Africa, a global push to rationalize patent laws and allow for generic drug manufacturing, and a reappraisal of global public health funding priorities. Between the Global Fund and the President’s Emergency Plan for AIDS Relief, funding for HIV/AIDS medications and other infectious disease has increased dramatically, but the dissemination of drugs remains uneven. “Global health,” as an arena of intervention and as a set of problems, grows out of this broader history of disease eradication schemes, shifting geopolitics, the neoliberalization of health care, and the quest to tackle pernicious inequalities through expanding access to lifesaving pharmaceuticals or other technological interventions.

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71 But for a complication of this story, see Steven Epstein, Impure Science: AIDS, Activism, and the Politics of Knowledge (Berkeley: University of California Press 1996).
75 For more on these longer histories of global health, see Randall M. Packard, Global Health: A History of Interventions into the Lives of Other Peoples (Baltimore: Johns
In Uganda, “new” global health initiatives are shaped by longer, proud histories of robust African biomedical research and practice at Mulago Hospital and Makerere Medical School dating back to the early 1900s, as well as the collective national experience of triumphantly tackling a severe HIV/AIDS epidemic in the 1980s and 1990s through government awareness campaigns and collective mobilization to provide care from below.\(^6\) *Research is Our Resource* situates the rise of “global oncology” within this much deeper historical context of research and experiment on the continent.

It is true that over the past decade, cancer has emerged as a far more politically and epidemiologically visible phenomenon in Africa to international health specialists and African public health authorities alike.\(^7\) This growing cancer epidemic is shaped by a number of factors. There are more HIV positive patients on antiretroviral therapy who are living longer and therefore developing infection-related cancers. Patterns of urbanization and consumption are rapidly re-shaping


\(^7\) See, for example, D. M. Parkin, J. Gerlay, M. Hamdi-Cherif et al. eds., *Cancer in Africa: Epidemiology and Prevention* (Lyon: International Agency for Research on Cancer, 2003).
the burden of noncommunicable diseases.\textsuperscript{78} To address a growing cancer burden, public cancer wards are opening across Africa from Botswana to Kenya to address “cancer without oncology.”\textsuperscript{79} New tools for studying oncogenes and vaccine development have reanimated research on the relationship between 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.\textsuperscript{80}

At the same time, this newfound visibility of cancer in Africa and the questions about the synergy between infections and cancers in particular is reminiscent of the 1940s, 1950s, and 1960s in east Africa when the Uganda Cancer Institute was established. And the knowledge produced at the Uganda Cancer Institute over the past half century continues to shape much of what we know about the treatments of certain kinds of cancers, such as Burkitt’s lymphoma, and more generally about the distribution and patterns of cancer on the African continent.\textsuperscript{81} One of the most common cancers in parts of sub-Saharan Africa where malaria is

\textbf{\textsuperscript{78} Ibid.}


\textbf{\textsuperscript{80} Ibid. For a critique of easy causal chains between infections, vaccinations, and cancer prevention in Africa and the violence this does, see in particular, 43-56.}

endemic is Burkitt's lymphoma. This cancer was first systematically described in the 

*British Journal of Surgery* in 1958. Colonial medical officer and Irish surgeon Denis Burkitt described this tumor in the following way:

A sarcoma involving the jaws in African children has recently come to be recognized at Mulago Hospital as a distinctive clinical condition and certainly the commonest malignancy of childhood. [..] In most cases the tumour started in the region of the alveolar process of a maxilla or the mandible. Loosening of the deciduous molars was often the first syndrome, the teeth involved area soon becoming embedded in tumour tissue only, and losing their insertion in bone. The next stage was irregular displacement of the teeth prior to their falling out. The tumour grew rapidly, grossly distorting the face. In only one patient did it ulcerate through the skin. Oedema of the eyelids and chemosis of the conjunctivae indicated invasion of the orbit and if the patient survived thee eye became propstosed and finally destroyed. Less commonly the tumour presented as a swelling high in the maxilla with early invasion of the orbit. Pain was not usually as severe as would have been expected from the appearance of the tumour. Within
In the late 1960s and into the 1970s, research conducted at the Uganda Cancer Institute on Burkitt’s lymphoma showed that this tumor could in fact be cured with both single agent and combination chemotherapy drugs that were available at the time. Between 2010 and 2015 when I worked at the Uganda Cancer Institute, I saw many of cases of this tumor that Burkitt described fifty years ago. The Institute still sees over a hundred children as year with faces was heavily distorted, jaws painfully swollen and enlarged, and loose teeth. These tumors often have unmistakable smell of rot. Most patients at the UCI receive a cocktail of cytotoxic agents commonly known as COM—cyclophosphamide, vincristine, and methotrexate. If this cocktail doesn’t work, they go on second line therapy known as CHOP—cyclophosphamide, Adriamycin, vincristine, and prednisone—or cytosine arabinoside plus Adriamycin, or ADM-ARAC. The drug regimens and cancer staging systems used at the Institute today draw from the knowledge created at the Uganda Cancer Institute in the 1960s and 1970s. In this dissertation, we meet some of the Ugandan health care workers

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who played an instrumental role in creating this knowledge about drug regimens and survival by following up with Burkitt’s lymphoma patients in cancer remissions across the country.85

Living Archives, Dying Wards: A Note on Hospital Historical Ethnography

This dissertation draws upon research conducted in archives and institutions across three continents over the past six years. In total, between 2009 and 2015, I spent over two years living in Uganda. I first ‘discovered’ the Uganda Cancer Institute while working in the American Philosophical Society archives in Philadelphia as a first year graduate student. I was already interested in the history of HIV/AIDS research in Uganda, and was surprised to learn that serious internationally collaborative cancer research started in the country in 1967. In 2009, I spent three months in Uganda assessing archival materials, visiting potential field sites, and engaging in language study. I returned to Uganda in summer 2010, and 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 on the Lymphoma Treatment Center’s wards shortly thereafter, and have been working at the Uganda Cancer Institute as “the historian” ever since. I returned to Uganda in summer 2011, worked as a historian-ethnographer in the country from January to October 2012, and made

return trips in 2013, 2014, and 2015. All said, I spent a total of over two and a half years in the country in a six year period. These trips were complimented with archival research conducted in the United Kingdom and the United States, as well as interviews in Seattle with colleagues at the Fred Hutch.

The methods I employed over the course of the research were decidedly eclectic. I drew a great deal of inspiration from the turn towards “hospital ethnography,” wherein a hospital or medical ward is used as a primary fieldsite. Hospitals are both social worlds unto themselves, liminal places where deep existential concerns about the end of life, as well as sites that offer a lens for more carefully examining the relationship between the public and the state. 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. But the ethnographic research in and of itself wound up creating a vivid yet partial account of a place that no longer exists. Most historians do not get the opportunity to live, for a time, in the pasts they painstakingly reconstruct, but this method enabled that opportunity.

I conducted the majority of continuous hospital ethnography research from January to October 2012, and also did shorter research at the trips in the summers of 2010, 2011, 2013, 2014, and 2015. During this time, I conducted many hours of participant observation research at various spaces of care at the Uganda Cancer Institute in research meetings, ward rounds, chemotherapy administration days, and in the laboratory. I went to meetings at the U.S. embassy on cancer control. I attended a valuable and interesting workshop on cancer registration. And I spent an all too short week in the north of the country at Lacor Hospital, getting a very different sense of up country cancer care. During this time, I amassed about twenty notebooks of handwritten fieldnotes that were taken off and on during the days I spent on the wards, in meetings, on tea breaks, or in between oral histories. Many of these notes were written immediately after events, often at a small coffee shop at the Johns Hopkins building located about a five-minute walk away from the Uganda Cancer Institute. In the evenings, I would type up my notes from the day and then write down at least 500 words reflecting on the events of the day. Roughly every week or every other week, I would set a loose agenda, based on the fieldwork done so far and the materials amassed, about where to take the inquiry next. Between the transcribed notebooks and 500 words a day, I amassed hundreds of pages of notes about everyday life at the UCI in 2012 and some of the labor of reconstructing its past. The notebooks are as messy as life in the field—coffee stains, smears of dust, sticky notes and phone numbers litter the pages along with the highs and lows of fieldwork. Many of these fieldnotes from the wards also recount stories of patients
coming to the UCI in the very late stages of illness and their deaths, either from toxicity of chemotherapy treatments, or metastatic growths, or infection related sepsis. I treat these fieldnotes as an additional archive, as a collection of personal papers, observations, and photo snapshots from the Uganda Cancer Institute as it was in 2012. Both the places and the people depicted in these fieldnotes, indeed Kampala itself, have changed dramatically in the space of just a few short years, and that distance and difference will continue to grow by the time this dissertation turns into a book.

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. I addition, I worked extensively in the Uganda Cancer Institute’s archives. When I first found out that the Uganda Cancer Institute had not thrown away its old patient records, I was stunned. And the INACTIVE records room is a treasure trove. Not only are there patient records from the 1960s to the present, but there are old personnel files, log books marking the events of a night’s shift on the wards, and old oncology journals from the 1970s. There are home visit reports from epidemiology studies in the 1960s. There are 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 things were during Uganda’s civil war in the early 1980s. The archive is in remarkably good shape given the years of benign neglect behind a padlock. As Dr. John Ziegler, the founding director of the
UCI said to me in email correspondence about these materials, “Uganda is extraordinary in that nothing is discarded. Offices are like museums.”

I came to think of working with these materials as negotiating between the living archive and the dying ward. Let me fill out what I mean here. I want you to imagine yourself for a moment in a dusty former pharmacy store for an AIDS research trial where you can still see the words cotrimoxazole written in sharpie black permanent marker on the wooden shelving. It’s a warm day, not too hot, not too cold, not too rainy, not too dry. It’s a typical day in Kampala. You are here in this room, now known as the Uganda Cancer Institute’s INACTIVE records room, surrounded, and I mean literally surrounded floor to ceiling with the files of mainly dead or long forgotten cancer patients. A tripod is set up along with a digital SLR camera for taking photographs of a selective sample of the thousands of patient records housed in this room dating back to the 1960s. There is rat excrement on the floor. Some of the files are water damaged. Through the metal cage of the door, you can hear the record’s staff interface with patients just coming in to open up files for the first time. Their information—name, tribe, age, village, cell phone number—is written into “Face Sheets” which have remained in the same format for the past 40 years.

While this room was meant to be an archive, it was also very much alive. Consider the following excerpt from my fieldnotes:

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87 John Ziegler, Personal Correspondence with author.
As I’m in the dusty room, pulling down patient files, photographing what I can selectively, a mzee comes into the records room. He is wearing a smart chocolate brown suit, a tie, and thick spectacles. I basically work in a room that’s like a cage, and so I’m hearing this conversation as it unfolds. The gentleman is unfailingly polite to A, who mistakenly identifies the man as a member of the clergy, when in fact his is a former army person. “I want to thank you for taking care of my wife here. She was a patient here in 2005 on this ward. She became good friends with the nurses. They loved her and would laugh with her. Every year around this time when I am remembering my wife, I come here to thank you for the care that you all gave her.” A suggests that this gentleman go and visit the Director to extend his thanks. I think to myself as I go back into the vault. . . that behind every single patient record that I’ve gone through, there is a constellation of family members and friends who have lost someone. And I’ll only get to sample a handful.

In conducting oral histories and meeting many of the staff who had worked at the Uganda Cancer Institute over several generations, lines similarly blurred between past and present, sickness and health, life and death. One of my key informants had not only worked as an administrator at the UCI for nearly thirty years. He also spent a significant amount of time at the Uganda Cancer Institute on the private ward as a primary caretaker of his son, who was slowly dying of cancer. When they exhausted the expertise and resources available to them at the Institute, the family went to Cairo where the son underwent further treatment. When I first met this informant, his son had only recently passed. Mr. N, who worked at the UCI
as head radiographer from 1969 to 1985 was my point of entry for accessing administrators, nurses, and patient outreach fieldworkers who were employed by the Institute in the 1960s and 1970s. He was also a colon cancer patient for the entire time we worked together. He was grateful that he was being treated as an honored family member and receiving “the best” care at the Institute after years of service. Over the course of the year, his tumor did shrink and go into remission under the watchful eyes of the UCI’s deputy director. “We will get you the history!” he would cheer in between his chemotherapy treatments, as we drove to the homes of colleagues in Kampala and elsewhere in my “lady sized” two door Rav 4. Mr. N treated the colon cancer crowding his abdomen and the pink drip of chemotherapy in the private chemo room at the Institute with a combination of enthusiastic hope and grim pronouncements. “I am a cancer survivor!” Mr. N boasted, wearing a polo shirt with American flags and palm trees with his hair still thin from the drugs. “The vomiting is so horrible that I would rather die if I cannot buy the drugs [to stop the vomiting] … and they are too expensive.” I discretely slipped him several 50,000 Ugandan shillings (USD $20) notes over the course of our friendship. To the best of my knowledge, he is also still vibrantly, vitally alive.

The Dissertation Ahead

The first three chapters of this dissertation lay out the institutional, scientific, and political history of the Uganda Cancer Institute and Africanizing oncology. This first chapter focuses on the establishment of the Uganda Cancer Institute in the
1950s and 1960s and addresses a simple but difficult question: “Why was a cancer research hospital founded in Uganda in the first place?” The two chapters that follow ask, “How did this cancer research hospital survive the years of Idi Amin?” and “Why did the UCI become the place where you were sent to die from complications from HIV/AIDS in the 1980s, 1990s, and 2000s?” These three historical chapters are followed by a brief interlude that discusses the rise of global oncology in Uganda and the UCI in the present. The last two chapters take place in the recent past. The first looks at the long-term repercussions of transferring the technologies of oncology to Uganda, through the case study of radiotherapy in the country. The second chapter discusses the repercussions of using research as a resource to at the Uganda Cancer Institute from 2010-2015.

In chapter one, I highlight both the contingencies and convergences that led to the establishment of the Uganda Cancer Institute in 1967. I argue that this was possible because of earlier health and research initiatives in the area that left behind case records, built infrastructure, and a culture and practice of medical training. The sedimentary layers of Albert Cook’s Mengo Hospital, Mulago’s history as a medical research clearing house, and Makerere Medical School all created a situation where it was possible to transfer tools of oncology research and technologies and establish a cancer research hospital within Uganda. At the same time, American research on pediatric leukemia and its responsiveness to chemotherapy in the 1940s and 1950s set oncologists on a mission to see whether or not chemotherapy drugs could not only create remissions in cancer patients but also long term cures. A combination of
careful observation and brash showmanship put a childhood cancer endemic to tropical Africa on the map—Burkitt’s lymphoma. The tumor was highly responsive to chemotherapy, and excitement about the potential curability of Burkitt’s lymphoma provided a bridge between international researchers and cancer specialists in Uganda. In addition, Uganda’s political transition in the 1950s and 1960s cannot be separated from why and how the Uganda Cancer Institute was established in 1967. Decolonization signaled the end of indefinite contracts for British Colonial Medical Officers, which left a cadre of mostly politically progressive and mainly white medical men to pass biomedicine on to a new generation of African physician-researchers. The Americans, Ugandans, and British colleagues who established the UCI made the Africanization of the medical profession their priority. Americans were in a more neutral position to do this than British expatriates. I conclude with a discussion of how these issues came together in the day-to-day operations of the Cancer Institute between 1967 and 1971.

In chapter two, I discuss the politics of Africanizing cancer research in Idi Amin’s Uganda. “This was a scientific unit. Not political at all.” And yet politics, both within the Parliament of Uganda and within the meeting rooms of the National Cancer Institute in Bethesda, shaped the realities of providing care and conducting science profoundly at the Institute from its inception to the present. The chapter discusses how and in what ways the realities of Idi Amin’s mercurially violent regime and Africanization policies shaped the Uganda Cancer Institute in the 1970s.

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What were the ways that staff at the UCI coped with the realities of a “disintegrating state” and navigated the infrastructural challenges of working in a context where electricity was in and out, soap was rarely on the shelves, and telephone lines would remain impossible to fix for months at a time? The chapter concludes with a brief discussion of the fate of the Institute after the end of Amin’s regime.

In chapter three, I explore the politics of why the Uganda Cancer Institute became “the place where you were sent to die” from the 1980s onwards. From its inception in 1967, chemotherapy, be it administering the drugs, managing the side-effects, and documenting whether or not the drugs created durable cancer remissions, defined the purpose and presence of the Uganda Cancer Institute. But from the 1980s onwards, the absence rather than the presence of chemotherapy defined work at the UCI. The first part of the chapter discusses the ways in which the violence and unrest from the war of liberation in 1979 and the prolonged civil war shaped everyday understandings and practices of care on the wards in the 1980s. Accounts from nurses and physicians who worked at the UCI in the 1980s discuss how technologies of violence, particularly Soviet manufactured rocket launchers that were used during the Tanzanian invasion, were akin to the embodied effects of cancer treatments, particularly chemotherapy. The second part of the chapter discusses the ways in which patients, caretakers, physicians, and nurses navigated the scarcity and absence of chemotherapy drugs on the Uganda Cancer Institute’s wards from the 1980s up to the late 2000s. Here, I focus on the story of Dr. F Okuku, a student health officer in the 2000s who now works at the Institute as
a medical oncologist. Dr. F’s story shows how the availability of chemotherapy at select moments, usually purchased with the money of patients and their caretakers, brought “success stories” in terms of prolonging life, but also how families and biomedical caretakers adapted to conditions of profound scarcity. The third part of the chapter brings the reader up to the present, where the advent of government supplied chemotherapy and the vast increase in patients at the UCI since institutional autonomy in 2009 has dramatically changed the administration and use of chemotherapy. Taken as a whole, this chapter shows how coping with the limited availability of chemotherapy, what Olweny called the “armamentarium” of the medical oncologist, defined everyday practices of cancer care on the wards of the Uganda Cancer Institute in the 1980s, 1990s, and 2000s.

In the Interlude that follows, I briefly discuss the transformations at the Uganda Cancer Institute in the last ten years, charting the rise of global oncology in the longer history of international health and global health. In chapter four, I discuss the technopolitics of radiotherapy technology transfer. On any given morning in the radiotherapy bunker at Mulago National Referral Hospital in Kampala, Uganda, 80 to 100 patients line up for radiotherapy, or being “roasted,” as it is known in Luganda. The services at Mulago rely on a Chinese manufactured Cobalt-60 machine, donated in the early 1990s with help from the International Association of Atomic Energy (IAEA). The machine frequently breaks, and uses an expired cobalt source whose half-life passed sometime in the mid 2000s. The Ugandan physician-scientists who have been trained from Cape? to Cairo in radiation oncology feel that it is their
moral and medical obligation to continue to run the unit, and do so by upping radiation doses and exposure times. They are unable to assess to what extent longer exposure times simply harm and burn rather than heal or alleviate suffering. And so, women rotting and bleeding from the inside out from cervical cancer, or men with bone cancer, or children with Hodgkin’s disease still spend time under the “roasting” machine, with the hopes that it can provide palliative relief and shrink tumors. This chapter explains why and how Mulago National Referral Hospital’s radiotherapy machine operates with an expired radioactive source. Focusing on the last 20 years of radiotherapy’s history in Uganda, I show how the historically situated techno-politics of a one-time radiotherapy donation continue to shape the ethical and practical realities of cancer care today in Uganda.

The final chapter examines the ways in which globalizing oncology is localizing inequality at the Institute. The chapter uses the analogy of the “camp” as a starting point for discussing the contemporary situation at the Uganda Cancer Institute as I encountered it over four years of fieldwork between 2009 and 2014. I discuss how patients have been displaced both by illness and by these new oncology research and care initiatives. There is unintended yet profound infrastructural violence that has come along with trying to transform the Uganda Cancer Institute from a dilapidated enclave to a site of public oncological excellence in the Great Lakes region of Africa. Cancer treatments, as we know, radically harm and uncertainly heal. They are ambivalent technologies at their best and devastating at their worst. Opening the doors of the UCI wide, turning the site into a place of hope
as well as death, and restructuring the infrastructure of the Institute to accommodate this explosion of patients, from less than 1000 a year to over 36,000 in just half a decade, also walks the fine line between healing and harming. For current patients, they are caught both in a liminal state of cancer’s uncertain prognostication and violent treatments, and are receiving care in an equally liminal treatment environment, somewhere between a bulldozed past, an unfurnished present, and a hopeful future.
CHAPTER ONE: ‘The Hospital Built from Scratch,” 1950-1972

Introduction

In July 1967, John and Audrey Ziegler stepped off the plane at Entebbe Airport with their children. It was warm, but not sticky, as the family arrived in the middle of the dry season. Their clothes, books, photographs, and other worldly possessions were stuffed into suitcases. Ziegler also brought “boxes and boxes of stuff. Mainly drugs, syringes, and needles, and gauze pads, and just about anything that I could think of that you would possibly need in a hospital.”89 They made their way up the Entebbe-Kampala road, a slender twenty-mile two-lane thoroughfare that snaked past Lake Victoria’s beaches, swamps, and banana gardens before finally arriving in Kampala. In contrast to the brick and mortar of New York or Washington, D.C., Kampala was more like a small town than a bustling city. It was lush, green, and full of trees, with houses tucked away behind gardens on several rolling hills.90 The family settled in at a colleague’s home on Makerere hill, and a few days later, the work began setting up a cancer research center.

John Ziegler came to Kampala under the auspices of the American National Cancer Institute with the task of establishing a small cancer chemotherapy clinical trials research unit—the Lymphoma Treatment Center—that would examine the

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89 Interview: John Ziegler, June 2012
90 For more on Kampala and its environs in the 1950s, see Aidan Southall and Peter Gutkind, Townsmen in the Making: Kampala and its Suburbs (Kampala: East African Institute of Social Research, 1957).
long-term survival outcomes of treating Burkitt’s lymphoma.\textsuperscript{91} A collaborative project between the Ugandan Ministry of Health, the Makerere Medical School’s Department of Surgery, the National Cancer Institute, and the British Empire Cancer Campaign, the Lymphoma Treatment Center was not supposed to provide comprehensive cancer care for the Ugandan population. Rather, the vision for the facility for nearly a decade prior to its inception was to create knowledge about cancer survival and differences in disease patterns and etiology between Africa and the west.\textsuperscript{92} As the US public health service press release on the LTC noted:

This form of cancer [Burkitt’s lymphoma] occurs rarely in the United States, but may bear a relationship to the most frequently occurring cancer of American children, acute leukemia. Patients with Hodgkin’s disease and Kaposi’s sarcoma will also be studied. [. . . ] Immune reactions and characteristics of blood and bone marrow will be evaluated in an effort to discover why many African patients seem to respond better to drug therapy than American patients. These findings will be correlated with a continuing National Cancer Institute study of environmental and genetic factors that may affect the

\textsuperscript{91} Interview: John Ziegler, June 2012. See also: John Ziegler, “Historical Vignette: Early Studies of Burkitt’s Tumor in Africa,” \textit{The American Journal of Pediatric Hematology/Oncology} 8 (1986): 63-65.

development of lymphoma in an African and his response to treatment.\textsuperscript{93}

The site of the Lymphoma Treatment Center was at the very top of the hill on Mulago National Referral Hospital’s campus. Ian McAdam and Sebastian Kyalwazi of Makerere’s Surgery Department secured the rights to an abandoned maternity ward from the “Old” Mulago Hospital. The building “was in horrible shape. Rat infested and everything needed a lot of work,” Ziegler remembered. He said:

We walked into an empty room and turned it into a hospital. It was all done in a resource-poor country where you have to hire all the nurses, hire all the floor-keepers, organize the food, organize the pharmacy, organize the lab, bring in beds and bedclothes and pillows, everything. Plus develop a major research lab. We had to build a hematology unit and a clinical chemistry unit, and all of this just sort of came together.

It was a lot of fun. […] It was building a hospital from scratch, really.\textsuperscript{94}

In many ways, Ziegler’s turn of phrase about the Uganda Cancer Institute being a cancer hospital built from scratch describes the situation at the top of Mulago Hospital in the late 1960s with tremendous finesse. The physical spaces of this former maternity ward were fundamentally refurbished and tailored to pediatric cancer research. The research protocols for conducting chemotherapy clinical trials


\textsuperscript{94} Interview: John Ziegler, June 2012.
had to be developed and then approved by Makerere’s newly formed research ethics committee.\textsuperscript{95} Burkitt’s lymphoma patients needed to be recruited from Uganda’s mission and district hospitals and brought to Kampala on buses.\textsuperscript{96} In short, Ziegler’s comment captures the \textit{feeling} around setting up the Uganda Cancer Institute, that it was an opportunity to actively build physical infrastructures and cancer research and care practices from the ground up, or “from scratch” with the talents and procurement connections of the Institute’s administrator, Mr. Hillary Martins.

But at the same time, Ziegler and his American colleagues built the Uganda Cancer Institute on the foundation of roughly 50 years of evidence generated by missionary and government medical physicians and researchers on the patterns, distribution, and prevalence of cancer in the area surrounding Kampala, the two longstanding institutions of Mulago Hospital and the Makerere Medical School which concentrated African medical talent in a central place in East Africa, and of

\textsuperscript{95} On the UCI and clinical trials review boards: “I wouldn’t say it was groundbreaking, but we performed the first randomized clinical trials to my knowledge ever done in Africa. It was very much the credit of my statistical colleagues who lived and worked there, Dick Morrow, Malcolm Pike, and later, Peter Smith. All of them are now world-class epidemiologists. They designed trials to make sure they were properly randomized and stratified, and that we followed some of the early rules of proper clinical trials. We recognized that we needed hospital committees to oversee the trials, to oversee human rights, and insure that the informed consents were proper,” in \textit{National Cancer Institute Oral History Project: interview with John L. Ziegler, MD, August 4, 1998} (Rockville: History Associates Incorporated): 40. See also: Informed Consent Form, Uganda Cancer Institute Archives, “During the past few years the overall research policies have been guided by the Uganda Cancer Institute Committee, Composed of members of the Makerere Medical School and Mulago Hospital Staff,” in Sebastian Kyalwazi, “Address, Solid Tumour Center Opening, 1968,” John Ziegler Papers.  
\textsuperscript{96} Interviews: Aloysius Kisuule, February 2012; Tom Tomusange, May 2012; Charles Olweny, May 2012; Richard Morrow, November 2012. See also Bus Travel Vouchers, Uganda Cancer Institute Archives.
course, the energetic research program on Burkitt’s lymphoma itself. The sedimentary layers of medical care and training infrastructures, the richly developed local evidence base on cancer, and the relatively abundant patients who were suffering from Burkitt’s lymphoma, Kaposi’s sarcoma, and other cancers, made Kampala an attractive site for establishing the Uganda Cancer Institute.

Critically, in the wake of national independence in 1962, Ugandan leaders and British physicians, many of whom were former colonial medical officers, also offered an extraordinary level of hospitality to their American collaborators even as they sought to ensure that Africans took over positions of leadership within Mulago Hospital and Makerere Medical School. The two key visionaries behind this process in the Makerere Department of Surgery were Professor Sebastian Kyalwazi and Sir Ian McAdam, who were also the formal co-principal investigators at the UCI. Kyalwazi, a Muganda, was one of the first Ugandans (and East Africans) to qualify as a formal surgeon at Edinburgh as a fellow at the Royal College of Surgeons, and became particularly interested in Kaposi’s sarcoma and chemotherapy research at

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99 For more on the politics of manners in central Uganda, see Carol Summers, “Radical rudeness: Ugandan social critiques in the 1940s,” Journal of Social History 39 (2006): 741-770. Also see Hanson, Landed Obligation.
Over the course of the 1960s, he climbed the ranks of Makerere Medical School’s Surgery department—he was appointed as a Lecturer (the British education equivalent of an Assistant Professor in the United States) in the department in 1968 and assumed the Chairmanship of the department in 1973.

McAdam, Professor of Surgery at Makerere Medical School, was deeply committed both to building the international reputation of the medical school and also to train the first generation of East African surgeons, as part of a broader vision of Africanizing medical research and care in Uganda and more generally across East Africa. McAdam was also a character on the larger stage of Uganda’s politics in the 1960s. As noted in his obituary, “There can be few surgeons who have had to deal with a major head wound sustained by their country’s president (Obote) after a failed coup and operate in a theatre full of excited soldiers with automatic weapons [in 1969].”


101 Fieldnotes from conversation with Keith McAdam, April 2012. Sir Ian McAdam did not formally deposit his papers, although there are traces of him in many of the collections deposited at Rhodes House. See also L. A. Reynolds and E.M. Tansye (eds), British Contributions to Medical research and Education in Africa After the Second World War, Wellcome Witnesses to Twentieth Century Medicine, vol. 10, (London: Wellcome Trust Centre, for the History of Medicine at UCL): 36-37.

In this chapter, I highlight both the contingencies and convergences that led to the establishment of the Uganda Cancer Institute in 1967. I argue that this was possible because of earlier health and research initiatives in the area that left behind case records, built infrastructure, and a culture and practice of medical training. The sedimentary layers of Albert Cook’s Mengo Hospital, Mulago’s history as a medical research clearing house, and Makerere Medical School all created a situation where it was possible to transfer tools of oncology research and technologies and establish a cancer research hospital within Uganda. At the same time, American research on pediatric leukemia and its responsiveness to chemotherapy in the 1940s and 1950s set oncologists on a mission to see whether or not chemotherapy drugs could not only create remissions in cancer patients but also long term cures. A combination of careful observation and brash showmanship put a childhood cancer endemic to tropical Africa on the map—Burkitt’s lymphoma. The tumor was highly responsive to chemotherapy, and excitement about the potential curability of Burkitt’s lymphoma provided a bridge between international researchers and cancer specialists in Uganda. In addition, Uganda’s political transition in the 1950s and 1960s cannot be separated from why and how the Uganda Cancer Institute was established in 1967. I conclude with a discussion of how these issues came together in the day-to-day operations of the Cancer Institute between 1967 and 1971.

Mulago’s history as a site of concentrated of biomedical services and trained African medical professionals made the establishment of the Uganda Cancer Institute possible. But the politics of newly independent Uganda and international
investments from the American National Cancer Institute created a unique set of circumstances where the Institute had a high degree of institutional, administrative, and indeed medical autonomy. Even though the UCI was part of the biomedical ecology of Mulago Hill, it remained a separate entity, a “hospital built from scratch.”

**Histories in the Hills: Mulago**

The Kampala of present day is, like many other capital cities across Africa, expanding at a break-neck pace. New buildings are mushrooming up on a daily basis in an architectural style that might be best described as ‘Dubai nouveau’. There is a booming middle class, and more and more cars on the road mean punishing traffic. There is occasional tear gas, 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 that was designed with a maximum of 300,000 residents in mind in the 1960s, not the 1.5 million people who call greater Kampala home.\(^{103}\) If you see baby goats butting heads on the side of the road or long 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.

Different patterns of agricultural settlement, racial segregation, and the particular bureaucratic and social functions of various hills have been written into

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Kampala’s landscape for over a century. In 1890, when F.D. Lugard first arrived in the area that is modern Kampala, he found Buganda kingdom’s Kabaka Mutesa I’s palace or lubiri situated at the top of Mengo hill. Historically, the thousands of followers of kings and the hilltop palaces themselves shifted from hillside to hillside, but this moment of encounter fixed what is now Kampala’s geography in a profound way. Lugard established a fort on the hill of what is now known as “Old Kampala,” with trading and administrative centers, while Mengo remained the seat of Buganda power. Over time, more Asian and European businesses and residences established themselves on the hills east of Old Kampala, including Nakasero and Kololo hills, while African cultivators resided to the west.  

Today, if you stand at the top of Makerere hill, which is home to the oldest university in East Africa, and you look to the south, there are Kololo and Nakassero hills, which house posh suburbs and government establishments. Farther to the east, Kamwokya is a rough and tumble 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 check out counter, but also a portrait of the current Kabaka, Ronald Mutebi, a reminder that Buganda kingdom is still celebrated. Standing at Makerere, if you look towards 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—the hill and the hospital.

Mulago hill, which was on the periphery of Kampala in the early 1900s, served as the hill for the palace of one of Buganda’s kings, Ssuuna II, who served as the kabaka from 1832 to 1856. Mulago the name is intimately tied to the history of King Ssuuna’s relationship to the hill, as a colleague who worked with anthropologists to reconstruct the history of Mulago hill in the 1950s remembers:

That hill at the time of King Ssuuna II was known by the name Nakyeyuwa (something which builds itself up). And so when Kibale (one of the chief ministers of the state) was commanded by King Ssuuna to go and look after a good place where he could build his palace, Kibale came to this Hill and the people told him that it was called Nakyeyuwa. But Kibale did not like this name although the hill itself was good. Then Kibale went back and told King Ssuuna how he had found a beautiful hill which was also very near. When King

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Ssuuna wished to go and have a look at the hill, Kibale had another job to do and so he could not accompany the King. King Ssuuna asked Kibale for a servant to take him there. Kibale told a house servant to go and show the hill to the King—*genda omulage* (go and show him). Kibale did not tell the servant the real name of the hill because he despised it. When King Ssuuna came to the hill, he liked it very much. And then he remembered Kibale saying, ‘*omulage*’ (show him) which he took to be the name of the hill. He called the hill *omulage* for a very long time. After some years the people dropped the initial vowel ‘o’ from the word *omulage* and it was changed to Mulago. And so the word Mulago has no meaning because no one ever meant to name it so.\(^{107}\)

In its present day incarnation, Mulago Hospital Complex includes a sprawling public teaching and referral hospital with over 1000 beds, a public health school, and a medical school. It is also a site of convergence for people across the country seeking care. Throughout the country, there are small municipal health dispensaries, slightly larger health centers that include maternity services, and regional referral hospitals. As the government’s flagship teaching and national referral hospital, Mulago receives the difficult cases from the national referral

hospital system and also serves as a hospital to the urban poor in the greater Kampala area.¹⁰⁸

Many patients, patient caretakers, physicians, nurses, social workers, and the like arrive at Mulago every morning via matatu (a 14 passenger minibus taxi that is also a ubiquitous form of transport in much of East Africa), footing, or increasingly by personal car.¹⁰⁹ 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 via ambulance, although every morning, if timed properly, one can see the morning commute’s motorcycle accidents 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 often unceremoniously pulled by the ankles from dark blue police truck beds and then thrust onto a wheelchair or dragged into the casualty reception area to


have their limbs cast back together or to be given blood.\textsuperscript{110} Or, all the more likely, they are delivered to the morgue.\textsuperscript{111}

Mulago the Hospital was originally opened by the Ugandan Protectorate government to serve as a venereal disease treatment center for Africans in 1913, a year before the outbreak of World War I.\textsuperscript{112} Throughout most of World War I, the site remained dormant, with most of the staff called to duty and service in the Great War rather than to crusade against venereal disease. In 1919, the site was reopened and renovated. By 1921, Mulago, under the supervision and direction of Major Keane, consisted of a laboratory run by Dr. W. L. Webb, three 30-bed mud and wattle wards with thatched roofs, and a set of permanent buildings including an outpatient department, an operating theater, and a new 25-bed ward.\textsuperscript{113} There was a sense, right from the beginning of establishing services at Mulago, that the needs of patients outstripped the capacity of the built facilities. Arthur Williams, who joined the Colonial Medical service in 1931 and who later became the head of the Makerere University College’s Department of Medicine in 1951,\textsuperscript{114} writes:

\begin{itemize}
\item \textsuperscript{111} Mika Fieldnotes, July 2012.
\item \textsuperscript{112} For more on the history of Buganda and venereal disease treatment and research, see Shane Doyle, \textit{Before HIV}.
\item \textsuperscript{113} A. W. Williams, “The History of Mulago Hospital and the Makerere College Medical School,” \textit{East African Medical Journal} 29 (1952): 253-263.
\item \textsuperscript{114} “Obituary Arthur Williams,” \textit{African Health Sciences} 6 (2006): 68.
\end{itemize}
The year [1921] began with hardly any patients. It ended with a hospital overcrowded, a staff overworked, and the conviction that the separation between venereal and non-venereal disease could not possibly sustained, and that Mulago must be developed into a general hospital. The popularity of the rural dispensaries, opened about this time at Mukono, Mpigi and Kasangati had exceeded all expectations, and contributed to the rapid increase of work at the parent hospital and the demands on its small staff. By the end of 1922 attendances at Mulago had multiplied again four times and a new 52-bed ward (now Ward 1) had been added.115

The volume of patients at Mulago and at other hospitals around Kampala raised the question of how to meet the demand for hospital based care and outpatient treatments for ulcers, hernias, malaria, syphilis, sleeping sickness, and other illnesses, given the paucity of staff and the relatively undesirable location of Kampala, where there was neither speedy access to big game hunting, nor the opportunity to hold land larger than a personal garden.116

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116 Incidentally, in interviews and memoirs with British Colonial Medical officers, many wax nostalgic for their gardening opportunities in Kampala and elsewhere in Uganda. In particular, they remember their rose gardens. See Interview: Denis Wright, November 2012. Steven Feierman has persuasively argued that the biomedical care and services on the ground in East Africa touched relatively few people and that the vast majority of care for illness happened (and continues to happen) well beyond the walls of hospitals, dispensaries, clinics, etc. See Steven Feierman, "Imaginary Care in the History of Eastern Africa," (paper presented at
others early on championed the need for Africans trained as medical officers and physicians, but there were ongoing squabbles about how and to what extent they should receive credentials. As early as 1913, Captain G. F. Keane brought a small group of highly promising African men to Mulago hill for training in laboratory skills, venereal disease identifications, mercury therapeutics, and writing up patient histories. Along similar lines, Albert Cook trained promising medical auxiliaries at Mengo Hospital in the early 1900s. By 1923, a training program for Africans to assume the role of medical assistants either capable of running small rural hospitals or working as medical attendants at hospitals and dispensaries coalesced at Mulago, under the guidance and directorship of Keane.117

By the mid 1940s, Old Mulago Hospital had expanded into 650-bed hospital in the “pavilion style,” across upper Mulago hill, but neither the beds nor the buildings offered enough space for care and medical education. As Mulago’s Medical Superintendent, A. A. Alderdice writes, “In many departments, however, facilities were restricted by overcrowding and inadequate buildings. There was a limit to the amount of improvisation to be expected of doctors and nurses in wards and theatres that were never designed for so many patients or such complex techniques. Worse,
still, in some respects the hospital could not cope with larger intakes of medical students."¹¹⁸

There were ongoing debates about how to best modernize Mulago Hospital to continue to serve as the government’s principle referral hospital and accommodate the demands of clinical teaching and medical education at Makerere.¹¹⁹ As Alderdice remembers:

There were two schools of thought, one, the demolition of the old hutted wards and replacement by new (no drawings were ever seen by me) and two; an entirely new hospital on a new site altogether. There was no doubt which scheme would create less interruption to the day to day hospital services, but there was the risk, which was borne out by later events, that building a new and retaining the old would result in a tremendous expansion in the number of beds in Kampala requiring a lot more money and staff.¹²⁰

If Old Mulago was “unplanned” and organically grew as a scattering of buildings across the hillside, the design of New Mulago imposed order, crowd control, and “modern” bed rest on the wards. As plans were drawn by architect K. P. Smith, formerly the resident architect on the Ibadan, Nigeria Hospital scheme, an imposing five-story structure the emphasized repetition of large wards on each and

¹¹⁹ For more on these debates, see the Williams papers and series of memos on planning and purpose of the hospital from Rhodes House. Also, see British National Archive documents on the failed schemes of Mulago Hospital in the 1940s and 1950s.
¹²⁰ A. A. Alderdice, Mss. Afr.s. 1872, Answers to Aid Memoir, Rhodes House Papers.
every floor, long hallways open to the elements, elevators, and wards that championed large windows to bring in the “tropical breeze” to beds as opposed to rolling patients outside onto the hillside, crystalized.\textsuperscript{121}

New Mulago Hospital was built with surprising alacrity and speed. Ground broke in 1960 and Her Royal Highness, the Duchess of Kent, opened the hospital with much fanfare in 1962, just as the Union Jack was lowered and the new Ugandan flag was being raised all over Uganda. Most of the hospital was made up of materials that were largely imported from England and Europe, and then transported to the Mombasa port in Kenya and then brought into Uganda via rail. Everything from elevator parts, to stainless steel drums for sterilization, to fine Italian marble tile, and wood paneling were imported. Today, the remains of these materials can be found all throughout New Mulago Hospital, particularly in the main entrance to the hospital, which is lovingly paneled in a dark, rich wood and still appears to have the original tile on the floor, and two commemorative groundbreaking and opening stones.

In 1962, it was a bit of a rarity in a government hospital for main outpatient and casualty entrances to be given such a place of prominence and priority at the center of the hospital. Mulago’s planning committee, however, felt that “the most important group of people attending the hospital should be given the best possible

\textsuperscript{121} For more on the architectural logic of these decisions, see \textit{Mulago Hospital}. 
Access. Access to either medical or surgical attention was also deeply embossed into the layout of the hospital, with symbolic and spatial divides dictating whether patients would go to the left or the right of the building. Today, outpatients coming into the main entrance of Mulago still either make a right turn into the waiting area for the department of surgery, or hang a left to the department of medicine.

In total, New Mulago Hospital cost 2.3 million British pounds in 1962. 2 million pounds went into the building, another 220,000 pounds went into procuring and purchasing medical equipment, and 80,000 pounds went into expanding the nurse’s quarters near the hospital. The British government offered up about half of the money. New Mulago Hospital was framed by many of the British Colonial Medical Officers who were leaving Uganda after independence and the expiration of their contracts as a major gift to the Ugandan public, as a replacement for a “dilapidated and inadequate hospital [. . .] with one conforming to the most modern standards of a teaching hospital.”

At the same time, the gift of New Mulago did not mean the end of Old Mulago. The buildings continued to be used, housing dermatology, venereal disease treatment, a childhood malnutrition unit, some maternity facilities, and, in a few years after the opening of New Mulago, the Uganda Cancer Institute.

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123 A. A. Alderice, “The New Mulago Hospital,” 238.
124 J. R. Billinghurst, Mss. Afr.s. 1872, Answers to Aide Memoir, Rhodes House Archives.
Within a year of opening New Mulago, many of the constraints on space and the crunch on medical staff dealing with a large number of patients that had characterized the daily rhythms of work at Old Mulago were just as acutely felt at New Mulago. J. R. Billinghurst remembers:

When it was built, [new] Mulago had a nominal bed complement of 850, but extra beds and patients on the floor swelled the numbers to at least on-third as many again. In a sense no patient needing admission was turned away, whatever ‘the bed state’. The consultants used to feel sometimes that one of the most important functions of their ward rounds was to decide who could be discharged and how soon. Once these decisions had been made the patient had to go; there were no mandatory enquiries about his home circumstances, etc. No patient was allowed to leave a ward without the most valuable of all medical documents, the MF 5, a small pale yellow sheet, kept by the patient himself, on which doctors wrote the briefest of comments and also the drugs to be dispensed at the pharmacy. Patients kept these sheets with the utmost care—polythene bags prevented them from disintegrating in storms and floods—and time and again they provided indispensable information all over the country.  

125 J. R. Billinghurst, Mss. Afr.s. 1872, Answers to Aide Memoir, Rhodes House Archives. We see the same dynamics at the Uganda Cancer Institute today when it comes to the purpose of ward rounds.
Even with the expansion of the referral hospital network in postcolonial Uganda, Mulago still remained a crowded and cosmopolitan clearing-house for all sorts of maladies, including cancer.\textsuperscript{126}

Although many Kampala residents who came to Mulago for treatment sought relief for mild ailments such as malaria or dysentery, many of the referral patients from the rest of Uganda and as well as residents local to Kampala came for relief for less quotidian illnesses and misfortunes. This concentration of patients, created an “abundance of clinical material,” and clinicians at the teaching hospital were in a unique position to engage in research projects on diseases common in East Africa. Much of this work started at Mulago during World War II and afterwards. As Shane Doyle notes:

The most important of Buganda’s fourteen hospitals by far was Mulago, the national referral hospital and home to East Africa’s medical school. During the Second World War, as specialization was encouraged by the suspension of home leave and the arrival on military services of a number of consultants from Britain, Mulago began to acquire a reputation for research excellence. Over the next two decades a remarkable group of clinicians gathered at Mulago, making breakthroughs of global significance in a number of fields including malnutrition, cancer, and heart disease. What was of

\textsuperscript{126} Iliffe, \textit{East African Doctors}, 137
immediate benefit to Buganda was that for many of these researchers, Greater Kampala was their laboratory.127

Much of the research conducted at Mulago from the 1940s onwards was characterized by the desire to characterize and articulate the specific disease ecology of East Africa, and also to consider the ways in which rapid urbanization and changing patterns of food and material goods consumption would reshape patterns of illness. This agenda had a political edge, as Iliffe argues in describing the style of medical research at Makerere in the 1960s:

[researchers wanted to] identify and explain the distinctive features of East Africa's disease environment. Initially, too, there was the same interest in kwashiorkor and venereal diseases. But just as Muwazi had helped to demonstrate that kwashiorkor was not due to congenital syphilis, so the next generation of researchers set out to demonstrate that in so far as East Africa's disease patterns differed from those elsewhere, the reasons were generally economic or environmental rather than ethnic or cultural. […]

Mulago's other and major area of research during the 1960s concerned cancer and heart complaints. This had stronger ideological implications for these had been thought 'diseases of civilization' from

127 Doyle, Before HIV, 299.
which Africans seldom suffered, so that blood pressure became a barometer of progress. But there were other reasons for concern with these diseases. They were at the cutting edge of medical research throughout the world, African students often learned the techniques in Western hospitals, the complaints were expected to multiply in East Africa in the future, and, perhaps most important, Makerere's staff realized they could make a major international contribution to the field.\textsuperscript{128}

\textit{Making Cancer in Uganda Visible}

Cancer research at Mulago started from the mortuary up in the 1940s and 1950s.\textsuperscript{129} When pathologist J. N. P. Davies arrived in Kampala in the 1940s to assume a teaching and service post on Mulago hill, his supervisor gave him the task of developing the pathology education program at Makerere Medical School. The laboratory space and autopsy room were rather barebones, but the bigger issue was an absence of readily available pathology slides, or organ samples preserved in chemicals and stored in ghoulish jars as part of a proper teaching museum. In addition, text books and medical journals were in short supply—many of these materials were stolen for their paper and used in the shops of Wandegeya to hold sugar and other sundries. On the other hand, Mulago had an abundance of patient

\textsuperscript{128} Iliffe, \textit{East African Doctors}, 141-2.
\textsuperscript{129} The following account is derived from J.N. P. Davies, Mss. Afr.s. 1872, Answers to Aide Memoire, Rhodes House Archives.
material and disease patterns that were highly specific to central Uganda. For example, one of the first cases Davies and his new group of African medical students collectively examined was a case of pulmonary tuberculosis that had also invaded the heart tissue. Davies assured his students that this was quite rare and extraordinary—totally uncommon and probably the only case they would ever see. They went on to see several more cases of the exact same presentation in the ensuing month.

Given the necessity of speedily disseminating information and documenting the ways in which diseases presented themselves in East Africa, it didn't make sense to write and then publish a full text book that captured the specificity of pathology in greater Kampala. Davies and students opted to use the *East African Medical Journal* as a makeshift text book of sorts. They wrote up interesting cases and published them as they went along. Through publishing detailed case histories and conditions, the *East African Medical Journal* became a key teaching tool, a text book published in real time and circulated widely.

At the same time, Davies finally got his hands on old autopsy reports at Mulago Hospital. Working with his wife after hours, they went through all of the old autopsy records and death reports to reconstruct the mortality patterns seen at hospitals around Kampala from the early 1900s to the late 1940s. Part of this mortality data showed that Africans were not only dying of “tropical” maladies such as malaria, but that they also suffered from cancer, heart disease, and other illnesses
that were associated at the time with “diseases of civilization.” But the cancers found in autopsy reports rarely mapped on to the patterns seen in Europe—liver cancers, Kaposi’s sarcoma, malignant melanoma, and a strange jaw cancer that appeared to be a sarcoma or lymphoma dominated the cancer records of Africans, suggesting that cancer, while present in Africa, looked quite different from cancer patterns seen in European hospitals.

**The Kampala Cancer Registry**

It was these experiences, both the visceral encounters with local biologies on the autopsy table, and the wealth of found autopsy data, that inspired Davies and colleagues at Makerere Medical School to start an inquiry into the patterns and incidence of cancer in Uganda. In 1964, the *British Medical Journal* published a two part series on cancer in Uganda from 1897 to 1956. The study compared two data sets of case records—one from Mengo Hospital, the old Church Missionary Society hospital founded by Sir Albert Cook in the late 1890s, and the other from the more recently established Kampala Cancer Registry, founded by the pathologist JNP Davies and colleagues at Mulago in 1951. The study aimed to answer two questions: “How common was cancer in the past? And were the varieties of cancers the same as we have recorded in recent years?” Davies continued:

The study starts at a time when everything imported into Uganda was carried by headload and when the first doctor to study and treat disease in the African population had walked the great distance from
the coast. It began in reed huts. It ended in days of concrete and chromium, of radioisotopes and autoanalysers brought in by modern railways or jet aircraft. Our study covers a period from almost the Iron Age to Rocketry. […]

We have found that the ratio of cancers to total admissions at Mengo Hospital has remained remarkably stable over six decades. The ratios are low, as low as those which in the past were used to support the idea that cancer was a rare disease of ‘primitive peoples.’ Yet out of such ratios in recent years it has been possible to construct incidence rates based on annual registrations which in the younger age-groups are comparable with those of Norway.\textsuperscript{130}

“Cancer in an African Community, 1897-1956” painted an evocative picture of both the profound changes in Uganda over a 60 year period and also an equally profound continuity over time. While diagnostic tools, medical infrastructure, railways, imported goods from clothing to soap, new legal structures, and bureaucratic machinery all proliferated throughout central Uganda from the time of the Mailo land agreement to the Buganda riots in 1949 to the eve of independence in the late 1950s, cancer patterns themselves did not change all that much, nor did

improvements in the tools available for detection and diagnosis dramatically alter
the epidemiological profile of cancer in Kampala and the surrounding milieu.

The African Lymphoma

When Davies and colleagues started the Kampala Cancer Registry in 1951,
they invited colleagues from a broad swath of Mulago Hospital, including surgeons,
pediatricians, and general physicians to join the efforts of the British Empire Cancer
Campaign in documenting the epidemiology of cancer in Kyadondo county.131 Denis
Burkitt, an Irish surgeon and British colonial medical officer working at Mulago
Hospital, declined. As Davies would later recall, “He [Burkitt] thought it a waste of
time as he could assure me as a surgeon that there was not enough cancer in
Kampala to make it worth investigating.”132

In 1957, however, physician Hugh Trowell asked Burkitt to examine a
pediatric patient for a surgical consultation.133 The boy was a five year old with
massive swellings in all four quadrants of his jaw. Jaw swellings were not

131 J. N. P Davies et. al., “Cancer in Kampala: a survey in an underdeveloped country,”
132 Davies papers, Rhodes House.
133 This account is drawn from the following materials: Denis Parsons Burkitt
Papers, Burkitt, Mss. Afr.s. 1872/20, Burkitt Memories, Rhodes House; Anthony
Epstein and MA Eastwood, “Denis Parsons Burkitt. 28 February 1911- 23 March
Story and David Kritchevsky, “Denis Parsons Burkitt,” Journal of Nutrition 124
Burkitt,” Pediatric and Developmental Pathology 1 (1998): 562-564; Cliff Nelson and
180-183; Bernard Glemser, Mr. Burkitt and Africa (New York: World Publishing Co.
1970).
uncommon, and children often came to Mulago with this sort of complaint, their jaw swelling either from infections or single tumors, but a swelling distributed in all four quadrants of the jaw simultaneously was quite rare. A few weeks later, Burkitt visited Jinja district hospital and found another young boy with jaw swellings in all four quadrants. Burkitt and colleagues convinced the family to come to Mulago, where they also established that the boy had abdominal tumors as well. Going back through old case records, Burkitt found that patients with this distinct jaw tumor often had other tumor deposits throughout their bodies, suggesting that this was a multi-centric tumor. Excited about the prospect of a new medical discovery, Burkitt took his notes, photographs, and tissue samples of these patients to J.N.P. Davies in pathology. Burkitt was “rather crestfallen” when he found that Davies and colleagues were already working on this multi-sited tumor both at the cancer registrar and in the pathology laboratory and radiography department, and presented on jaw tumors to the Colonial Medical Research Council and International Cancer Congress in London.\textsuperscript{134}

Burkitt became obsessed with this unusual tumor, and working with colleagues at Mulago, started to investigate the clinical presentation, geographical distribution, and pathological features of the tumor in force. In 1958, the British Journal of Surgery published “A Sarcoma Involving the Jaws in African Children,” which detailed the features of this “distinctive clinical condition and certainly the

\textsuperscript{134} J. N. P. Davies Papers, Rhodes House.
commonest malignancy of childhood” in Uganda. This tumor was (and still is) grotesque in its presentation. Photographs taken by Burkitt documented swollen jaws, loosening teeth, eyes bulging out of sockets, and the infected lips of Ugandan children. When “A Sarcoma” was published in 1958, it made little to no impression on either the east African or British medical community, but collaborations with the pathology department and the broader medical community in Uganda suggested several interesting avenues for research.

Firstly, this lymphoma grew very rapidly and was also highly responsive to nitrogen mustard. Treatment with chemotherapeutic agents alone in a context where there was no radiotherapy proved to induce temporary remissions. Secondly, the tumor had a unique geographic distribution which was suggestive of environmental factors, possibly a viral infection spread by an insect vector. Mapping the distribution of Burkitt’s lymphoma, Burkitt worked with A. J. Haddow, Director of the East African Virus Research Institute in Entebbe. They concluded that the geographic distribution of the lymphoma across Africa corresponded with altitudes below 5,000 feet and areas with more than 20 inches of rainfall a year, that

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is, environments where mosquitoes thrived and insect-vector driven diseases were common.\textsuperscript{137}

Burkitt made the lymphoma his centerpiece at two lectures in the United Kingdom in 1961, showcasing photographs, maps, and hypotheses about an insect vector and viral cause.\textsuperscript{138} It was at a lecture at Middlesex Hospital Medical School in London where he met Anthony Epstein, who was interested in chicken tumor viruses at the time, and more generally human cancer viruses. Burkitt and Epstein struck up a collaboration—sending biopsy and blood samples to London for analysis.\textsuperscript{139}

In the early 1960s, Burkitt connected with American oncologists touring east Africa and was offered chemotherapy drugs—methotrexate, vincristine, and cyclophosphamide—to use in the treatment of the lymphoma back at Mulago.\textsuperscript{140} As Epstein remembers, “With minimal doses, and in some cases even single doses, Denis achieved astonishing regressions, remissions and apparent cures, which


\textsuperscript{140} Denis Burkitt, “The reasons for going to Africa,” in Grant Taylor ed. \textit{Pioneers in pediatric oncology} (Houston: University of Texas MD Anderson Cancer Center 1990): 39-44; Owen Smith, “Denis Parsons Burkitt CMG, MD, DSc, FRS, FRCS, FTCD (1911-93) Irish by birth, Trinity by the grace of God,” \textit{British Journal of Haematology} 156 (2012): 770-776.
caught the attention of cancer chemotherapists world-wide and of the popular press which naturally made much of the ‘simple bush surgeon’ who discovered a horrific cancer of children in Africa and then went on to produce dramatic cures.”

Despite the shock and awe of the power of cytotoxic drugs to create Burkitt’s lymphoma tumor regressions and long-term remissions, the data coming out of Mulago had a major empirical hole in them. There were so many patients who were lost to follow up that it was difficult to say, using the statistical standards of the day, whether or not these results were due to chance or bona fide therapeutic efficacy. Burkitt and colleagues were aware of these issues. As he remembers: “It was not uncommon for a child under treatment to be removed from hospital by her mother in the middle of the night. […]”

While Burkitt may have coined the method of the tumor safari in his drives with colleagues throughout eastern and central Africa, looking for signs of the lymphoma at various government and mission hospitals, he did not spend time engaging with central and eastern Africans themselves in the context of meeting with village chiefs of seeking out local healers who may have had exposure to treating tumors with a variety of herbs or prayers. Burkitt’s gaze was a biomedical one. His medical networks were muzungu networks. Although Burkitt was praised for his powers of keen observation over the years and commemorated for making

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141 Epstein and Eastwood, “Denis Parsons Burkitt,” 95.
142 Denis Burkitt, “The reasons for going to Africa,” in Grant Taylor ed. *Pioneers in pediatric oncology* (Houston: University of Texas MD Anderson Cancer Center 1990): 43.
clinical problems in tropical Africa visible, the village life of the patients and families he engaged with remained starkly invisible to him. When patients “vanished,” he lacked the social and technological know how to do something other than mark these patients as “lost to follow up.”

In addition to the problem of being lost to follow up, there was also the issue of the ethics of how and under what circumstances these drugs were administered to pediatric patients in the first place. The vast majority of Burkitt’s lymphoma patients that Burkitt saw were from rural up country villages. Neither the patients nor the parents spoke much English, and Burkitt did not speak much of the forty or so languages commonly spoken across the country. This isn’t to minimize the fact that Burkitt did see his patients as people as well as clinical material:

Treating children with cancer is inevitably associated with emotional attachments. I got to know most of my patients by name and visited many of them regularly in their homes, usually thatched roofed mud huts, after their discharge from hospital.

I still remember vividly two of the first children I treated, both boys aged about 7. One we cured, and my excitement mounted as weeks passed without any recurrence of his tumour. I kept in touch with him during the 4 years preceeding my departure from Uganda. His name was Kibakda. I imagine he is now a young man. The other responded
initially, but again and again relapsed after successive courses of treatment. He was to leave the ward and come over to my house, which was just outside the hospital perimeter, with his grotesquely deformed jaw, frightful to look upon and he retained such pathetic faith in me. It is a reward to know that our work has saved some children from this slow form of premature death.\textsuperscript{143}

Burkitt saw himself as the part of the newest generation medical missionaries and doing the good work of being a Christian by being a surgeon. When he went on the long tumor safari, he took a copy of David Livingstone’s travel diaries from his explorations of central Africa in the mid 1800s, and would read entries at the end of the day’s long drives by hurricane lamp or a bare light bulb.\textsuperscript{144} And like Livingstone, Burkitt practiced what we could consider to be “heroic” medicine. There is a powerful continuity here that ultimately ends with the fact that in both early missionary medical times and in the 1950s and 1960s, self professed Christian men of God were injecting African bodies with therapies that were either dangerous or at their best only partially tested. Reflecting on the Burkitt’s lymphoma research conducted in Uganda in the 1950s and 1960s, Jackson Orem commented to me that this is the sort of “heroic medicine” that just simply wouldn't have been approved by Mulago’s current Institutional Review Board protocols.

\textsuperscript{143} Denis Burkitt, Mss. Afr.s. 1872, Answers to Aide Memoire, Rhodes House Archives. 
\textsuperscript{144} Ibid.
Meanwhile, At Memorial Sloan-Kettering

In June 1965, while interning at Memorial Sloan-Kettering in New York City, Ziegler admitted a sixteen year-old girl from Connecticut with a lymphosarcoma. The clinical presentation and histopathology appeared to be much like Burkitt's lymphoma. Drawing on dosage and treatment practices from east Africa, particularly Burkitt's work at Mulago, Ziegler and colleagues treated the girl with a dose of cyclophosphamide and, “Two days later a striking decrease in the size of the left breast was noted and there was a 50% reduction in the size of the abdominal mass. Four days later the breasts were normal in size and no tumor could be palpated. [...] The patient was discharged feeling well on July 10, with no medications, and in apparent complete remission.”145 These initial results were similar to data coming out of Mulago Hospital in Kampala, Uganda and elsewhere in East Africa, where colleagues reported similar tumor melting effects from the drugs and the ability to create extraordinary remissions in Burkitt's lymphoma.146 But less than a month later, the Connecticut girl was back at Sloan Kettering with “recurrent swelling of the breasts and was treated with irradiation and a short course of cyclophosphamide given orally. [...] The patient suffered progressive deterioration marked by pancytopenia, paraplegia due to spinal cord compression, and terminal

respiratory distress unresponsive to supportive measures. She died on September 8 [1965] following a grand mal seizure.”

Since the 1940s, American cancer researchers had experimented with cytotoxic drug therapies, particularly focusing on pediatric leukemia, where it appeared that chemotherapy treatments would bring about temporary cancer remissions, leading researchers on a quest for permanent cures for cancer with toxic drugs alone. By the early 1960s, there was more and more interest in combining different cytotoxic agents, and in 1961, the NCI launched their flagship VAMP trial for leukemia that capitalized on combination drug therapy—vincristine, amethopterin (methotrexate), 6-MP (mercaptopurine), and prednisone. This was incredibly risky. As Siddhartha Mukherjee writes:

A child with leukemia was already stretched to the brittle limits of survival, hanging on to life by a bare physiological thread. People at the NCI would often casually talk of chemotherapy as the ‘poison of the month.’ If four poisons of the month were simultaneously pumped daily into a three or six year old child, there was virtually no guarantee that he or she could survive even the first dose of this regimen, let alone survive week after week.

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148 Siddhartha Mukherjee, The Emperor of All Maladies: A Biography of Cancer (New York: Scribner, 2010), 143-144.
But the patients who did undergo the VAMP trials did initially have astonishing remissions. The vast majority of patients eventually succumbed to leukemia, which persisted in their central nervous systems, although a few did survive.\(^{149}\) In contrast to VAMP, the ongoing results of chemotherapy used on Burkitt’s lymphoma were incredibly hopeful. Children were often only receiving one dose of one cytotoxic agent and then going into full long-term remissions. For example, according to preliminary follow up data on Burkitt’s lymphoma published in 1965, of the 63 Burkitt’s lymphoma patients treated with cyclophosphamide at Mulago between 1960 and 1963, 19 were living in 1965 with full remissions, 28 were lost to follow up and 16 had passed away.\(^ {150}\)

By the time they saw the Connecticut girl, Burkitt’s lymphoma had already captured the imaginations of several key cancer chemotherapy pioneers at Memorial Sloan-Kettering, namely Joe Burchenal and Daniel Karnofsky.\(^ {151}\) Burchenal himself had visited Nairobi in January 1960 with a team from Sloan Kettering to meet with the surgeon Peter Clifford, who ran a small cancer treatment ward on site. Burchenal also visited Kampala and met with Burkitt. Burchenal was taken aback by the presentation of Burkitt’s lymphoma. Reflecting on that visit, he


\(^{151}\) Joseph Burchenal, “Burkitt’s Tumor as a Stalking Horse for Leukemia,” *JAMA* 222 (1972): 1165
said: “I thought I had seen all childhood tumors in Memorial Hospital during the past twelve or fourteen years, but I had never seen anything like these tumors.”

Discussing the treatment options available at Mulago where there was no radiotherapy and surgery proved ineflectual, Burchenal suggested that Burkitt try treating patients with methotrexate, which he had leftover from the Kenya visit. The remissions were impressive.\textsuperscript{152}

Over the next five years, linkages expanded between cancer researchers in east Africa and medical oncologists at in the United States such as Sloan-Kettering and the National Cancer Institute, as well as colleagues in Sweden at the Karolinska Institute and of course, physicians and laboratories in the United Kingdom. These colleagues framed their collective cancer research agenda as “geographic chemotherapy,” that is:

\[\text{\ldots} \] the study of the chemotherapeutic response of similar tumors from different geographic regions. It takes advantage of the differing incidence of certain tumors in various geographic areas, presumably due to environmental or genetic factors: (a) to bring the best chemotherapy available to bear on various sensitive tumors, such as choriocarcinoma or Burkitt’s tumor, which constitute a real problem with certain countries, and (b) to determine whether tumors with similar pathologic appearance from different regions respond similarly to chemotherapy. If differences are found, this might suggest

\textsuperscript{152} Glemser, \textit{Mr. Burkitt and Africa}, 133. Burkitt also treated some patients initially with nitrogen mustard. See Burkitt, \textit{A Sarcoma Involving the Jaws in African Children}
that environmental or genetic factors also affect the response to chemotherapy.\textsuperscript{153}

Between 1965 and 1967, colleagues across east Africa, America, and the United Kingdom decided that the best way to approach this research agenda in geographic chemotherapy would be to continue the work of Burkitt’s lymphoma treatment research. Burkitt and his fellow British colonial medical officers conducted cancer research during a decade of transitions, both within the institution of Mulago itself as the doors of the new hospital opened in 1962, and also as Uganda itself became independent. Decolonization signaled the end of indefinite contracts for British Colonial Medical Officers. Burkitt himself left in 1967. The expatriate medical officers who remained after independence particularly in the surgery, medical, and pathology departments were a politically progressive group. They saw Africanization of the medical school as a chief priority, and were excited to work with and mentor this next generation of African physician-researchers. Setting up a cancer research center in Kampala at Mulago with the combination of the Makerere Medical School, the Kampala cancer registry, and the existing research on Burkitt’s lymphoma made the most practical and logistical sense. Similar sites in Nairobi in Kenya and Accra in Ghana did not offer the same alchemy of personalities or ongoing cancer research programs.\textsuperscript{154}

Ultimately, it was Paul Carbone’s chemotherapy research group at the National Cancer Institute that assumed the task of establishing a research center in Africa to study Burkitt’s lymphoma and its responsiveness to chemotherapy. John Ziegler had just arrived at the National Cancer Institute in 1966 under the auspices of the Public Health Service in part to avoid going to Vietnam. He came to the NCI most excited and interested in chemotherapy and Burkitt’s lymphoma, and wound up just down the hall from Paul Carbone. Carbone had just returned from a series of meetings across east and west Africa, and asked Ziegler if he would be interested in running the day-to-day operations of this soon-to-be-established unit. As Ziegler remembers, “I don’t think he knew very much about me [at first] and I think I knew even less about what they were doing, but as we talked we hit it off just fine and I said sure let me talk it over with my wife and we said ok, let’s do this.”

A few months later, in January 1967, Carbone and Ziegler attended a conference on “Cancer In Africa” in Nairobi. It was “sort of a perfect storm of really good people coming together” to discuss a variety of cancers endemic in Africa, including Burkitt’s lymphoma, Kaposi’s sarcoma, hepatocellular carcinoma, esophageal cancer, and others that “were very much indigenous” on the continent.

When the conference closed in Nairobi, Ziegler, Burkitt, Carbone, Dick Morrow,

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Interview: John Ziegler, June 2012.

Angus McCray and Malcolm Pike piled into a car and drove from Nairobi to Kampala, via Lake Nakuru. “By the time we got back to Kampala we were the best of friends.”157 And in meetings with Ian McAdam, Denis Wright, and a new cadre of African physicians, “there was right away a kind of camaraderie, an acceptance, and a willingness to make this happen. Thinking back now in various research settings that I’ve seen, you could imagine people would be very threatened and say no this is our turf and all these muzungus in Uganda [shouldn’t be here]. Other people might say what are you going to offer? Is this going to make us better or is this going to threaten my career? So what you ended up with is this is this perfect collection of like minded people who somehow not a one of them was threatened or pushed back.”158 Six months later, Ziegler and his family flew to Kampala to begin work setting up the Lymphoma Treatment Center.

158 Ibid. If this sounds too good to be true, in conversations with other colleagues and in their memoirs, those who worked at the Uganda Cancer Institute in the 1960s and 1970s echoed Ziegler’s sentiments, that this was an exceptional stew of likeminded people. And these were feelings that cut across the American, Ugandan, and British colleagues. See for example, interviews with Robert Comis, Avrum Bluming, Richard Morrow, Denis Wright, Tom Tomusange, Alosyius Kisuule, Nsalabwa, and Charles Olweny. See also memoirs by Chuck Vogel and Avrum Bluming, fieldnotes from conversation with Keith McAdam, April 2012, and fieldnotes from Uganda Cancer Institute Symposium August 2014. See also “Letter to Gordon Zubrod, National Cancer Institute from Calvin M. Kunin, M.D. Professor and Chairman, University of Virginia,” April 28, 1969, John Ziegler Personal Papers. There is of course an uncomfortable and unfortunate silence in the record regarding the experiences of Sebastian Kyalwazi as the Ugandan co-principal investigator. Kyalwazi died of cancer himself in 1992, and while I made several attempts to contact his family and tried to track down his personal papers over the course of fieldwork in 2012, I was unsuccessful.
Building a Hospital from Scratch

The building that Mulago Hospital and Makerere Medical College cordoned off for the National Cancer Institute’s work was an abandoned maternity unit, part of the “Old” Mulago hospital. The task of equipping and refurbishing this shell of a building, with a collapsed roof, peeling paint, and plenty of rat poop on the floors, fell largely on a long time Mulago hospital administrator, Hilary Martins, who the NCI hired to run the day to day administration of the new unit. Part of the Goan community, Martins had extensive and expansive networks with many of the Asian-run businesses in town, and plenty of experience in what it took to furnish and equip a hospital ward at Mulago Hospital. Ziegler, Martin, and other colleagues spent most of the summer of 1967 outfitting the unit and tracking down patients. Outfitting the unit took on an organic and improvisational quality. “We realized we needed beds and bed curtains for privacy. And we needed some furniture and a table and chairs and a dining room for feeding people. So over the summer we put this together and it was entirely ad hoc. We said what about this? What about that? So we would jump into the car and get what we needed and would haul it back and set it up.”

By the time the unit was completed eight weeks later, the Uganda Cancer Institute comprised the Lymphoma Treatment Center’s wards, a pharmacy, a laboratory for doing both basic blood counts and more experimental techniques, a

\[159\] Interview: John Ziegler, June 2012.
dining room, a kitchen, cleaned up bathrooms, and offices. Relationships with the pathology department for biopsy processing and the medical imaging department for taking photographs of patients were also established. In the most literal of sense, the Uganda Cancer Institute was a “hospital built from scratch.”

In addition to setting up the built infrastructure of the unit and the hiring of staff, they also needed Burkitt’s lymphoma patients. Ziegler worked with an American epidemiologist, Richard Morrow, who was already in Uganda under the auspices of the World Health Organization. They did a two-week driving tour of the country, looking for patients. They visited mission and government hospitals from Hoima to Arua to Gulu to Soroti, “all around in a big circle […] and showed them pictures of Burkitt’s lymphoma and said if you have patients with this condition and want to send them to Kampala for treatment this is the place to send them.” They handed out maps to the Lymphoma Treatment Center, and offered to pay for the bus. “At the end of the safari we had put the word out and put in on the radio as well.”160

When the Lymphoma Treatment Center opened officially on August 4, 1967, foreign dignitaries and local politicians alike came to see this small joint research endeavor to study “certain types of cancer common in Africa and of theoretical and

160 Interview: John Ziegler, June 2012.
practical interests to US scientists.” Ian McAdam welcomed colleagues and visitors, saying:

This Unit which is being opened today has the unique opportunity of adding a vital chapter in the fight against cancer. The first objective is to provide the best available treatment for patients suffering from malignant lymphoma. On this foundation the research staff will investigate some of the fundamental problems concerned with cancer—the aetiology of Burkitt’s tumour, the host response to cancer and the dramatic remissions (I am not saying cures) which have resulted from treatment with chemotherapeutic agents. Answers to some of these problems would be of benefit to the whole human race. Is it too imaginative to see this building the workroom of a future Nobel Prize winner? The Ministry of Health has provided the building and the National Institutes of Health in the United States have generously given the money to renovate the building, to equip it, and pay the salaries of the staff, which includes a Consultant Chemotherapist.

We now have an ideal environment in which the research team of Makerere and Government Consultants can work. Your presence here, Mr. Minister, is an indication of Government support.162

After the speeches, Ugandan Health Minister officially opened the Lymphoma Treatment Center by bestowing a commemorative dedication plaque to the building, honoring Denis Burkitt and his contributions to Burkitt’s lymphoma research in Uganda.163 Burkitt’s medical officer contract with the Ugandan government had already come to a close. On the tour of the brand new ward, it was Professor Sebastian Kyalwazi, the Muganda surgeon with a keen interest in the power of chemotherapy and the co-investigator for the newly established unit, who engaged with patients and examined them at bedside on that day. Burkitt looked on, his hands neatly folded across his camera.164

The Lymphoma Treatment Center opened about a year after Milton Obote abolished the kingdoms and took full control of the Ugandan government. It was an extreme move to address political troubles around the geographic and social cleavages that had dominated the Ugandan protectorate from the early 1900s

162 Sir Ian McAdam, Lymphoma Treatment Center Opening Speech, August 1967, John Ziegler Personal Papers.
163 Photograph of Uganda Minister of Health John Lwamafa hanging the commemorative plaque at the Lymphoma Treatment Center honoring Denis Burkitt, August 1967, John Ziegler Personal Papers.
164 Photo of Sebastian Kyalwazi, Denis Burkitt, and others at the grand opening of the Lymphoma Treatment Center, August 1967, John Ziegler Personal Papers.
In this political climate, Ugandan government support for the Lymphoma Treatment Center was extremely important. The Lymphoma Treatment Center was intended to address the national concern of cancer rather than health issues surrounding greater Kampala. At the same time, those who planned the LTC saw it neither a paternalistic gift from the British in the spirit of New Mulago Hospital, or an exclusively nationalist project. Rather, the colleagues who built the Lymphoma Treatment Center saw it as a symbol of international cooperation, a practical site for doing cutting edge cancer research, and perhaps the home to a future Nobel Prize winner.

**If you build it, how will you get them to come?**

As Burkitt’s lymphoma patients started coming in to the Center for care and treatment in the first six months of being open, Ziegler and his American colleagues found that the relatively narrow mandate of the research site did not map onto the realities either of the disease burden of cancer, or the ways in which Ugandan families provided care to the ill. As Ziegler remembers:

> After the safari the patients started to flow in. We quickly realized two things. Number one was that not everybody had Burkitt’s lymphoma. Some of them had other stuff but we couldn’t literally turn them away.

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166 Uganda National Cancer Institute Annual Reports, John Ziegler Personal Papers
We ended up being a children’s cancer ward, basically. And we saw rhabdosarcomas and neuroblastomas and Wilm's tumor, retinoblastoma. Every children’s tumor came to us because nobody knew what to do with them. And so we began to see every childhood cancer that there was in the country that could travel.

The other interesting thing was that these parents, mostly moms but a few dads also brought the rest of their children with them. So they brought little kiddies, usually packed on their backs, and we gave the moms mattresses to sleep on under the kiddies’ beds. So very quickly [the ward] filled up with families. The kid would be in the bed and the mom would be under the bed and the rest of the family would be under the bed with her. And we fed them all and we took care of them all and of course when the little kids came in, many of them had malaria. They had hookworm. They had all of this other stuff so we ended up treating everybody, literally. If mom came in with a cough she would have x-rays and if she had TB we would give her treatment. pretty soon it was just a general-purpose ward with a focus on childhood cancer. [...]^{167}

\footnote{167 Interview: John Ziegler, June 2012.}
Ziegler and his American colleagues understood that they were working in a caregiving landscape where their pediatric patients were entangled in much larger family support networks than most of their pediatric patients in Bethesda. They quickly and intuitively grasped that if they had any hope of treating Burkitt’s lymphoma patients and controlling for infections on the wards, they would have to treat entire families. At the same time, chemotherapy trials necessitated that patients and their families stay at the UCI for several days and sometimes weeks at a time to monitor tumor regression and also to manage the side effects of treatment regimens, which could bring kidney failure and immunosuppression. To meet patient caretaker and patient concerns about school, the Center hired a full time primary school teachers. To address concerns about planting seasons and following up with the needs of the rural homestead, they offered bus vouchers for parents and patients to go back and forth between Kampala and the village. The hospital also provided several generous meals a day to both patients and their families.

Patients and their families shaped both the infrastructure and the approach to research that was done at the UCI in the 1960s and early 1970s. Problems of *caretaking, mobility, ethnic and linguistic heterogeneity, and material poverty* of patients and families who came to the UCI impacted the practice of research. The material circumstances facing patients mattered, particularly the agrarian rhythms of farming that are headily disrupted by multiple cycles of chemotherapy. The sheer ethnic and linguistic diversity of patients and families required the presence of an astute translator. The way that the Uganda Cancer Institute engaged with these
issues was to take life in the village seriously, and to employ a set of Ugandan medical officers and field staff who were responsible for patient follow up and outreach.

Vicki Mujuzi, one of the long time administrators who started at the UCI in the 1960s as a “young girl” remembers:

In those days, we actually had a tailor on site who would sew patient clothes of different sizes. We had sheets and towels, all in a supply room with cubbies. Let me tell you how we used to feed the patients. We used to go around in the morning and take orders. . . this one wants fish, that one wants chicken. We would use our switch boards to make the call down to the surgery in Kololo, which would make the food and deliver it. We would give breakfast in the morning with porridge and milk and maybe a bun. . .and dinner too. Patients were allowed to have one caretaker with them, and they usually stayed around Mulago. If they were Karamajong and came without any clothes we would go into town and get them second hand clothes to wear.168

The day to day caregiving systems that Ziegler and colleagues intuitively established appreciated something which historians of health and healing in Africa have long discussed—the role of the “therapy management group” in determining the course,

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168 Interview: Vicki Mujuzi, February 2012.
duration, location, payment system, and caretaking burden involved in providing relief for ill family members.¹⁶⁹

While staff on the wards of the Lymphoma Treatment Center adapted the space and the structure of day-to-day activities to accommodate the needs of patients and their families, the Center was still fundamentally a research center and ran as a clinical trials facility. Americans on staff also brought a sense of urgency in the style of “Cornell medicine,” which is Ziegler’s gloss for the rigorous style of tending to emergencies and providing excellent care, which he learned as a medical resident. Makeshift dialysis units, punishing night shifts, and hustling to get blood diagnostic work ups done in a timely fashion was the norm, and in contrast to a style of medicine practiced in lower Mulago which was more crowded, more chaotic, and largely structured around clearing beds as quickly as possible. Within about six months of opening the Center, Ziegler himself fell ill with a bad case of meningitis and was told by his more locally seasoned colleagues, British and Ugandan alike, that he needed to dial down the pace of tending to emergencies, or that he would risk burning out.

Day-to-day activities at the Uganda Cancer Institute settled into predictable routines. Ziegler and colleagues would arrive at the Cancer Institute between eight and eight thirty in the morning. They would gather in the nurse’s break room and would discuss any events that happened during the night shift over steaming cups of

¹⁶⁹ Janzen, The Quest for Therapy and Livingston, Improvising Medicine.
coffee. Then, they would proceed to the ward round, laying hands on bodies, ordering blood counts, and marking tumor regression or growth. The wards were usually full, and so this ward rounding work would take until eleven or eleven thirty in the morning. Staff would then take a brief tea break, and then prepared patients for lumbar punctures and bone marrow exams as needed, as well as chemotherapy orders. To save time and also to spare the pediatric patients from the worst of the pain of a bone marrow aspirate, they autoclaved lumbar puncture and bone marrow needles together in the same bundled kit, administered a calming dose of Demerol, and then quickly drew spinal fluid while the child was held down. They would quickly run the spinal fluid to the laboratory on site, and, if necessary, administer methotrexate to mitigate central nervous system involvement for Burkitt’s lymphoma. They averaged between five and six children an hour. After procedures, there was a brief lunch break, and the afternoon was then devoted to seeing outpatients and running the general purpose clinic for patient families and attending to the “lumps and bumps” referrals from lower Mulago Hospital. Afternoons often also meant continuing education and teaching in the form of journal clubs, lectures, or rounding in the main hospital. By four in the afternoon on most days, activities would come to a close. Doctors would go for a swim or off to play tennis, and then families would congregate for dinner. Patients would look forward to dinner and to another, one would hope, quiet night on the wards. These daily cycles of rounding, working up patients for blood and liver functions, drug administration, downtime, outpatient care, education for both medical students and
patients, and all-important meals formed the backbone of everyday life on the wards.\textsuperscript{170}

It became clear over the course of 1967 that there were also a sizeable number of adults with interesting tumors, including Kaposi’s sarcoma, hepatocellular carcinoma, and melanoma. The National Cancer Institute provided the funds and staff for an additional ward to open—the Solid Tumor Center—run by another young American chemotherapist named Chuck Vogel. In 1968, the Solid Tumor Center opened. It was a former surgery building. Together, the Lymphoma Treatment Center and Solid Tumor Center made up the “Uganda Cancer Institute.”

**The Importance of Follow-up**

As I mentioned previously, while Burkitt captured, in extraordinarily vivid photographs, the work of cytotoxic drugs in causing jaw tumors to go into remission, his capacity to follow up on patients and their long-term survival was quite limited. And Burkitt, for all of his charisma and creativity, lacked both the training, and perhaps even the interest, to conduct systematic clinical trials of chemotherapy on BL in Uganda. The teams at the National Cancer Institute and the Makerere Medical College established the Lymphoma Treatment Center to address this issue and study the long-term responses of Burkitt’s lymphoma to

\textsuperscript{170} Interviews: John Ziegler June 2012, November 2013; Avrum Bluming March 2015; Bob Comis September 2013; Charles Vogel Memoirs, shared with author; Photographs of the Uganda Cancer Institute from the 1960s, John Ziegler Personal Papers.
chemotherapy treatments in a controlled setting. The cornerstone of this work was a rigorous patient follow up program developed in large part by Richard Morrow, a WHO epidemiologist who worked extensively with Ziegler in the early days of setting up the Lymphoma Treatment Center.\textsuperscript{171}

Upon his arrival in Uganda with his family in 1966, Morrow overlapped with Denis Burkitt for about two week’s time, and this two week overlap was enough to chart an course of initial inquiry—what happened to the Burkitt’s lymphoma patients that Sebastian Kyalwazi and Denis Burkitt had treated with a variety of cytotoxic drugs over the past decade? Were they still alive? Had they died or become debilitated? Were they still living with their parents in villages that spanned from Koboko in the farthest corner of West Nile bordering Zaire to the bustling border town of Busia on the road from eastern Uganda to western Kenya? How would Morrow adapt the routine method of case finding in epidemiology to a national setting with such extraordinary linguistic, ethnic, and geographical diversity?

Morrow did something both smart and ordinary—he asked his colleagues who they would recommend among Mulago’s expanding number of Ugandan medical officers to act as a translator and case finder for the initial work of tracking down Burkitt’s lymphoma patients long lost to follow up. And this was how he met Aloysius Kisuule, a medical officer working in the pediatric ward at Mulago, who

\textsuperscript{171} Interview: Richard Morrow, November 2012.
also happened to know 20 of Uganda’s 30-40 languages, “including the northern ones, which were not Bantu.”\textsuperscript{172}

Kisuule became interested in working as a medical officer early in life, as he put it, “Right from birth I liked treating patients that personal feeling that I would like to treat patients, to take care, especially of the children.” After going through training as a clinical officer in Mbale town, he was sent to Karamoja where he worked for four years.\textsuperscript{173} But as Kisuule put it, recalling his four years there, “It is the largest district mind you in Uganda. I was helped by learning Karamajong in six months. I was purely speaking Karamajong. Therefore, I didn’t find problems with the Karamajong. Indeed, they were wild.”\textsuperscript{174} Kisuule’s commitment to learning the language, of going out into villages for outreach on a regular basis, and building relationships with local political authorities enabled his clinical work.

After four years in Karamoja, Kisuule applied for a transfer to Mulago Hospital and was posted to the pediatric outpatient section in Mulago, where his work was:

\textsuperscript{172} Interview: Aloysius Kisuule, February 2012.
\textsuperscript{173} In the 1960s, Karamoja was considered a real backwater when compared to the rest of Uganda, and indeed it remains a remote corner of the country today, plagued with ongoing regional political instability and cattle raiding violence. For most people living in Kampala today, the Karamajong are most strongly associated with the numerous barefooted street children in the city, sitting and actively begging on the sidewalks, or sleeping slumped in the fetal position in the mid afternoon heat, palms still open and on the ground.
\textsuperscript{174} Interview: Aloysius Kisuule, February 2012.
Purely clinical. . . you don’t have any machines to help you. You are just looking at the patient, sensitizing him or her on your findings, what you are actually doing, and why you are doing it. That is clinical to me because we didn’t have a laboratory. We didn’t take blood from the fingers to find malaria parasites and so on. But you had it in your head, this clinical medicine enabling [you to decide?] that this patient may be suffering from malaria, pneumonia, and so on.¹⁷⁵

Kisuule quickly developed a reputation of working well with patients and their families, engaging in his “purely clinical” style of education and interaction. And so, when Dick Morrow asked around for referrals to medical officers with linguistic acumen and an ability to interact well with families from all over Uganda, Kisuule immediately came to mind.

Aloysius Kisuule first worked for Morrow and then worked as the principle administrator of the Uganda Cancer Institute in the 1970s. The Americans who worked with him describe him as “truly extraordinary” in his counseling of patients, his linguistic ability, his perseverance, and his intrepidness. Kisuule remembers the Americans as generous—salaries were much better at the Uganda Cancer Institute than they were in usual government posts—a real “incentive to the worker.” Issues of compensation aside, more than thirty years later, Kisuule’s memories that remain of working with Morrow, Ziegler, Vogel and other Americans are fond ones that

¹⁷⁵ Interview: Aloysius Kisuule, February 2012.
conjure paternal relations. Talking about the history of the UCI when we were taking a tour of the Lymphoma Treatment Center in October 2012, he said, “It was through obedience and commitment that this place was built.” And it was largely through Kisuule’s work in patient outreach and follow up that Ziegler, Morrow and others were able to turn clinical outcomes into meaningful survival data points.

So what was Kisuule’s method of patient outreach in practice? When Morrow and Kisuule started working together in 1966-67, they had little to work with other than a list of patients from Denis Burkitt and their accompanying “face sheets” of basic patient information that were routinely filled in on admission to Mulago Hospital. These sheets recorded names of patients and his or her relatives, age information, “tribe,” diagnosis and date of admission, and the location of where the patient was from, starting with the district, saaza, gombolola, and finally, the village. Using this data, Kisuule set about tracking down patients who had been treated by Burkitt and Kyalwazi for follow up interviews with questionnaires would provide baseline demographic and survival data for Morrow to work with. The research instrument of choice was the Volkswagen Beetle. As Kisuule recalls:

AK: This patient follow up was more than 7 years. It was made up by experiences. Memory. Long drives. Mud going through the bush. We were doing these things with Tomasange.

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176 This Face Sheet is largely unchanged at the Uganda Cancer Institute over the past fifty years.
(Very LOUD Luganda in the background. M asking very politely for the conversation to be taken elsewhere)

AK: These long drives were very tiresome. Driving Volkswagen Beetles. They are really helpful. They can go through swamp.

(Pause to meet the firstborn son)

Long drives, I repeat, were very tiresome. Kampala to Gulu is 200 miles. Kampala to Fort Portal is 194. You can see. Fort Portal is in the West. Gulu is in the North East. Right up to Moroto is 336 miles from Kampala. From Moroto to Kaabong is 175. You can see. You can see Uganda.177

The geographic distribution of Burkitt’s lymphoma across Uganda structured data collection for survival analysis in time consuming ways. The system of roads functioned as the connective tissue linking major towns, but for the most part Uganda was still largely off the tarmac—and is today. Being a patient at the UCI over several years required mobility to Kampala, familiarity with buses, and an ability to navigate the city upon arrival. Certainly the long distances covered with the attendant challenges of mud, swamp, and fatigue for Kisuule and other UCI fieldworkers demanded patience and time. But the long distances from Kampala and central Buganda also meant that the cultural, linguistic, and ethnic terrain encountered was quite different and variegated. Independence in Uganda in 1962

177 Interview: Aloysius Kisuule, February 2012.
did not translate into a national project of smoothing over the extraordinary heterogeneity of the country's agricultural, ethnic, and linguistic makeup. If anything, independence further entrenched cultural, linguistic, and ethnic divides between the northern part of the country and the rest of Uganda.\(^{178}\)

Despite the connectivity of roads, the networks of missionary and government hospitals, the movement of foodstuffs to the city, the circulation of daily newspapers, and the soundscape of radio across the country, fieldworkers from the UCI were inevitably strangers when they showed up in remote villages looking for patients. Kisuule remembers:

\[. . .\] on this long driving, on this tiresome driving, approaching patients was the problem because you were surrounded by them and the village chief along with his askaris (soldiers or guards) and so on.

To know who is this foreigner, though I'm an African. In Uganda, I was a foreigner in those areas. It took me time to get in and out and then to say please, can we see the patients? Can I be introduced to where his

\(^{178}\) Americans who worked in Uganda in the 1960s and 1970s remember these divisions as largely linguistic and cultural ones—the “Nilotic” speakers of the north and the “Bantu speakers” living below the dividing line of Karuma falls. Ugandans whom I interacted with from this time period—mostly administrators and fieldworkers self identifying as Baganda—remember these divides largely along the abolition of the Kingdoms and the exile of the Kabaka. For people such as Tom Tomasange, Obote’s biggest problem was that he couldn’t understand the importance of having a king, because he was deprived of one in the north.
home is and taken there. And then they would say no no, he’s actually
doing something else. I would say no please, I am honest in my
approach to you. […] And then succeeding to get into that home and
beginning interviews with these people, it took time.179

Taking time was part of Kisuule’s “careful approach” to finding patients and
conducting patient follow up work. After gaining permissions and access from
village chiefs to find and approach patients, Kisuule also had to ensure that family
members understood his reasons for visiting the households of patients, in order to
fill out questionnaires and also in some cases to take blood for serum studies on the
relationship between Burkitt’s lymphoma and malaria. In these interactions, both
the careful approach of taking one’s time, and facility with language were critical in
engaging with families and parents:

M: So what were some of the ways that you would build trust or?

[Kisuule bursts into laughter and the interviewer does as well. There
is a long pause as we collect ourselves.]

M: Do you remember any particular families?

AK: I made headway in that area my friends. Mothers, mothers like
children very much as you like yourselves so when you have a child
from ward A from the labs you make friendship. And then you are

179 Interview: Aloysius Kisuule, February 2012.
using their own language. Ibrumabel. You are in Lango. Wachano. You are in Luo. Matalobey. You are in Karamoja. And you go to the West. Ruahaneza. You are in Rwanda.

This sort of thing. You are looking for the family, the sibling. You have made friendship with the mother first, therefore you are friends with the family.

M: And friendships with the fathers?

[More laughter. This time a bit more uneasy.]

AK: They are looking at what you are doing. They are listening to your words. They are dictating in mind what you are doing. Sort of investigating. Ahhh, they look at you suspiciously mostly for the whole day. If you have this method of going out soon you don’t get what you want. You need time.\[180\]

For the Americans who worked with Kisuule, what was most striking to them was his fluency and fluidity with languages from across the country. On wards, Kisuule was frequently brought in to translate, especially for patients who were coming from the north and not able to “hear” their own languages in the Bantu language of Luganda, commonly spoken by Ugandan nurses, and part of the medical vocabulary the bazungu were able to pick up over time. But up country in the village and on the

\[180\] Interview: Aloysius Kisuule, February 2012.
wards of Mulago Hospital beyond the Lymphoma Treatment Center, Kisuule also understood how to take his time in establishing relationships. Uganda is a country where the rudest thing that you can possibly be is in a hurry. Greetings are elaborate performances of interest and concern. A willingness to take your time and have a cup of tea, or to walk at a smooth and steady pace in town—these are all ways that people perform politeness. Kisuule and Morrow recognized this, writing in their initial follow up of patients who had been treated by Burkitt at Mulago in the 1950s and 1960s:

We attribute our success to having a non-hurried approach, in particular to being willing to spend considerable time explaining what we were doing to people encountered in our searches. After this explanation information was often forthcoming that the informant either denied knowing beforehand or did not bother to remember.181

Kisuule embodied a common sense in Uganda that transcended ethnic and regional variation. Part of this, of course, was through his linguistic acumen and his ability to speak fluidly across Uganda. But Kisuule also understood, in a sort of deep common sense way as well, the familial dynamics of everyday caregiving for sick children, which most usually fell on mothers or female kin, and the necessity of gaining approval for travel and treatment from fathers or other male heads of household. Kisuule’s approach of engaging with mothers and “making friendship” through the

work of socializing and quietly listening before approaching fathers with travel requests was time consuming, but necessary for ensuring that patients would actually come to the Institute (and keep coming back).

The Political and Social Meanings of the Uganda Cancer Institute

In a political and social context where cleavages between the north and the central, southern, and eastern regions of recently independent Uganda often dominated, the Uganda Cancer Institute was remarkably national in scope. It was understood that the Institute had to reach out beyond central Uganda and engage with patients and families across the country. Epidemiologically, this was necessary, as many of the Burkitt’s lymphoma patients were concentrated in the northern and eastern regions of the country. There was also political value in the geographic reach of the Cancer Institute. By researching cancers found to be important in east Africa as a whole and not narrowly constrain the site’s activities to Kampala and the surrounding area, this site transcended some of the rifts between the north and south of the country, and the high politics of Buganda and the State House. Although the support and nursing staff at the UCI were primarily Baganda, and, at the time predominantly Catholic, these fieldworkers, administrators, and nurses learned languages, expanded the offerings of the kitchen to meet different dietary tastes, and rendered the Kampala city familiar and navigable to a largely rural patient and caretaker population who had little reason to leave their farms. This isn’t to say that the Institute staff were blind to differences across the country. Difference mattered.
The ethnicity and geographic location of patients and their family caretakers were carefully noted on “Face Sheets” in the patient files as the first entry. The sartorial norms of Kampala city were important. As we know from Mjuzi’s memories, if a Karamajong patient came without clothing that would be remedied with second hand clothes from town. But nevertheless, on the wards, cancer, be it the illness identity of being a cancer patient, or cancer survivor, or caretaker of someone with cancer, subsumed other kinds of identities on the wards. The Institute was at once strikingly heterogeneous, but also unified, in large part because of the common cause of researching and studying cancers.

It is perhaps not surprising then that the Uganda Cancer Institute had multiple personal, political, and social meanings. For the Burkitt’s lymphoma patients, many of them between the ages of five and ten, the Lymphoma Treatment Center and the dreaded bone marrow procedures area, was a scary place. It was a place of pain. One of Ziegler’s first patients, who was cured of his cancer from chemotherapy treatments alone and is today himself a medical doctor, was a thirteen year old when he started treatment at the Institute. On at least one occasion, dreading another round of chemotherapy, he told the American physician attending to him that day, Dr. Avrum Bluming, that he was just going to head to town to pick up a few things in between his blood draws and starting the drug dose for the day. He vanished from Mulago and only came back the next week.
For Dr. Bluming, a young and eager American physician, working at the Uganda Cancer Institute was, in his words, “fun,” but also an opportunity to actually potentially cure cancer. In the United States, Bluming had actually sworn off pediatric oncology after treating a wonderful child with retinoblastoma at the NCI who subsequently died because the drugs didn’t work.\textsuperscript{182} At the Lymphoma Treatment Center, it was different because so many of the kids actually got better and stayed better. It was an “incredibly empowering feeling.” Other American physicians like Dr. Robert Comis were similarly amazed by the power of these drugs and the astonishing remissions. Comis remembers treating one patient in particular where the tumor did in fact melt away over the course of a night shift after receiving drugs.\textsuperscript{183}

For American researchers, there was also the adventure and the thrill of being in a newly independent African country, of enjoying Kampala’s excellent restaurants and beautiful weather, and of course, up country drives. Chuck Vogel, who is remembered by his Ugandan colleagues as extremely social and outgoing, maintains that most of closest American expatriate friends were actually CIA operatives, many of whom he played regularly with at the Kampala Rugby Club. He remembers:

The Rugby Club and families and camp followers became our family’s home away from home. Drank lots of beers, sang lots of songs and the

\textsuperscript{182} Interview: Avrum Bluming March 2015.
\textsuperscript{183} Interview: Robert Comis, September 2013.
club became one of the focal points of our family's social life. Once, a
local former rugby player, a sergeant named Idi Amin stopped by to
talk and joke around with us. [...] Amin must have been an imposing
player standing well over 6 feet tall and weighing well over 200
pounds. I remember him as friendly, jovial and very sociable.
Fortunately that was my only encounter with him during my four
years in Uganda but certainly not my last encounter with members of
his secret police during 1972 and 1973.184

For the Ugandan physicians, medical students, and staff who worked at the
Uganda Cancer Institute in the 1960s and early 1970s, research opportunities made
the hospital at the top of the hill the place for serious study. In contrast to lower
Mulago where the work of a medical officer was largely to push patients out of beds
as quickly as possible, the Uganda Cancer Institute offered young medical officers
and students an opportunity to learn how to conduct clinical trials and do routine
medical procedures needed to work up oncology patients. Dr. Edward Katongole-
Mbidde, then a medical student, was so fascinated by the research being conducted
at the Institute that he applied to be the student officer in residence for the year. He
went on to work at the Institute for the next several decades. For Charles Olweny, as
part of the inaugural class of Master’s in Medicine, the Institute marked a place

184 Chuck Vogel Memoirs, shared with the author. Much of the rest of the memoir is
written in the tone of the tall but true tale. I think of these memories as part of the
broader travel narrative genre. See Mary Louise Pratt, Imperial Eyes: Travel Writing
where he could engage in cutting edge research for his master’s thesis, rather than write an essay on typhoid fever. For Institute staff, such as Tom Tomusange, Aloysius Kisuule, and Mr. Nsalabwa, the salaries were excellent and standards were high. Ugandan staff also enjoyed the parties with the Americans that flowed with beer and surged with dancing and music. The Uganda Cancer Institute offered both camaraderie and cutting edge science.

**Conclusion**

In contrast to New Mulago, which was designed with 850 beds in mind, but that often saw at least 200 more “floor cases” at any given time in the 1960s, the scale of the operations at the Cancer Institute, with its 40 beds, was appreciably smaller. Even with the general purpose outpatient family clinic and the “lumps and bumps” policy of at least seeing all the referrals of cancer from the bottom of the hill, the emphasis was on Burkitt’s lymphoma, Kaposi’s sarcoma, hepatocellular carcinoma, and malignant melanoma. The need to create reliable data and replicable approaches to clinical management in the form of standardized disease staging and blood work up protocols shaped a strong culture of diligent excellence at the Institute.

This culture was seen most clearly in the Institute’s approach to conducting chemotherapy clinical trials in Uganda. In contrast to the Cytoxan experiments conducted by Burkitt in the early 1960s, where the drugs were often administered ad-hoc and where it was nearly impossible to get a sense of the long term value of
the drugs in creating remissions, given the fact that patients often “vanished” after their first course of treatment from Mulago, Makerere and NCI colleagues were insistent on creating a meaningful informed consent process and set of approved protocols for chemotherapy research. “We recognized that we needed hospital committees to oversee the trials, to oversee human rights, and to ensure that the informed consents were proper.”\textsuperscript{185}

But cultivating research excellence necessitated triage. They simply could not treat everything. What I want to underscore here is that from its inception, the raison d’être of the Uganda Cancer Institute was to engage in cancer research. It was never supposed to be the only cancer hospital in the country. These forty beds were never meant to provide care for Uganda’s total cancer burden. These wards were designed to conduct clinical trials with new cutting edge therapies on patients who had ostentatious tumors. But from the moment the doors of the Lymphoma Treatment Center opened, Ugandan patients and patient caretakers began to reshape the scope and mandate of the Lymphoma Treatment Center. The demands of care and caregiving, particularly with regards to extending support to caretakers of the very ill in the form of bus vouchers easing the distance between the village and the city, fundamentally shaped research practices. In the next chapter, we will see how these experiments survived and even thrived in extremely difficult times under Idi Amin.

\textsuperscript{185} Interview: John Ziegler, 1998.
CHAPTER TWO: Africanizing Cancer in Idi Amin’s Uganda, 1971-1979

Introduction

In November 1972, the Lasker Foundation honored a group of cancer chemotherapists who, for the past two decades, conducted research demonstrating that chemotherapy drugs could bring about durable long-term remissions for leukemia, lymphomas, and other cancers. Much of this research was supported by the National Cancer Institute, which, since 1955, had poured over $400 million into chemotherapy research. As Mary Lasker put it, “A fairly large number of cancers can now be cured, or prolonged survival achieved, with drugs . . . We now have an extra push in the form of more funds and the potentialities of immunotherapy. By and large, neither the public nor most of the medical profession is fully aware of what can be done. We are highlighting the progress that has been made and the men who have contributed outstandingly to it.” Among the honorees were a group of physician-researchers working at a research center called the Uganda Cancer Institute (UCI) in eastern Africa. The Uganda Cancer Institute was founded in 1967 through a joint venture with the American National Cancer Institute, the Makerere Department of Surgery, and the British Empire Cancer Campaign. The two original wards of the Institute, the Lymphoma Treatment Center and Solid Tumor Center,

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186 On the history of cancer chemotherapy research see Alberto Cambrosio and Peter Keating, _Cancer on Trial: Oncology as a New Style of Practice_ (Chicago: University of Chicago Press, 2012), Siddhartha Mukherjee, _The Emperor of All Maladies_ (New York: Knopf, 2010).

were designed to provide space for clinical trials of chemotherapy on cancers that were highly common in east Africa but rare in the United States. It was at this small treatment center of 40 beds where physician-researchers generated the bulk of cutting edge data on a key cancer of interest—Burkitt’s lymphoma.

Burkitt’s lymphoma (BL) is a fast acting lymphoma that typically presents as a horrendously disfiguring jaw tumor. These Lasker awardees demonstrated that BL is highly responsive to chemotherapy treatments, which can bring about long-term remissions. In 1972, there was tremendous excitement that these long-term remissions suggested that Burkitt’s lymphoma was curable, either with cyclophosphamide or combination chemotherapy treatments of cyclophosphamide, methotrexate, and vincristine.188

But while the Lasker honorees were sipping on cocktails and exchanging stories at the Awards Ceremony in New York, the situation in Uganda was rapidly deteriorating. Idi Amin came to power in 1971 in a military coup, and, soon after, the country fell into a state of violent uncertainty and profound economic crisis. After Amin declared an “economic war” in 1972 and expelled the Asian community

188 For more on Burkitt’s lymphoma and the history of its treatment at the Uganda Cancer Institute, among others, see Dennis Burkitt and Denis Wright, eds. Burkitt’s Lymphoma (London: Livingstone, 1970), “Special Issue: Burkitt’s Lymphoma,” British Journal of Haematology, 156 (2012): 689-783.
largely responsible for trade and commerce, American research scientists working in Uganda felt they needed to leave for their safety.\textsuperscript{189}

A fierce debate ensued at the Uganda Cancer Institute. Should they close the unit and halt research, including ongoing follow up with patients to see if Burkitt’s lymphoma could in fact be cured by chemotherapy treatments? Or should they keep the Institute open in a political climate where doctors, civil servants, and even Vice Chancellors were being put into the trunks of cars and killed, never to be seen again?\textsuperscript{190} The solution they saw was to entrust day-to-day operations to an exceptional Ugandan oncologist, Charles Olweny, who was trained by the NCI and mentored heavily in Bethesda. He and his team of Ugandan fieldworkers, technicians, nurses, and administrators would keep the UCI open, and continue to run studies, provide care, and follow up with long term survivors of BL who were scattered across Uganda. The NCI would provide drugs and additional financial support. Remarkably, amid profound political and economic chaos, Ugandan researchers generated a decade’s worth of knowledge about the relationship between chemotherapy treatments and BL survival. This knowledge production hinged on following up with long time Burkitt’s lymphoma patients through ongoing


patient outreach and site visits across the country. Out of a cohort of over 200 patients, only about 6% were lost to follow up in the 1970s in Idi Amin’s Uganda.\textsuperscript{191}

This is an astonishing story of maintaining scientific capacity in times of crisis, particularly in a context where, as historian John Iliffe puts it, “the near disintegration of the state in the 1970s and 1980s during General Amin’s military tyranny and the prolonged succession struggle that followed” devastated Ugandan physicians, and state health services as a whole.\textsuperscript{192} Mulago National Referral Hospital, the parting gift from the British colonial government, was hit particularly hard over the course of the 1970s, where institutional atrophy and decline was the most visible. Iliffe says:

\begin{quote}
Its [Mulago’s] piped water supply broke down in 1974 for a decade. The mortuary’s refrigeration system was out of action from 1975 and sewerage ceased to function at about the same period. […] At that time [1978] not one of the hospital’s twelve X-ray units was functioning. […] Yet they kept the hospital functioning.\textsuperscript{193}
\end{quote}

Further up Mulago hill at the Uganda Cancer Institute, Professor Olweny and his colleagues were publishing four to five scientific papers a year during the 1970s, mainly on the subject of combination chemotherapy trials for Burkitt’s lymphoma, hepatocellular carcinoma, and Kaposi’s sarcoma. The wards of the Uganda Cancer

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\textsuperscript{192} Iliffe, \textit{East African Doctors}, 136.
\textsuperscript{193} Ibid: 147.
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Institute were usually full and patients were well fed.\textsuperscript{194} An international pipeline from the American National Cancer Institute stocked the Cancer Institute with drugs and money for salaries until 1977, but even after their financial support ended, Olweny and his team continued clinical trials and care.

The story of the Uganda Cancer Institute’s survival offers an invaluable historical case study of the long-term work of African professionals to maintain and uphold the capacity of health facilities in challenging times. In the pages that follow, I unpack the circumstances that made the political survival of cancer research and the production of survival data possible in the middle of Amin’s disintegrating state. The chapter begins with a brief account of Idi Amin’s agenda for Africanizing the Ugandan economy in the 1970s. This desire to put the economy in the hands of ordinary Ugandans dovetailed with the Uganda Cancer Institute’s overall mission to “Africanize” research at the Institute and put the day-to-day activities in the hands of African scientists. From there, I examine the work involved in generating data on long-term Burkitt’s lymphoma patients. I explore the politics of patient follow up and outreach, the ways in which research shaped cancer care on the wards of the UCI, the labor involved in shipping samples overseas for further analysis, and tactics for coping with infrastructural uncertainty. To conclude, I discuss the uneasy political relations between the Institute and Amin’s government in the 1970s.

\textsuperscript{194} Interview with Vicky Mujuzi, March 2012. See “Letter from Charles Olweny to the Chief Engineer, Uganda Electricity Board, November 10, 1975,” Uganda Cancer Institute Archives.
Taken as a whole, the history of the Institute in the 1970s offers a window into the challenges of maintaining the capacity, continuity, and viability of a research enclave in challenging times. The narrative places Africans at the center of scientific networks as knowledge producers, rather than simply as bodies that provide materials for study and exchange.\textsuperscript{195} I argue that patients and staff at the Institute struggled against malignancies and malignant politics, working to care for both cancer-riddled bodies and necrotic equipment. I show how committed administrators, resourceful nurses, politically savvy physicians, and artful technicians kept the Uganda Cancer Institute open by demonstrating to Amin's government that they were engaged in cutting edge research in Africa by and for Africans.

**Malignant Politics in Idi Amin’s Times**

Idi Amin inherited a Ugandan state cleaved along various lines when he assumed power in a *coup d’etat* on January 25, 1971, while President Milton Obote was attending a Commonwealth Conference in Singapore. The Ugandan army supported Amin and backed the coup. Much of the Ugandan public from Kampala to Kitgum welcomed Amin with great enthusiasm. But within two years, the violent reality of Amin’s government could not be denied. In the military these divisions were particularly pronounced, with ethnic divides between Obote’s Langi and Acholi

loyalists and Amin’s Nubi soldiers. Amin’s strategy for remedying these cleavages often further entrenched them. Ethnic purges of Langi and Acholi in the army in favor of soldiers from West Nile, and state sponsored violence aimed at prominent members of the intelligentsia and civil service maintained and consolidated power at a terrible price.

The economy was another arena of crisis. Military spending after the coup amounted to a third of the national budget. Following Obote’s lead, Amin’s government tapped into anti-Asian sentiment to frame the ongoing problems with the Ugandan economy around Asians who had failed to properly integrate into Ugandan life. As Holger Hansen argues:

As the economic crisis escalated and created shortages in the army and among his otherwise supportive groups Idi Amin took action by declaring ‘the war of economic liberation’ in August 1972. He fed into the increasing resentment of the Asian business community by cancelling entry permits and certificates of residence first for non-citizen Asians, but a month later also for any person of Asian origin. This was followed by a number of decrees that ordered all properties and businesses belonging to the departed Asians to be vested in the Government and eventually by sale transferred to Uganda citizens.\(^\text{196}\)

At the heart of Amin’s economic war was an agenda for the “Africanization” of the Ugandan economy. No longer would Ugandans be beholden either to colonial masters demanding cotton for cash cropping or to Asian businessmen hiking up the prices of basic commodities. Ugandans would own the means of production and commerce. At least that was the theory. Over the 1970s, the reality of the “Africanization” of the Ugandan economy was that the national Ugandan economy functioned on a very low level as the East African economic community collapsed, while a second invisible economy based largely on coffee growing, goods smuggling, and subsistence cropping thrived. The “Africanization” of the economy made everyday life and survival contingent on the illicit.

Amin’s emphasis on “Africanization” and the centrality of an African identity also shaped many of his international diplomatic dealings over the course of the 1970s. At the core of these dealings were shifting relationships with Israel. Israel contributed heavily to infrastructure development and military equipment in Uganda after independence. These relations started to atrophy when Amin took over, the economy soured, and the Israelis were seen as “slow” to fulfill their promises of supplying top shelf military equipment. Amin radically shifted political alliances to favor the Arab world, and Israelis were expelled from Uganda in April 1972, a harbinger of the subsequent expulsion of the Asians between August and December 1972.
Amin’s realignment with Libya and the Arab world also enabled a strategic disengagement with western imperial powers and realignment with Socialist interests that included the Soviet Union, China, and Cuba. But perhaps more importantly, Amin used his position to champion African independence and an anti-imperial agenda that he strategically used against Britain and to cement his place among newly independent African nations as the spearhead of an Africanization agenda. As chairman of the Organization for African Unity in 1975 to 1976, Amin excelled at presenting himself as an anti-colonialist crusader.

While Amin’s agenda for the “Africanization” of the economy and championing the anti-colonial struggle of Africans throughout the continent were, in theory, strategies to smooth out the cleavages in Ugandan society inherited from the policies of the Protectorate and the politics of the years following independence, the reality was that these policies were aimed at consolidating and maintaining power in a military backed state. The deep rifts between ethnic groups in the army continued to shape periodic purges. Amin established a large and complicated secret state intelligence apparatus that had a reputation on Nakasero hill for torture and disappearances. It is estimated that between 80,000 and 300,000 Ugandans lost their lives over the decade due to state-related violence.197

But for the 10 million or so Ugandans who survived the 1970s, be they civil servants or farmers or mechanics, life in this decade was punctuated by two

197 See Mark Leopold, Inside West Nile (Oxford: James Currey, 2005).
extreme events—the 1972 declaration of the economic war and the 1978 invasion or liberation of Uganda by the Tanzanian army. Over the eight years of Idi Amin’s tenure, which culminated in the fall of Kampala and the retreat of Amin’s army to the north in 1979, most Ugandans were touched in some way by the violence and uncertainty of the period, and many developed strategic and savvy ways to ensure survival in difficult economic and political times. A prime example of this was the magendo or illicit market that grew into prominence over the 1970s. Another example was the Uganda Cancer Institute itself.

**Africanizing Research**

Well before Amin declared his economic war, the UCI’s founders intended to hand over the facilities and day to day services at the Institute to an entirely Ugandan staff in the early 1970s. “By 1972 or 1973, only one or two NIH-seconded advisors will be necessary, and by 1975 the Uganda Cancer Institute will be administered totally by Ugandan doctors.” This ethic of “Ugandanization” came not only from the American National Cancer Institute, but was also the overall vision for handing over the administration and clinical operations of medical services at Mulago to a new generation of extraordinary African gentlemen. Sir Ian McAdam,

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199 “Uganda Cancer Institute 5 Year Plan,” John L. Ziegler Personal Papers. I am grateful to Dr. Ziegler for granting me access to his personal archives regarding his work at the Uganda Cancer Institute.

200 Ibid.
who was head of Makerere’s Department of Surgery and also a great supporter of the Institute, enacted this ethic of training, mentoring, and handing over responsibilities both at the hospital and also in everyday life. His home in the hills of Kololo was often turned into an informal medical education salon, with Ugandan medical students and colleagues discussing the latest strange surgical cases, often with both beers and photographs from the medical imaging department in hand.\textsuperscript{201} 

Charles Olweny was the first trainee of what was envisioned as a much broader oncology training fellowship program and one of the early beneficiaries of this ethic of “Ugandanization” at Makerere Medical School, as part of the inaugural class of the Master’s in Medicine program. The Master’s program hinged on doing original research, and Olweny originally proposed a project on the epidemiology of typhoid fever. Dr. William Parsons, the convener of the class, took a short look at the proposal and said, “Charles, sorry. There is nothing new in typhoid fever. It will never make a difference. […] Go and think again.” Cancer, rather than tropical illnesses, was at the forefront of medical research and excitement at Makerere, and Parsons directed Olweny up to the top of Mulago hill to meet with Dr. John Ziegler, the American director of the UCI from 1967-1973. “So I went and met Dr. John Ziegler. And he said, ‘oh, you are the very kind of person we are looking for.

\textsuperscript{201} Fieldnotes, April 2012.
Someone young. Someone enthusiastic. Someone who can move things forward and I’ve heard a lot about you.”

Olweny collaborated with Ziegler and the staff at the UCI to design a randomized controlled trial of the treatment of adult Hodgkin’s disease with chemotherapy drugs. This was seen as particularly innovative in a setting where no radiotherapy treatments were available. Over a two-year period, Olweny worked at the Lymphoma Treatment Center on a periodic basis, mixing and administering different cytotoxic drug combinations to adults with Hodgkin’s disease, and doing patient follow up. The results published in the journal Cancer in 1971 were warmly received by the international scientific community, many of whom were surprised that 76% of the patients achieved full remission through chemotherapy treatments alone. As Olweny remembers it, “As a result of my work on Hodgkin’s disease both Ziegler and the late Paul Carbone and late Sebastian Kyalwazi said, ‘you know what, we better start capacity building, and he’s the right person.’”

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202 Interview: Charles Olweny, May 2012.
203 Interview: John Ziegler, November 2013.
204 Charles Olweny, et. al. “Adult Hodgkin’s Disease in Uganda,” Cancer 27 (1971). The abstract of the paper gives a summary of the results as follows: “A retrospective analysis of 26 cases recorded in Kampala Cancer Registry over a 5-year period and a prospective study of 18 patients admitted to Mulago Hospital since July 1968 were carried out. Clinical and histopathologic features and response to combination chemotherapy were investigated. Hodgkin’s disease in Uganda commonly affects children and young adults, particularly males, and is a more aggressive disease than seen elsewhere, both with respect to clinical stage and histopathology. Combination chemotherapy is an effective form of therapy and induced complete remission in 13 of 17 patients (76%), all but three of whom had Stage IV disease.”
205 Interview: Charles Olweny, May 2012.
One of the main reasons Olweny was particularly promising as the future Ugandan leader of the Institute was his ability to run a randomized chemotherapy clinical trial smoothly. Olweny was a talented chemotherapist. Drug mixing requires a careful attention to calculating doses by body surface area, a very humane, careful approach to administering the drugs so as to avoid tissue necrosis, and an eye for managing adverse side effects. But perhaps more importantly, like the oncologists at the NCI, Olweny was excited about the potentially curative effects of chemotherapy and about the prospect of doing research on cancer in Uganda that would be relevant to the broader scientific community in sub-Saharan Africa from Lagos to Nairobi. Olweny’s enthusiasm for the method of the clinical trial and an ability to publish independent research made him the preferred candidate for training in Bethesda at the American National Cancer Institute.

**From the First to the Only: “Charles is the Institute”**

In August 1972, Olweny was half-way through a training program in oncology at the NCI in Bethesda, having been hand picked as the first Ugandan head of the UCI, when he was told over the phone, “Better come back now. If you don’t, there will be nothing to return to.”\textsuperscript{206} While Olweny finished the last of his training and his family packed their bags, acting UCI director Charles Vogel and Lymphoma Treatment Center director Ian Magrath worked to ensure that Olweny would have something to return to. “Mulago is in turmoil. The medical school is going to have

\textsuperscript{206} Ibid.
enough on its hands simply trying to supply health care and a modicum of teaching to the students,” Vogel wrote to Ziegler on October 16, 1972. Vogel went on:

It's an incredibly good thing I returned [from travels outside Uganda]. There were rumors going as high as the Ministry that I would not return and that NIH was cutting aid. Kyalwazi was visibly moved by my return and the words of NIH support I brought with me. The Ambassador feels the UCI is one of the best things the US is doing in Uganda and with our goal of Ugandanization almost completed, the continued support is another example of US goodwill. My personal appearance here, as suspected was an invaluable shot in the arm for Ugandan-US relations.

Professor Kibunamuseke [...] says he will place no obstacles in the path of our future plans for the institute. By this I assume he means that he will not call on Charles too heavily for routine Dept. of Medicine chores. He is fully aware that Charles is the Institute and the only hope for continuing support and expansion.207

Negotiating with the Dean, Vogel and Ziegler were able to wrangle an appointment for Olweny in the department of medicine, which guaranteed housing, but also

ongoing teaching and administrative duties within the department. “We’ll have to work, from within, to carve out his autonomy,” noted Vogel.208

At the same time, the situation in Kampala continued to deteriorate. The Institute’s Sir Ian McAdam, who put his personal safety at risk to shepherd his Langi and Acholi students out of Uganda, also wrote a series of recommendation letters for his expelled Asian students and physicians at Mulago and elsewhere so they could take up further studies or medical positions elsewhere in the British Commonwealth. Amin’s government caught wind of this work, and McAdam and his family were expelled as well. They were given 24 hours notice. They boarded up the house. They shot the dogs. They tried to ensure for the safety and financial support for the staff at the house in Kololo. McAdam would never come back to Uganda during his life.209

The Ugandan physicians who remained at Mulago Hospital and Makerere Medical School in the 1970s faced the Herculean task of maintaining a national referral hospital and medical school in the midst of stock outs, political uncertainty, and mercurial violence. Much of this labor rested on the shoulders of newly trained African physician-researchers like Charles Olweny who were charged with keeping departments and units going.

208 Ibid.
209 Conversation with Keith McAdam, April 2012. Incidentally, McAdam’s ashes were repatriated to Uganda. Today there is a commemorative plaque and tree on the grounds of Mulago Hospital, directly facing the entrance to the Infectious Disease Institute, where McAdam’s son Dr. Keith McAdam worked as the founding director in the early 2000s.
When Olweny reported for duty in Kampala in March 1973, he met with the head of the medicine department at Makerere who said, “Charles, welcome back. You are going to run the Cancer Institute.” Olweny remembers being flabbergasted. “I said, me? What do I know about this?” The medicine department head said, “Yes. You will run the cancer Institute. Don’t you worry. Go and meet with Professor Kyalwazi.” Professor Kyalwazi, a formidable surgeon who was the Ugandan co-investigator for the UCI for the past five years, met with Olweny that same week. “When we met, he held my arms and said, ‘son, don’t you worry. We are here to support you.’ He did. He was there to support me. Every week, he came for ward rounds.”

As the only practicing medical doctor with formal oncology training, Olweny quickly realized that he needed to delegate labor on the wards wherever possible. Usually, medical doctors at the UCI were responsible for chemotherapy preparations and administration of drugs to patients. Olweny strategically hired two chemotherapy nurses to take up these practices, and invested his time in training nurses to be able to manage everyday drug complications. To make up for fewer physicians on the wards, Olweny also set up a research fellowship program for student health officers in their fourth year of training. The students were put in charge of emergencies and night duty on the wards.

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210 Interview with Charles Olweny, May 2012.
211 Ibid.
212 Ibid.
Olweny’s experience as the only oncologist working in Uganda in the 1970s mirrors the experiences of many of the other physicians who survived purges and disappearances at Makerere Medical School. Professor Raphael Owor, who worked as the Dean of the Medical School for much of the 1970s was the only pathologist. He managed the pathology laboratory, taught tissue fixation methods, ran the cancer registry, and worked as an administrator. When I met Professor Owor for an interview at his private laboratory in June 2012 and asked how he could manage to keep a pathology laboratory up and running in the 1970s, he took me into his bench area and pointed to the microscope and to his temple. With these two things—some good optics and a sound mind—he noted, you could run a pathology service. As long as you were strategic and ordered formalin in bulk, you could keep a laboratory open.\footnote{Interview: Raphael Owor, June 2012.} Maintenance of basic equipment, strategic ordering of supplies, and stocking a handful of essentials that could be used either to treat a broad variety of medical conditions or run laboratory tests were indispensable to keeping the doors of the only oncology and pathology services in the country open.

Olweny, Owor, and others felt a strong filial duty to the mentors who had chosen them to lead the country as the first Ugandan experts in oncology, pathology, and other fields. Circumstances in the 1970s recast these figures as the only Ugandan experts in their fields, and under a great degree of obligation to their teachers and mentors, sometimes described as fathers, to keep units and facilities open and running under this process of accelerated “Ugandanization”.
Maintaining a research enclave

When Olweny took over the day-to-day operations at the Institute in 1973, he inherited a broad spectrum of research activities. It was, as Olweny put it, “a lot of balls in the air.” Much of the research at the UCI focused on Burkitt’s lymphoma, and involved the continuation of existing treatment protocols, patient follow up, and the shipment of tissue specimens and serum samples to a variety of different laboratories across the globe. Research at the Institute in the 1960s had already established the tumor’s pathology, responsiveness to treatment, geographical distribution, and potential links to Epstein-Barr virus (EBV), making Burkitt’s lymphoma a useful model for continued study on cancer therapeutics, etiology, and epidemiology. In the 1970s, research at the Institute focused on three critical areas: (1) the long term survival of patients treated for Burkitt’s lymphoma; (2) better drug regimens to prevent tumor relapse and the involvement of the central nervous system; (3) EBV, the environment, malaria, and their relationship to the development of Burkitt’s lymphoma.

“The UCI made its name not only because we were able to treat people well, but we were able to follow up everyone,” remembers Olweny. “And we knew what happened to every patient. […] During those days they literally had to drive to West Nile. To Northern Uganda. To Eastern Uganda. To Karamoja. To trace these patients.

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214 Interview: Charles Olweny, May 2012.
215 Dennis Burkitt and Denis Wright, eds. *Burkitt’s Lymphoma*.
And we traced everybody.”217 Staff at the Institute continued to maintain a cohort of approximately 109 long-term Burkitt’s lymphoma survivors across Uganda.218 These survivors were part of a larger cohort initiated in 1967 that was made up of 240 patients over the ten-year period from 1967 to 1977. During this time, 155 died either from complications of late stage disease or from illness relapse or other causes. 16 patients, about 6% of the study population, were lost to follow up. Writing about these patients in a ten year retrospective analysis of Burkitt’s lymphoma survival in Uganda, Olweny et. al. noted “All attempts to trace them have been unsuccessful because they have crossed the national borders into neighboring Kenya, Rwanda, Sudan, Tanzania or Zaire. Most of these patients are probably still alive judging by remission status in excess of 1 year when last seen.”219

“Making Friendship” and Patient Safaris

How did this work in practice? In any clinical trial setting, losing 6% of a study population to follow up is quite remarkable. In the 1970s, staff at the UCI built upon the foundation of patient outreach and follow up methods established by WHO epidemiologist Richard Morrow and Ugandan clinical officer Aloysius Kisuule in the 1960s. These practices involved going out to remote villages to recruit patients and

217 Interview with Professor Charles Olweny, May 2012.
218 Maintaining the follow up of this study population under Public Health Service Contracts, the National Cancer Institute, and a grant from the National Research Council of Uganda was expensive—of the $142,871 total budget for the UCI for 1975-1976, patient follow up and petrol and vehicle maintenance totaled $25,000, or about half of the operation’s budget not cordoned off for salaries
bring them back to Kampala for further treatments. Kisuule noted that a lot of village outreach was about “making friendship”. If parents could not trust Kisuule or feel at ease with him, they would be inclined to hide the child, or simply refuse to go to Kampala. Persuading a father to allow mother and child to travel to Kampala for experimental care could take days of negotiating with families and village chiefs.\textsuperscript{220} After Amin’s coup in 1971, the work of “making friendship” entailed more than the social savvy of fieldworkers to negotiate with reluctant families who feared blood taking, hair loss, or Kampala city life. Fearing the violence occurring along geographical and ethnic identity lines, many villagers and families associated with long term care at the Lymphoma Treatment Center were reluctant to leave the daily work of cultivation on their farms to make the journey.\textsuperscript{221} And yet, patients and their caretakers still made pilgrimages to Kampala for serum draws, clinical exams, and follow up photographs up until the NCI stopped funding patient cohort outreach between 1977 and 1978.

Following up with patients was politically delicate and geographically expansive work, and it is worth detailing in some length how this sort of follow up work in the practice of the “patient safari” endured in the 1970s in a climate where mobility was often perilous and subject to road blocks and police intimidation. Notes from a “patient safari” by the Uganda Cancer Institute’s administrator Tom Tomusange in June 1971, approximately six months after Idi Amin’s January coup

\textsuperscript{220} Interview: Aloysius Kisuule, February 2012.
\textsuperscript{221} “Report on Trip to Northern Region By Gerald and Emmanuel 13.10.72 to 22.10.72 Inclusive,” Uganda Cancer Institute Archives.
give us a sense of these stakes. Driving a Volkswagen Beetle, Tom went eastwards, past the banana gardens, sugar cane fields, and tea bushes. He drove through Jinja, over the Owens Falls dam that harnesses the power of the Nile River for electricity, and into the flatter lands of eastern Uganda. This is where papyrus and swamps dominate the landscape, just until the road curves northwards into the green hills of Tororo and Mbale town at the foot of Mount Elgon—coffee cultivation country. Upon arriving in the east, “the car was producing queer noise from the engine, and so I took it to Mbale Prudential Garage who cleared the carburator [sic].”222 After solving his vehicle problems, Tom spent the next twelve days visiting village homesteads, mainly to meet with the families of young children with Burkitt’s lymphoma, who either needed to come back to the Institute or who were in danger of being “lost to follow up.” He also hoped to track down the reasons for the deaths of several patients who had not survived their cancer treatments at the Institute.

On the first leg of the trip, the main challenges Tom faced centered on mobility, both his own car troubles, and the financial troubles of parents strapped for cash who were in need of bus warrants in order to make the journey to Kampala. Patients were also doing well, so well that they were in school, feeling fine, and not all that interested in coming back to the hospital for a follow up exam, as evidenced by Tom’s reports:

6.6.71 Apoloti (Teso)

222 “Follow up Teso-Lango Trip by E.B. Tomusange. 1.6.71 -16.6.71,” Uganda Cancer Institute Archives.
She was also overdue. She was quite well growing up and at school in primary V. Father had paid a visit to a relative in Jinja. Yet he never bothered to come along with Apoloti since Jinja was near Kampala! however I told the mother to see that father brings Apoloti to LTC when he comes back. And I gave them bus warrants.

7.6.71 Edyelo (Teso)

Edyelo was late too. Father reported that he had no money for transport to LTC. Edyelo was at school where I went with father and asked the Headmaster to let off Edyelo for about three days for a check up at LTC. Father was given bus warrants.223

The issues Tom encountered on the next leg of his trip to Obote’s home district, Lango, were about financial mobility and the overall conditions of the patients, but also about the political climate of potential violence in Kampala. For the past six months, rumors and news of fighting in Kampala in the wake of Idi Amin’s coup, and the violent targeting of soldiers and civilians from Lango and Acholi faithful to Obote by Amin’s police forces and army circulated through northern Uganda. Roadblocks and dangerous travel conditions between Lira and Kampala led to the defaulting of about 19 patients, whom Tom needed to convince and cajole to come to the Lymphoma Treatment Center. The coup in Kampala made this work even more challenging, as we see from Tom’s reports:

223 Ibid.
7.6.71 Odongo Ojede (Lango)

This was my first home to visit in Lango after the overthrow of Dr. M. Obote (a Lango by tribe). Naturally I was fearing to visit Lango after hearing of Guerilla recruits (Pro-Obote) going on in Lango. People on the way were quiet and some looked depressed and very much suspicious and to ask for directions to somebody's home, I had to explain clearly the reason why I want to visit that home. Others could pretend to be visitors in that village and tell you that they don't know the man you are looking for. But in the end you find out the very man you are looking for to be their neighbor. This is the sort of situation I faced in most homes I visited in Lango. Odongo was supposed to return to LTC on 5.10.70.

Father of Odongo was at home. But Odongo was no longer staying with them. He was taken away by grandmother which was about 6 miles away. The father was open to me. He even told me that the rumour-mongers had told him that there was fighting in Kampala that is why he feared to return in time. I reassured him that Kampala was quite okay. He accepted to go with me to Grandmother and collect Odongo and then bring him to LTC. On our way to the grandmother he told me that his sisters had advised him not to return the child to LTC and had wanted him to even tell me that Odongo had died!
I foresaw that if Ojede (Father) stayed another night at his home, he was going to be advised strongly not bring Odongo back to LTC and thus I had to drive them to Soroti to catch a night Express to Kampala that very day.224

Even in the quietest of political times, a Muganda gentleman wearing a black suit, fashionable tie, shiny shoes, a freshly pressed handkerchief in his suit pocket, and Ugandan flag lapel pin travelling by Volkswagen Beetle was odd and potentially frightening to those living in rural villages in remote corners of Uganda. Asking for the location of a specific village home where a child known to be disfigured and bewitched and then miraculously cured by a visit to Kampala was delicate business. Tom had to strategically distance himself from being seen as an intelligence agent of the Ugandan government or a tax collector. He needed to present himself as a representative of Mulago Hospital there to "help".225

Fear, anxiety, misinformation, and “rumor mongering” shaped both sides of the negotiations with families, as we can see from the efforts to bring Odongo back to the Lymphoma Treatment Center for a follow up visit. On the one hand, Tom was quietly terrified of the potential violence of a guerilla attack in Lango, and on the other hand, fear of violence in Kampala shaped an elaborate strategy on the part of Odongo’s family to keep him safe. And as much as Tom Tomusange worked to

224 “Follow up Teso-Lango Trip by E.B. Tomusange. 1.6.71 -16.6.71,” Uganda Cancer Institute Archives.
convince up-country patients that rumors about Kampala were nothing to be concerned about, and as much as day to day activities and even international workshops continued on normally at the Uganda Cancer Institute, rumors circulating about violence, disappearance, and conflict often reflected the actual circumstances in Uganda.²²⁶

Fears not only of violence in Kampala but also the procedures on the ward made it difficult to convince parents to keep bringing their children back to the Lymphoma Treatment Center for follow up care. As Tom writes about Muko on 9.6.71:

Parents here are very difficult. They told me that too much blood is drawn from their boy whenever he comes to LTC. And thus disliked the idea of returning their boy to LTC. I explained to them that the doctors at LTC take blood from Muko and other patients at LTC not for drinking or for sale as Muko’s parents through but for tests which guide the doctors in the sort of treatment to give to Muko and then patients at the LTC. I reassured them that all the tests done are meant to benefit the patient like Muko and not to hurt him. They asked me for bus warrants and I issued them some. Note: But on 12.6.71 I

²²⁶ Of course for a far more coherent discussion of rumor particularly in the context of medicine and politics than I can offer here, see Luise White, Speaking with Vampires: Rumor and History in Colonial Africa, (Berkeley: University of California, 2000).
checked on this home but Muko was still at home. I very much doubt whether he will turn up.227

Other families feared Kampala because of the huge divides between city life and village life with regards to everyday comportment and dress. Another patient Tom visited in Lango had a challenging father who was:

Only interested in drinks and not in his daughter and he doesn't mind about dressing. He is always half naked. Fear of coming to Kampala half naked, makes him dislike the idea of bringing Akoli to LTC. And money given to him for transport back to LTC, is used on drinks. I then had to buy him a vest of three shillings plus shorts of four shillings and then returned Akoli to Centre.228

Patient follow up relied on savvy fieldworkers like Tom Tomusange. We see that Tom’s patient outreach work took on the quality of convincing families of patients that not only is the medical care meant to “help” and ensure that patients get well and stay well, but that Kampala was still safe and navigable, even for Ugandans living in Lango and Acholi areas in northern Uganda.229 Tom’s labor involved ongoing maintenance—of vehicles, of social relationships with patients

227 “Follow up Teso-Lango Trip by E.B. Tomusange. 1.6.71 -16.6.71,” Uganda Cancer Institute Archives.
228 Ibid.
and their families, and of reliable maps of where patients lived, which were carefully marked on patient follow up reports. These efforts ultimately determined whether or not these patients would be included as data points in cancer survival charts, and in some cases, whether or not they would return to Kampala for another round of chemotherapy. Being a medical man granted Tom greater mobility. Soldiers at roadblocks were willing to let Tom through without a scratch largely because he was able to produce papers that showed he worked at the Uganda Cancer Institute. “If you told them that you were doing medical work,” Tom recalls, “the soldiers would let you move more freely throughout the country.”

**Research and Care on the Wards**

Throughout the 1970s, patient follow-up relied on time, petrol, political savvy, and financial support and continued through 1977 when the budget for such work ended. On the wards, patient care required both chemotherapy drugs and food. When the Institute was established in the 1960s, supportive care was cast in broad terms—bus vouchers, translation on the wards, ensuring that family members had a place to sleep—were just as important as cytotoxic drug regimens. Administrators, nurses, technical, and service staff continued to uphold these everyday courtesies at the UCI in the Amin period. But shortages and infrastructural disruptions plagued this work. For example, the UCI went to great lengths to ensure that the food-catering program at the Institute continued to operate not only for

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230 Fieldnotes, May 2012, Conversation with Tom Tomusange
patients and their families, but also for the staff. There were periodic shortages, however. Suppliers sometimes fell flat, leaving periods where it was “extremely difficult to run this Unit without soap, salt, sugar and cooking oil.”

Shortages and stock outs also plagued the laboratory. In the 1960s, the Cancer Institute had a well-stocked laboratory in the Lymphoma Treatment Center. When Olweny assumed the day-to-day operations of the UCI in 1973, he also assumed the directorship of the laboratory, where tissue cultures, tumor marker assays, and chemotherapy mixing took place. From 1973 to 1975 or so, many of these research protocols, laboratory, ward, and field, were kept “in house” in Uganda. But disruptions of electricity supplies were particularly challenging. Take the following example. In November 1975, Olweny wrote to the Chief Engineer at the Electricity Board to voice his complaints about frequent disconnections of power to the Uganda Cancer Institute. He said:

I would like to point out that Uganda Cancer Institute is a hospital and as such we find it extremely difficult to render efficient services to our patients when power is disconnected for long periods without prior notice. Furthermore, we have a walk-in cold room where drugs are kept at -20 and a Revco refrigerator where valuable medical drugs, specimens and chemicals are stored, and it is now becoming virtually impossible to keep these drugs at the temperature recommended by

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231 “Letter to the General Manager, Food and Beverages LTD, from Professor Charles Olweny, April 20, 1976,” Uganda Cancer Institute Archives.
the manufacturers. We have in the past relied on your prior notice and transferred some materials to other buildings, but of late no notice has been given to us and recently our patients even went without food as we had not made prior arrangements.232

This letter provides a glimpse into the ongoing efforts to strive against ruptures, blackouts, and disruptions.

Harnessing electricity to keep freezers at a nail biting temperature and samples sheltered from the vagaries of noon day Equatorial sun at the Institute during this period could only rely for so long on what Derek Peterson and Edgar Taylor have called “the politics of exhortation.” This was a common practice in 1970s Uganda, in which civil servants were consistently called upon to fix, cajole, jerry rig, and repair services that were in a broken state.233 But the politics of exhortation was not enough to keep the freezers running consistently. When Magrath and Ziegler left the Cancer Institute in 1972 and 1973, they made provisions with the National Cancer Institute to send tissue and sera samples to Bethesda to circumvent the threats of power outages, military upheavals, theft, or broken refrigerators that would not be easily fixed. As Olweny recalls, although the UCI had freezers and a cold room for cold storage, “anything could happen,”234 and

232 “Letter to the Chief Engineer, Uganda Electricity Board, from Professor Charles Olweny, November 10, 1975,” Uganda Cancer Institute Archives.
234 Interview: Charles Olweny, May 2012.
by 1975, it became clear that the decision to pack the collections of the UCI and ship them to Bethesda was a prescient one. Already stretched by his duties on the wards, Olweny ultimately decided to end the laboratory's work in tissue culture and tumor marker studies, and focus on research on the wards that had more direct clinical relevance through the tailoring of chemotherapy protocols and working to prevent central nervous system relapse in Burkitt’s lymphoma patients.235

“Be sure the caps don't leak”

After the laboratory's in house studies closed, the Institute continued to supply tumor tissues, sera, cell lines, and survival data to metropolitan cancer research centers. In the 1970s, the UCI maintained shipping relationships with a wide variety of colleagues and studies focusing on Burkitt’s lymphoma.236 The UCI also continued to send tissue cultures of Burkitt's lymphoma and Kaposi’s sarcoma to the NIH for further research.

Operating this tissue and serum bank was contingent on a set of preparation practices, supply chains, telegram operators, airports, quality control of the samples,

235 Ibid.
236 “Proposal Contract for the Uganda Cancer Institute, 1974/1975,” Uganda Cancer Institute Archives. These collaborators included: the International Association of Research on Cancer to study biological carcinogenesis; Professor Phillip Fialkow in Seattle and Professor George Klein in Stockholm for a study of foreign particles and EBV in Burkitt’s lymphoma patient sera; Dr. Sutherland in Baltimore for a study of immune-complex deposition in the renal basement membrane of Burkitt’s lymphoma tissue; Dr. Pagano at the University of North Carolina for a study of EBV DNA in Burkitt's lymphoma tissue; Dr. Henle in Philadelphia and Dr. Gunven at the Karolinska Instiutte for a study of the epidemiology and association of EBV antibodies.
and laboratory labor. This was a precision exercise, as instructions written by a technician at the IARC’s Unit of Biological Carcinogenesis reminded staff in Kampala about the gathering the tissue of Kaposi’s sarcoma patients and a close relative: “IT IS OF ABSOLUTE IMPORTANCE THAT SPECIMENS ARE PLACED AS SOON AS THEY HAVE BEEN REMOVED ON CRUNSHED ICE AND SHIPPED TO PARIS. SERA ALSO SHOULD BE SENT ON CRUNSHED ICE OR FROZEN [emphasis original].” With periodic black outs and power failures, acquiring “crunshed” ice was not always easy. There was room for improvisation within the IARC’s shipping system. If no dry ice or regular ice was available, picnic bags were always an option: “Pack in a box, four previously frozen picnic bags on bottom of container, pack 10 to 12 cm of cotton above and place cardboard on top. Above place tubes, bottles, etc. previously wrapped in cotton.” Equipment and supplies were kept in the Lymphoma Treatment Center’s laboratory—sterile bottles, media and reagents, colored labels—and once a week, sometimes more often, the assistant administrator, would accompany a driver to Entebbe to ensure that the samples were kept out of the sun until they made it onto the East African Cargo Plane to their next destination.

The shipments out of the UCI were a substantial operation, and one that was also shaped by the scarcity of materials and an ethos of conservation to stretch out supplies as much as possible. A letter from the technician of Dr. George Klein’s

237 “Shipping instructions for the Unit of Biological Carcinogenesis,” Uganda Cancer Institute Archives.
238 Ibid.
239 Interview with Vicky Mujuzi, February 2012.
laboratory concerning the quality of the biopsy shipments from the Uganda Cancer Institute stages the conflict between the viability of the materials being shipped and the realities of stretching out vials and media:

It is very important that you don’t put too big biopsies into small bottles and that you really fill the others up tot the edge with medium. If you have a lot of material please put it into 2 or more bottles. And last, a very important thing. Be sure that the caps don’t leak. Please use adhesive tape instead of scotch tape.\textsuperscript{240}

What the technician highlights as room for improvement is, I think, a reflection of the fact that laboratory workers were most likely carefully conserving supplies and did not always have access to different sized bottles or the proper adhesive tape. These issues with conservation and mis-matched supplies were common across Mulago’s campus. In August 1976, the Department of Medical Illustration at the Medical School notified all members of the Medical School staff that the department was nearly out of printing paper and films, and therefore would only be printing color slides and lantern slides of requested images.\textsuperscript{241} Mr. Nsalabwa ordered X-ray films in bulk to shelter the X-ray department at the UCI from shortages. Cars would need repairs and there would be no spare parts obtainable in Uganda. Soap would be in such short supply that wives of civil servants, in an effort to conserve what

\textsuperscript{240} “Letter from Technician of Professor G. Klein to Professor Olweny,” Uganda Cancer Institute Archives.
\textsuperscript{241} “To All Members of Staff Medical School from W. Serumaga, Head of Medical Illustration Department, August 26, 1976,” Uganda Cancer Institute Archives.
little they had, would wash only the cuffs, collars, and armpits of their husband’s shirts so they would be presentable at work.

**The War on Cancer in Idi Amin’s Times**

Some maintain that even throughout the 1970s, “This was a scientific unit. Not political at all.”\(^\text{242}\) And yet, the threat of state violence fundamentally constrained and shaped the fieldwork, research, and care practices at the Uganda Cancer Institute, largely by constraining the mobility of fieldworkers, patients, supplies, and research samples. The reality of scarcity brought about by Amin’s politics of Africanization and the waging of the “economic war” could not be separated from the science at the UCI, which shaped patient follow up work and laboratory work.

But Amin’s anti-colonial politics and Africanization agenda also helped to shelter the Institute. He saw the site as a place where Ugandans were doing cutting edge biomedical research, and frequently visited the Institute. On one such visit, in 1975 or 1976 (the exact year is unknown), Olweny took Amin on a tour of the Lymphoma Treatment Center and the Solid Tumor Center, where nurses made beds and mixed chemotherapy, patients ate two meals a day, and student health officers did ward rounds and lumbar punctures. “This place does not smell!” Amin declared, his point of comparison being the wards of New Mulago Hospital, where services

\(^{242}\) Interview: A, February 2012.
were already caving in under the pressure of shortages of necessary items—soaps, antibiotics, cleaning materials, staff.

Amin visited the UCI’s X-Ray department, where Mr. Nsalabwa, the head radiographer, shook Amin’s hand and showed him how they performed chest X-rays for every patient admitted to the Institute. The facilities were humble—the equipment hadn’t been updated for several years. Nsalabwa, gregarious and also keen to capitalize on Amin’s impression of the place, started to talk about the state of the equipment, hinting that it was old. Amin turned to Nsalabwa and said, “what do you need? A new machine? We will get you a new X-ray machine! Get this man a new X-ray machine!” Miraculously, several months later, a new state of the art X-ray machine arrived at the UCI, wrapped neatly in a large shipping box. The service contractors commissioned to set up the machine and calibrate it, however, did not arrive. The machine was manufactured in the United Kingdom, and the company refused to send their technicians to set up the X-ray machine because of company policy to not send staff to Amin’s Uganda. The machine sat for years in its unopened box in the x-ray department. It was not set up until the Tanzanian invasion in Kampala in 1979, when the service contractors were given the go-ahead to travel and liberate the machine from its box.243

According to the memories of some Institute staff but not all, Amin was so impressed with the Institute, this place that did not smell, that it was his preferred

243 This account is derived from ongoing conversations with Mr. Nsalabwa in 2012 and a formal interview conducted with him in February 2012.
site at Mulago Hill for the medical care of his soldiers. Syringes for blood-work, antimalarials that were not expired, and nurses who came on time were much easier to come by at the UCI than Mulago Hospital. Staff could not turn these soldiers away, nor could they do anything less than provide impeccable service, lest they become targets themselves of state sanctioned violence. Amin either cast a blind eye to the NIH’s financial pipeline to the Institute, or was unaware of it, as he routinely brought international visitors to the UCI to see Ugandan scientists working at a center of excellence throughout the 1970s.244

It was creative and dangerous work for staff to navigate the mercurial violence of the state. Take the following example. In addition to fieldwork and laboratory work, the UCI collaborated with Kenyatta Hospital’s radiotherapy department to examine the effect of radiotherapy on Burkitt’s lymphoma. Since some of the drugs themselves were unavailable in Kenya, Olweny arranged to ship vials of the drug from Kampala to Nairobi via Akamba buses as part of this clinical trial along with the UCI’s pediatric patients to Nairobi for radiotherapy. The staff member in charge of weekly shipments of drugs to Nairobi did not return to the office one afternoon. He had been arrested and taken to Nakaserro hill by Amin’s state services, where he was interrogated and charged with smuggling Ugandan drugs out of the country and into Kenya. Olweny went to Nakaserro to attempt to bring the staff member back to the Institute in one piece, and was charged with

244 Interview: Charles Olweny, May 2012. Amin’s status at the UCI during this period is also institutional lore at the site. See fieldnotes with Dr. Jackson Orem and others about the memories of Amin and his relationship with the Cancer Institute, 2012.
“stealing the Ugandan nation’s drugs”. In his memories, Olweny recounts patiently explaining to state police what a clinical trial was, and attempting to reason with the soldiers to let him and his procurement officer go. The state police were also familiar with the Institute, had visited the Institute, may have even received an X-ray or anti-malarials at the Institute at one time or another, and finally agreed to let Olweny go. “But your man will stay here and we will release him tomorrow. And they didn’t go back on their word. They released him the next day. But in retrospect people say you must have been a fool. How could you have gone? They could have arrested you and you would never be seen again.”

Amin’s fondness for the UCI and its contributions to African science offered some immunity from the political violence and uncertainty that pervaded the atmosphere in Kampala. But this political support from the state provided a meager buffer against problems of scarcity and broken things that characterized everyday life in the 1970s. It became more challenging over the course of the decade to conduct fieldwork with patients and their families in remote villages, or keep the refrigerators humming at the laboratory. These challenges stemmed partially from the overall deterioration of basic services in Uganda and the soaring costs of petrol, and were much exacerbated when the National Cancer Institute cancelled

245 Interview: Charles Olweny, May 2012.
its financial and administrative support of the UCI in 1977. Olweny was able to negotiate a stand alone budget for the UCI under the Ministry of Health, ensuring that it did not get folded into the administrative crises of Mulago, and also strategically shopped around for partners willing to donate chemotherapy drugs, but work at the Institute greatly slowed after 1977.

But without the support of outside funding, the financial and material limitations of the Ministry of Health made it more and more difficult to pay the salaries of nurses or supply enough serum vials. And public infrastructure continued to deteriorate. Consider Tom Tomusange’s letter to the Engineer in Charge responsible for the operations of telephone in Kampala, penned on October 17, 1977. Tom wrote:

Dear Sir,

Ref: Telephone 41232 at Makerere North House No. 3

This is a residential Telephone for our Director Prof. C.L.M. Olweny. This telephone has been out of order for about two months. We have been contacting your department via telephone 997 almost daily but up to now 41232 is not working!

247 I write about the circumstances driving this decision elsewhere. The short story is that the director of the NCI during the 1970s, Vince DeVita, decided that the research being produced out of the UCI no longer merited the expense and challenges of financing the Institute in an increasingly precarious economic and political situation in Uganda. Further, the UCI’s efforts did not easily mesh with the rest of the agenda for Nixon’s War on Cancer.
Sir Uganda Cancer Institute is a hospital with over 40 patients and this doctor being the over all in charge, is bound to be called any time for emergencies. His house is situated about two miles away from the hospital; and surely without a telephone we are bound to loose [sic] some lives! Please save us before such calamity takes place.

Sir we suggest that if this particular telephone is beyond repair, you give him a new telephone number, we are ready to pay for any extra service rendered.248

Conclusions

After the NCI ended its financial support, the Institute continued to operate at a low level. The results of these studies were published in the Lancet in 1979, at the time of Amin’s departure from Uganda and a war between Uganda and Tanzania.249 The Institute was folded into Mulago National Referral Hospital as a palliative care and triage center for cancer, and an HIV/AIDS research site. Today, the current director of the Uganda Cancer Institute, Dr. Jackson Orem, has strategically used the history of Burkitt’s lymphoma research in the 1960s and the

248 “Letter from Tom Tomusange to the Engineer in Charge, October 17, 1977,” Uganda Cancer Institute Archives.
1970s to make a case that cancer research should be revived in Uganda. Indeed, the Institute’s current slogan is “Research is Our Resource,” which you can see etched into the UCI’s signs pointing up the hill at Mulago, in the board room, and on the UCI’s stationary. This can be read both as a commentary on the state of public health goods in sub-Saharan Africa, and as an invocation of the UCI’s history, in which research, care, and resources, were fundamentally intertwined.

On the wards of the Lymphoma Treatment Center, long-term legacies of research at the Institute persist. Many of the drug regimens that were studied at the UCI to treat Burkitt’s lymphoma, and prevent relapse in the central nervous system are still utilized as the standard of care. But the supporting infrastructure—pathology services, close ties with the surgery department, warm referral relationships with up country hospitals, Volkswagen beetles, time, petrol, and translators who can speak 40 languages and communicate with families—all systems that made Burkitt’s lymphoma survival possible, have atrophied substantially, and are now in the process of being reinvented.

Even though the 1970s were “this political era, the deep years, where all progress was destroyed. All efforts were interfered with. Physically, morally, economically as such things,” staff at the Uganda Cancer Institute kept practices and patients alive. During the 1970s, staff at the Uganda Cancer Institute worked to keep politics out of science through constant acts of creativity in crisis. An ethic of

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250 Interview: Aloysius Kisuule, February 2012.
providing first-rate care in a context of extreme scarcity characterized the work at the Institute. Drawing upon these experiences, Olweny became heavily involved with the World Health Organization’s efforts to put together an essential drug list both for basic hospital care but also for oncology, a lasting contribution to increasing capacity of health systems.\footnote{Interview: Charles Olweny, May 2012.} He argued with a strong painkiller, a multipurpose antibiotic, a broad based deworming drug, and a handful of reliable cytotoxic drugs, you could run a hospital as long as you had dedicated staff. This essential drug list, and long term survival data are just two examples among many that illustrate how the Amin years brought creativity as well as destruction.

Introduction

On October 9, 1978, Idi Amin decided to invade northwestern Tanzania, annex the land bordering the north of the Kagera river, and preemptively stop the Tanzanian government which was apparently plotting against him.252 As Peter Nayenga notes, the invasion was meant to “divert attention from internal problems,” including ongoing conflicts in the leadership of the military and the deteriorating economy.253 The invasion escalated on October 22, 1978, when a group of Ugandan soldiers crossed the border between southwestern Uganda and northwestern Tanzania to have drinks at a Tanzanian bar. The Ugandan soldiers became progressively more and more intoxicated over the course of the afternoon. Later in the evening, one of these drunken Ugandan soldiers, who happened to be an army intelligence officer, opened fire on Tanzanian soldiers who had come into the bar. The Ugandan was shot and killed. Shortly thereafter, Radio Uganda announced that this soldier had been “kidnapped’ and Amin was demanding his return, or there

252 This account of the 1978-1979 Tanzanian-Ugandan war is mainly derived from Tony Avirgan and Martha Honey, War in Uganda (London: Zed Press, 1982). They were two journalists working and living in Tanzania who, upon hearing about the seizure of the area north of the Kagera river by Ugandan forces, requested permission from the Tanzanian government to go and cover the war from the frontlines. The account is written largely from the perspective of observing the Tanzanian army in action, and consequently, highlights the atrocities of Amin’s soldiers, while perhaps overlooking the devastation from a Ugandan perspective. Still, it remains a rich and important account of the war.

would be serious repercussions. Over the next several days, soldiers exchanged fire and heavy mortars. Ugandan pilots flew Soviet MIGS and dropped bombs over bustling towns, such as Bukoba. According to Avirgan and Honey, two journalists who covered the war with soldiers at the frontlines on the Tanzanian side, the invasion of the Kagera region was devastating:

Ugandan troops began an orgy of looting, raping and killing. A total of about fifteen hundred Tanzanian civilians were killed and their bodies left to rot in the African sun. [...] Everything worth taking was looted, from thirteen-thousand prime head of cattle at the Kigengule state ranch to tin sheets from the roofs of peasant houses. Vehicles that would not start were stripped for spares. Personal belongings were looted from houses along with pots and pans. Everything moveable was taken from the Kagera Sugar Factory. Amin's soldiers then set up mortars and, as they swigged waragi, a favorite Ugandan alcohol, they blasted the remaining and heavy machinery into ruins.

Within a few days, Amin flew down to Tanzania and declared that the Kagera River was now the new border between Tanzania and Uganda. Over the next several weeks, Tanzania made the decision to drive the Ugandan army out of the Kagera region. In the process of reclaiming Kagera, Tanzania opted to “liberate” Uganda by invading the country and fighting the Ugandan army until Amin had no choice but to

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254 Avirgan and Honey, War in Uganda, 56-67
255 Avirgan and Honey, War in Uganda, 61-62
back down and in all likelihood surrender his power and authority with the establishment of a new Ugandan government. Idi Amin was like a cancer that needed to be cut out of the region.256

The war that followed in southwestern Uganda, especially in Rakai and Masaka, was devastating to villages and infrastructure, although, for the most part the fighting and bombings spared banana gardens, the major source of survival and livelihood in the region.257 By April 1979, the Tanzanian soldiers had reached Kampala. “Shika Kampala!” translated as “take Kampala” in Swahili, was the call of Tanzanian soldiers as they marched up Entebbe road. According to Avirgan and Honey, as the soldiers approached Kampala, “civilians were waving branches, beating drums and cheering wildly, running alongside and among the advancing Tanzanian troops.”258 Although the Tanzanian soldiers became quite lost in Kampala on their way to Kololo hill, the taking of Kampala was relatively easy. But the looting, criminal activity, and overall insecurity in the city that followed the arrival of the Tanzanian army was intense. People were crushed in efforts to take sugar out

256 Holly Hanson, personal communication.
258 Avirgan and Honey, *War in Uganda*, 133.
of warehouses. Bicycles were pilfered. Rumors circulated that Tanzanian soldiers were raping women in Kampala.

Although it was wracked by long term shortages and infrastructural breakdown, Mulago became a war hospital in 1979. Physicians treated soldiers from both Amin's and Tanzania’s armies. Civilians still came for care. At the top of the hill at the Uganda Cancer Institute, the administration of chemotherapy and the treatment of patients continued. Charles Olweny submitted manuscripts to the Lancet for publishing the survival data on Burkitt’s lymphoma patients who were followed for a ten year period from 1967 to 1977. In September 1979, the manuscript was formally accepted by The Lancet. The editor remarked that the publication “records and extraordinary achievement in the middle of chaos.”

Student health officers stayed overnight in their small room on site in order to tend to emergencies. They remember dodging bullets at night in order to check in on patients whose immune systems were crashing or to manage a patient in the middle of kidney failure. In the midst of these disruptions, long-term cancer survivors still came to the wards for check ups to see whether or not their cancers were still in remission. One long term survivor from the wards of the Lymphoma Treatment

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259 Avirgan and Honey, War in Uganda, 135.
260 For an important rejoinder to these rumors, see Holly Hanson, “Privatized Public Healing: Women’s Narratives of Escaping Violation in Kampala’s Violent Times,” (paper presented at the annual meting for the American Historical Association, Washington, DC, January 2-5, 2014).
261 John Iliffe, East African Doctors, 149.
262 “Letter to John Ziegler from The Lancet editor, September 12, 1979,” Uganda Cancer Institute Archive
263 Interviews: David Serwadda, June 2012, Alex Coutinho, April 2012.
Center who went on to work as a medical officer at the UCI came late for his annual check up, “due to the war of liberation.” In the last entry of his file, this patient signs off on his own blood work, a pause in the middle of chaos that many hoped would promise a new period of peace and stability in Uganda.\textsuperscript{264}

With Obote’s second presidency, the good fortune that had shielded the Institute from the worst of Uganda’s malignant politics under Idi Amin came to an end. Charles Olweny left the directorship of the Institute and Uganda in the early 1980s.\textsuperscript{265} His successor Edward Katongole Mbidde inherited the UCI’s two wards, a laboratory, the X-ray unit, a scientific legacy around combination chemotherapy clinical trials, and a dedicated staff. But Mbidde was unable to negotiate for the continued financial and institutional autonomy for the Institute, and in the mid 1980s, the Uganda Cancer Institute was formally absorbed by Mulago Hospital’s administration and budget.\textsuperscript{266} The Ministry of Health and Mulago Hospital did not prioritize cancer drugs in its budget or staffing needs for the UCI’s 40 beds. In the 1980s, 1990s, and 2000s staff remember getting a few scattershot shipments of drugs a year that were finished within a matter of weeks. Families were asked to

\textsuperscript{264} Patient Files, Uganda Cancer Institute. The potential signifiers of the patient’s identity, such as age of first admission, home village, and diagnosis are not included here to protect the patient’s privacy.


\textsuperscript{266} Interviews: David Serwadda April 2012; Alex Coutinho April 2012; Fieldnotes from conversation with Edward Mbidde August 2014.
shoulder the burden of purchasing chemotherapy treatments for their patients in need.\textsuperscript{267}

The 1980s marked a significant break from the original founding purpose of the UCI, where chemotherapy trials and supportive cancer care were entangled with one another. When the Institute was folded into Mulago Hospital’s bureaucracy, it transformed from being a research institution with beds for chemotherapy clinical trials to a palliative care triage unit.\textsuperscript{268} The Institute’s central purpose was to care for the hospital’s unit for patients with late stage cancers, who were often terminal and living with AIDS. Research efforts remained, especially regarding Kaposi’s sarcoma but these studies were no longer synonymous with the provision of potentially curative or at least remission-inducing cancer drugs.\textsuperscript{269} The cancer chemotherapy clinical trial gave way to a research culture that focused on HIV/AIDS patients who found themselves at the Cancer Institute. Tissue samples from Kaposi’s sarcoma patients were taken and analyzed in labs outside of the country.\textsuperscript{270} Some AZT trials were hosted at the UCI.\textsuperscript{271} Cryptococcal meningitis and its treatment were

\textsuperscript{267} Interviews: MK March 2012; FO March 2012; SB August 2012. These accounts are corroborated by patient records from the 1980s, 1990s, and 2000s.

\textsuperscript{268} Ibid.


\textsuperscript{271} The Uganda Cancer Institute’s archive held boxes of expired AZT medications from a prior clinical trial. They were thrown out in June 2012.
investigated. This is simply to say that by 1986, the UCI was no longer a place where researching the effects of chemotherapy on long-term cancer survival was at the top of the agenda. And in the absence of chemotherapy clinical trials, the financial and institutional support that guaranteed a regularly available therapeutic arsenal withered. The Uganda Cancer Institute developed the reputation at Mulago Hospital as the place where you were sent to die.

From its inception in 1967, chemotherapy, be it administering the drugs, managing the side-effects, and documenting whether or not the drugs created durable cancer remissions, defined the purpose and presence of the Uganda Cancer Institute. The harming properties of the drugs could bring about nearly magical healing, which captured the imagination of Denis Burkitt and a whole generation of Burkitt’s lymphoma researchers. The drugs were the principle therapy for cancer in a place without radiotherapy technologies. Chemotherapy was an expensive commodity, only available through patronage, be they drug companies, the National

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276 This was true from the time of the UCI’s founding in 1967 up to the mid 1970s. Radiotherapy services did not come to Uganda until Lacor Hospital, a private Catholic Hospital in Gulu run by Italian Comboni Missionaries set up a donated radiotherapy machine on the hospital grounds in the late 1970s. Mulago National Referral Hospital received a donated radiotherapy machine in the early 1990s.
Cancer Institute, the Ugandan state, or the pooling of family resources. The drugs were the independent variables in randomized clinical trials. Evaluating the effects of combination chemotherapy clinical trials and tracking the long terms survival of cancer patients was the research agenda that kept the UCI open and supported by external partners in the 1970s. Maintaining these studies was the key to accessing a steady supply of drugs in the 1970s, first through funds from the NCI and later through support from Amin's Ministry of Health.277 But from the 1980s onwards, civil war, structural adjustment, and HIV/AIDS all shaped the reconstruction of health services.278 Revitalizing chemotherapy clinical trials research on cancer in Uganda was not a priority.279 The sporadic availability and frequent absence of

279 National Cancer Institute politics helped to shape why resuming chemotherapy clinical trials in Uganda did not occur in the early 1980. Most of the strong supporters of the UCI in Bethesda left to pursue careers in academic oncology at the University of Wisconsin and the University of California, San Francisco, among other institutions in the late 1970s and early 1980s. Knowledge about treating Kaposi's sarcoma, which came out of evidence produced at the UCI in the 1960s and 1970s was used and helped to shape approaches to managing and treating KS as a
drugs due to limited government drug procurement budgets, rather than the continuous presence of freely available chemotherapy thanks to sponsorship from NCI sponsored clinical trials, defined work at the UCI from the early 1980s up until the late 2000s.

The first part of the chapter discusses the transformations at the Uganda Cancer Institute in the early 1980s, with an attention to institutional transformations and the discovery of HIV/AIDS on the wards. In the following section, I discuss the ways in which the violence and unrest from the war of liberation in 1979 and the prolonged civil war shaped everyday understandings and practices of care on the wards in the 1980s. Accounts from nurses and physicians who worked at the UCI in the 1980s discuss how technologies of violence, particularly Soviet manufactured rocket launchers that were used during the Tanzanian invasion, were akin to the embodied effects of cancer treatments, particularly chemotherapy. The third part of the chapter discusses the ways in which patients, caretakers, physicians, and nurses navigated the scarcity and absence of chemotherapy drugs on the Uganda Cancer Institute’s wards from the 1980s up to the late 2000s. Here, I focus on the story of Dr. Fred Okuku, a student health officer in the 2000s who now works at the Institute as a medical oncologist. Dr. Fred’s story shows how the availability of chemotherapy at select moments, usually purchased with the money of patients and their caretakers, brought “success consequence of HIV infection. See, for example: C. Olweny, M. Hutt, and R. Owor, editors, “Kaposi’s Sarcoma,” Antibiotics and Chemotherapy, 29 (1981).
stories” in terms of prolonging life, but also how families and biomedical caretakers adapted to conditions of profound scarcity. The chapter concludes with a coda about chemotherapy in the present, where the advent of government supplied chemotherapy and the vast increase in patients at the UCI since institutional autonomy in 2009 has dramatically changed the administration and use of chemotherapy. Taken as a whole, this chapter shows how coping with the limited availability of chemotherapy, what Olweny called the “armamentarium” of the medical oncologist, defined everyday practices of cancer care on the wards of the Uganda Cancer Institute in the 1980s, 1990s, and 2000s.

*The Liberation War That Did Not Bring Peace*

After the war of liberation, Charles Olweny and Edward Mbidde imagined that they would transform the Uganda Cancer Institute into a center of oncology excellence in the country. In the early 1980s, the World Health Organization planned to create three cancer centers in sub-Saharan Africa, and the UCI made a strong case that one of these centers should be in Uganda. Olweny envisioned a site that would continue to do cutting edge research, but also offer cancer care to the general population with the acquisition of a radiotherapy unit and a rehabilitation of the pathology department. This required serious re-investment in the Institute, and the rehabilitation of Mulago’s infrastructure and services as well.

In October 1979, six years after Olweny left the United States to come back to Uganda and run the Institute, he returned to Washington, D.C. on a mission to secure
the funds to restore Makerere Medical School and Mulago Hospital. In the wake of the war of liberation, the remaining physicians and administrative staff of the Medical School and Mulago took stock of the fall out of eight years under Amin. The situation was dire and difficult:

The health care services provided that once was the envy of most of Black Africa had almost become nonexistent. There was a continuous brain drain throughout the 8 years and some of the departments within the faculty had to close down for lack of personnel. Recruitment became impossible. Laboratories could not offer even the simplest tests for lack of reagents. Drugs were constantly in short supply, and even life-saving drugs were more often than not out of stock. Equipment were never serviced and because of lack of spare parts the hospital workshop was turned into a graveyard for some very vital and expensive equipment. The linen was never replaced and because of soaring inflation some mattresses, sheets, blankets, were carried away by petty thieves. The Faculty library stopped stocking new books and periodicals were never paid for. Research laboratories closed down for lack of proper supervision, chemicals, equipment and above all competent technical staff. This, briefly, was the state of
affairs when the new regime moved in at the overthrow of dictator Amin.280

The Deans of the Medical School, the Director of the hospital, and the Ministry of Health requested $4,625,000 in aid from the United States for immediate needs. New basic equipment needed to be ordered for nearly all of the wards to replace the old that was either broken or stolen. Drugs and vaccines were needed to stave off the threat of measles and polio epidemics. Many of the buildings were damaged during the war and most were poorly maintained during Amin’s period. These facilities were in need of re-electrification, sewerage, and basic repairs. On the manpower front, expatriate and Ugandan physicians who had fled Uganda in the 1970s needed to be given incentives to come back and rehabilitate the medical school’s teaching program. The plan was to reinvigorate and establish partnerships with American medical schools. In addition to these immediate needs, $5,250,000 was requested for a variety of smaller but vital projects. The medical records room was in chaos. The blood bank had ceased to function and was in need of reagents and refrigerators. There were no working clocks on the walls. The intercom system had been decimated. 18 ambulances, 36 bed trolleys, and 24 wheel chairs were needed for the movement of patients inside and outside of the hospital.281

280 “Summary Proposal for the Rehabilitation of Makerere Medical School Mulago Hospital Complex in Kampala, Uganda,” Uganda Cancer Institute Archives.
281 Ibid.
Olweny also used this travel opportunity to highlight the importance of maintaining the Uganda Cancer Institute, and renewing the vital connection between U.S. based institutions and the UCI. He was particularly anxious to resume the provision of chemotherapy drugs. The cost of the drugs, prohibitively expensive, made it difficult to treat patients at the Institute.\footnote{The prohibitive costs of drugs came in part because the Ugandan economy was severely gutted and the Ugandan shilling was all but worthless for purchasing drugs. See Frederick Cooper, \textit{Africa Since 1940} (Cambridge: Cambridge University Press, 2004) for a discussion of the catastrophic economics of the 1970s and 1980s in Africa.} In the context of reconstruction, where basic medications like aspirin and materials like bed sheets were out of stock, making a case that purchasing cytotoxic drugs should be a priority was a challenge. Olweny argued that the UCI was a touchstone of US-Uganda relations as a whole and a vital center of knowledge production. As the proposal noted, “The UCI has been a source of good will between the respective governments of Uganda and the USA. The cancer research program has added a great deal to Makerere’s reputation on the academic map. Over the past 12 years, over 200 publications in international journals have been generated from the Institute.”\footnote{“Summary Proposal for the Rehabilitation of Makerere Medical School Mulago Hospital Complex in Kampala, Uganda,” Uganda Cancer Institute Archives.} Revitalizing the Institute would mean renewing and strengthening US-Uganda relations. And maintaining the Institute depended on a steady supply of chemotherapy drugs and other tools of the medical oncology trade. As Olweny wrote, “The last 8 years have placed the Institute under considerable strain. Cancer chemotherapy drugs are extremely expensive and
since radiotherapy facilities are not available the drugs are a must to the armamentarium of oncologists practicing in Uganda.”

Olweny received an emergency grant of $10,000 for vital chemotherapy drugs and other sundries. They purchased needles for bone marrow aspirates and chemotherapy administration as well as allopurinol tablets to prevent tumor lysis syndrome. In terms of chemotherapy, they procured $5,684.04 worth of methotrexate, $2,470 of cosmogen (dactinomycin), and $1,330 of mustagen (mechlorethamine). (These drugs are particularly suited to treating lymphomas and some childhood tumors like Wilm’s tumor.)

On his visit to the US and the UK, Olweny succeeded in making the rehabilitation of Mulago a central issue for foreign aid dollars, and one that would have an immediate impact in Uganda. As he wrote, “The trip was fruitful, worthwhile, but tiring. It is hoped that the State Department will probably provide funds to enable the program to take off.” Renewing ties and exchanges with long term expatriate physician friends of Uganda and those who had run away under Amin would be critical, and it would be necessary to show them proper hospitality, accommodation, and “all amenities including food and transport.”

284 Ibid.
286 “Report on Visit to USA and UK by CLM Olweny, October 29 1979,” Uganda Cancer Institute Archives.
287 Ibid.
Although Amin fled to exile in Saudi Arabia, the Tanzanian liberation of 1979 did not bring peace. Squabbles and power struggles regarding who would assume control of the country followed, and within a few months, Uganda’s ousted leader, Milton Obote, returned to State House as President. From 1980 to 1986, a period of prolonged civil war and conflict between Milton Obote’s second government and guerilla forces of Yoweri Museveni’s National Resistance Army devastated central Uganda.\hspace{1em}\textsuperscript{288}

Obote’s second presidency proved to be disastrous for the Institute. Olweny, decided to leave Uganda and go into exile after it became clear that his life was in danger in the early 1980s.\hspace{1em}\textsuperscript{289} Olweny left the Institute in the very capable hands of Dr. Edward Mbidde, who worked on the wards for much of the 1970s. His professionalism, accomplished intuition as a chemotherapist, and research abilities made him an obvious fit for training as the country’s second oncologist. Arrangements had already been made in the early 1980s that Mbidde would pursue an overseas advanced training in medical oncology, with the expectation that he and Olweny would work together to ensure the smooth functioning of the unit while Olweny worked at the helm of Mulago Hospital and, eventually, the Ministry of Health. But given Olweny’s quick decision to decamp from Uganda and work in Zambia (and later on, Zimbabwe, Canada, and Australia), this smooth hand over did not occur. Decades later, as I was driving in my own Rav4 along Bombo road by

\hspace{1em}\textsuperscript{288} See Hansen and Twaddle, \textit{Uganda Now}.

\hspace{1em}\textsuperscript{289} Interview: Charles Olweny, May 2012.
Mulago Hospital with some of the now elderly administrators who worked at the UCI during the early 1980s, they reminisced about that handover. They said they saw soldiers driving Olweny’s red Volvo around town on joyrides after his departure. They joked that there was more thorough hand over of Olweny’s possessions to the Ugandan state than there was of the administrative and institutional duties of the UCI. Uneasy laughter accompanied their memories of this period when they said, “With Olweny and Ziegler, there was a hand over. With Mbidde, there was no hand over.”

**Mbidde and the Museum**

Edward Mbidde first came to the top of the hill when he was a medical student at Makerere and on his vacation between first and second year. In March 1967, he had an opportunity to come work with Dick Morrow who was doing Burkitt’s lymphoma epidemiology research at the time. It was Mbidde’s first contact with the site. Over the next few years, Mbidde lived down the road from the UCI in medical student housing, and used to see Vogel and Ziegler coming and going up and down the hill from the Institute. He was fascinated by the work on the wards with cancer and oncology and also intrigued by the research opportunities. At the end of his third year of medical school he had the opportunity to apply for a studentship, which was extremely competitive. It turned out that they thought he was a fourth

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290 Fieldnotes, May 2012.
291 This account of Edward Mbidde’s story is derived from a public round-table with past UCI directors at the Institute’s first history symposium in August 2014, and a conversation with Mbidde that I fieldnoted on the same day, August 2014.
year in his studies because he seemed so impressive. Nonetheless, he was able to join and worked on the Lymphoma Treatment Center side and, “Never looked back.” Like Olweny, Mbidde was heavily mentored by Ziegler, Vogel, Kyalwazi, McAdam, and other mentors that the Uganda Cancer Institute. In his final year of medical school, Mbidde became involved with research on big spleens at the Institute. He and colleagues were traveling 60 miles out into rural areas, collecting blood samples, separating out sera, securing it in freezers for further study and transport. These two activities—on the wards and in the research capacity—cemented both tireless work ethic within Mbidde and a commitment to patients. He remembers one evening doing up country work and preparing to leave the Lymphoma Treatment Center that night after processing serum. At that point, Avrum Bluming had brought in a 13 year old girl who desperately needed care. “Edward, you have to stay and work up this girl.” And so he did.

After this work he did an internship in New Mulago and later had an opportunity to rejoin the UCI as a Medical Officer. This was the time that Amin came in on the scene—the manpower at the hospital dropped down to a third of its normal capacity. He joined the UCI in May 1974 and continued to work at the UCI on the wards as the a Medical Officer special grade after finishing up his internal Med Masters. Mbidde was for all intents and purposes, the deputy of the Unit and worked closely with Olweny on the wards and in the lab. In the early 1980s, when Olweny went on sabbatical, he never came back. This left Mbidde as the only doctor in charge, trying to maintain standards was very difficult in these times. They were
able to secure some lines of credit for drugs, but it was very hard to get staff, and patients found that their mobility was very challenging in these times of great insecurity.

In 1984, Mbidde went to Edinburgh for about three months of further training and then later received a WHO fellowship for more formal training in medical oncology for a two year fellowship in the UK. All the while the situation in Uganda was no better. There was war. There was death. And there was a question: “Should I come back?” Colleagues in the UK asked, “Are you sure you want to go back?” Mbidde said, “the people who paid me were the peasants [to go to school]. Am I going to abandon them?” Mbidde came back just as Museveni had taken over as president and there was relative peace. Mbidde’s work was to “try and put things together” to get drugs and other sundries. “I started from scratch, getting infrastructure, better drugs.” And meanwhile although Mbidde had people coming in and working and going, most left or “disappeared.” Of this team, it was really only Jackson Orem who, as a Student Health Officer ground his heels into the culture of the place, and who stayed over night tending to emergencies.

Mbidde was able to keep the place going in the 1980s, 1990s, and 2000s when resources were so limited by maintaining high standards. “I wanted things [done] the right way.” He used to arrive very early, and “could not go home until I finished my work.” He had colleagues who would come and ask what was keeping him in his office at such late hours “there’s a lot of work for me to do.” Sometimes
that would mean ward rounds at 9:30 in the evening. He had an incredible team of nurses who were committed to patients and also to getting him what he wanted, when he needed it. “I had my own systems.” He could get a blood slide in 10 minutes. With a lumbar puncture, he could get the results immediately.

These systems operated alongside a series of research partnerships mainly focused on HIV/AIDS. As early as 1987, collaborators were coming to the Uganda Cancer Institute to conduct HIV research. Fogarty, NIH, UCSF, Case Western, Oxford University—they all came with research protocols for specimen collection, survey research, and clinical trials—but with just enough equipment to get the job done.

Although the UCI became a triage unit operating under conditions of “normal emergency,” the everyday practices of cancer care established in the 1960s at the Institute continued. Nursing procedures, ward rounding practices, X-ray taking, and meticulous record keeping remained relatively intact, despite the fact that the drugs were rarely available and the patient follow up fieldwork, so critical to maintaining the Burkitt’s lymphoma studies across the country in the 1970s, had

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293 For more on the idea of triage and medical practice as it relates to HIV/AIDS in sub-Saharan Africa, see Vin-Kim Nguyen, The Republic of Therapy, (Durham: Duke, 2010). For more on the practice of medicine at the precipice of emergency, see Peter Redfield, Life In Crisis: The Ethical Journey of Doctors Without Borders, (Berkeley: University of California, 2013).
long ended. Dr. John Ziegler, who returned to work in Uganda in the early 1990s at the UCI as a lecturer at Makerere Medical School noted in an oral history:

I’ve been back off and on since 1990 and the place is like a museum. It still runs exactly the way it used to run, and everything is still in place. Some of the nursing sisters who were there are still there, and Dr. Mbidde, of course who was trained by us and then went on to further oncology training in Britain, still runs the center very much in the same way. He’s an extremely competent oncologist.294

This “museum,” was an exhibition of practices and procedures that had not changed dramatically since the 1960s. Although they often lacked the materials necessary to offer meaningful treatments for cancers that had been successfully treated at the Institute in its heyday, the Institute still saw patients who offered a great wealth of case material, particularly with regards to Kaposi’s sarcoma.

**AIDS in San Francisco, SLIM in Kampala**

In June 1981, Alex Coutinho, a third year medical student, moved into the small living quarters on the Uganda Cancer Institute’s campus to take up residency at the Solid Tumor Center as part of the Institute’s annual prestigious medical training program in oncology. During the day, Coutinho and his Sudanese counterpart at the Lymphoma Treatment Center were just normal medical students

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attending classes. But in the evenings, at five pm just as the rest of the students were retiring to have dinner or study for exams, the work picked up for Coutinho. He would walk into the ward of the Solid Tumor Center, check in with the nurses, and start the evening ward round. Going from bedside to bedside, he would meet the new patients who were admitted earlier that day, address the side effects of chemotherapy, particularly kidney failure or dehydration from extreme vomiting, and try to finish up before it got too late or too dark. Then, he would return to his quarters, try to ignore the sounds of ongoing gunfire at night, and wait and see if the land line would ring—the signal that there was a patient emergency on the wards of the Solid Tumor Center. Or sometimes, there would be a knock on the door, as the landlines were often out of service.295

In the aftermath of the war with Tanzania in 1979 and the increasingly violent unrest between the National Resistance Movement’s guerilla army and the Ugandan government’s military, the atmosphere in Kampala was decidedly tense and also quite physically insecure.296 At Mulago Hospital and Makerere Medical School, there were both shortages of basic supplies and also teaching staff, making the Uganda Cancer Institute, which was headed at the time by Olweny and Mbidde, as a decidedly attractive place. As Coutinho remembers, “Hungry students would be looking for someone of caliber to teach them.”297 Ward rounds with Olweny and Mbidde, who had 30-40 years of experience in oncology between them, an ongoing

295 Interview: Alex Coutinho April 2012.
296 Kasozi et. al., The Social Origins of Violence in Uganda, 145-163.
297 Interview: Alex Coutinho April 2012.
oncology research program, and the patients all made the UCI a hugely desirable place to learn. Despite the bullets at night, “the beauty of working there was that you could do proper medicine.”298 Because there were x-ray services and laboratory services in house, they were less dependent on Mulago Hospital, although there were still stock outs and shortages to contend with. “Somehow we were fatalistic. We never complained. We never went to Olweny to say sorry we need security guards because security guards were also running away.”299

Despite these insecurities, in the early 1980s, before Olweny went into exile and before Mbidde went to the United Kingdom for further oncology training, colleagues at the Uganda Cancer Institute continued to conduct research and stay connected to the international cancer research community through a combination of reading journals, attending international conferences, and hosting them. In early 1980, the Uganda Cancer Institute hosted the second international conference on Kaposi’s sarcoma, distilling the key findings conducted at the UCI in the 1970s.300

Essentially a year later, colleagues agreed that they seeing more and more cases of Kaposi’s sarcoma in women and children on the wards of the Solid Tumor Center. “I saw my first HIV patient in the Cancer Institute. I had no idea it was HIV of course. But it was one particular ward round. I remember it clearly. And we were seeing more and more Kaposi’s sarcoma in women despite it being historically a

298 Interview: Alex Coutinho April 2012.
299 Ibid.
male disease. And Carswell commented I’ve just been reading a paper that they’re seeing a lot of Kaposi’s in SF and New York and it’s some new disease among gay men. No connection. But I realize now that it was the first HIV case that I saw.\textsuperscript{301}

At the time of our conversation about his memories of working at the Uganda Cancer Institute, Coutinho was the director of the Infectious Diseases Institute on Mulago’s campus. From his days as a medical student at the Uganda Cancer Institute to the present, much of his career in medicine was shaped by directing medical services for the care and research of the HIV/AIDS epidemic in sub-Saharan Africa, both in Uganda but also farther afield in Southern Africa.

In Kampala, staff at the Uganda Cancer Institute read about the emerging epidemic in the United States through the international postal system as they saw more and more cases of aggressive KS. The Institute ran a journal club on various topics of interest in oncology. Even in the midst of unrest, up to date copies of \textit{The New England Journal of Medicine} and \textit{The Lancet} still made it to the Institute for reading and discussion. Sitting around the table, staff at the UCI discussed the papers trickling in on Kaposi’s sarcoma in young, white, otherwise healthy males in America. As David Serwadda, who went on to be a co-principle investigator in Rakai on numerous HIV related research studies, recalls, “Now, on solid tumor, we had been dealing with KS for a long time. And so that’s why these articles were of interests to us. They talked about aggressive sarcoma among white men. So you

\textsuperscript{301} Interview: Alex Coutinho, April 2012.
know, the KS that we saw at the cancer Institute was anything but aggressive. It was very mild and usually you would treat it with a cytotoxic drug. I saw a number of people who were cured, really. Put on their shoes and they went back [home]. But if you saw it in women, it was of the aggressive type that we were seeing in white males in the US.”

Colleagues at the Uganda Cancer Institute were deeply curious about why there were such profound gender and racial differences in the presentation of aggressive KS between the United States and Uganda. Of course, there was lag time in learning more about how the situation was unfolding in America. As Serwadda said, “Remember. No Internet. They [the journals] were coming by post. But they would take a while. [The lag time] was huge. No international calls. You’d have to call the post office and make a booking.”

Initial research and publications concerning this new manifestation of Kaposi’s sarcoma on the wards of the Uganda Cancer Institute carried on in a style similar to much of the work at the Institute as it was practiced over the past fifteen years. For one, it was highly descriptive and case driven. Serwadda’s 1984 publication on KS in Uganda focused on four cases of aggressive Kaposi’s sarcoma and included detailed case notes and photographs of two of the four patients, visibly deformed and swelling from the cancer. And in the style of many Cancer Institute inquiries, the patients were randomized to different chemotherapy drug regimens.

302 Interview: David Serwadda, June 2012.
303 Ibid.
In this case, they either received repeated infusions of a single agent of Adriamycin or a cocktail of Actinomycin-D, vincristine, Adriamycin, and imidazole carboxamide. These combinations and single agents followed the treatment regimens for KS established at the Institute first by Chuck Vogel et. al., and then refined by Charles Olweny. And, in the spirit of keeping practices within the systems of the Institute, they also made laboratory assays in house, using ELIZA techniques and HTLV-III antigens derived from local patients.304

By 1983, colleagues across east and central Africa were also making note of aggressive KS. For example, in Lusaka, Zambia, the surgeon Anne Bailey noticed more and more cases of aggressive KS on the wards and partnered with Olweny, who was now affiliated with the World Health Organization, to set up KS surveillance and treatment in the country. Between 1983 and 1985, colleagues worked between Kampala and Lusaka to determine if they were in fact seeing the same sort of aggressive Kaposi’s sarcoma in both places, and if existing drug regimens developed at the Uganda Cancer Institute in the 1960s and 1970s would help to mitigate aggressive Kaposi’s sarcoma. They were also interested in whether

patients with either generalized or aggressive Kaposi’s sarcoma tested positive for HTLV-III.305

Meanwhile, in the early 1980s, John Ziegler left the East Coast and the National Cancer Institute for a position at UCSF in San Francisco. The timing of his arrival in the city of sand and fog was auspicious. His colleagues were seeing an explosion of young gay white men in emergency rooms and in hospital beds throughout San Francisco presenting with Kaposi’s sarcoma and suppressed immune systems. Ziegler was one of a handful of American physicians who had clinical experience with Kaposi’s sarcoma. Much of the working knowledge regarding disease presentation, chemotherapy combination treatment, and staging systems came directly from prior research experiences in Uganda in the 1960s and 1970s. Ziegler also drew upon the experiences of running clinical care systems in underfunded contexts. He and colleagues such as Paul Volberding spearheaded the initial San Francisco based Kaposi’s sarcoma clinic, and later expanded this to the San Francisco AIDS Clinic. In this way, knowledge and practices developed at the Uganda Cancer Institute made their way far beyond Kampala.306

305 Letter Ann Bayley to Charles Olweny WHO Tropical Diseases Research Centre Box 71769 Ndola, 26 November 1982, Ann Bayley Papers, PP/Bay/F/3, Wellcome Library.
The early work conducted at the Institute on the emergence of the Kaposi’s sarcoma epidemic in Uganda in relation to the outbreaks of KS in young adult men in San Francisco and New York proved to be extremely important. Resolving the apparent incommensurabilities between what would become HIV in San Francisco and HIV in Kampala was fiercely productive, creating a rich exchange that relied fundamentally on knowledge previously generated at the UCI about KS and the patients coming to the STC.\textsuperscript{307} But the research agenda that emerged about HIV in Uganda over the next decade—the fundamentals of its etiology, the disease’s heterosexual patterns of transmission, the time from HIV infection to AIDS, identifying who was at risk—reflected a set of research priorities that were quite different from the care priorities on the wards where very, very ill patients needed immediate comfort and care. The research questions being asked in the 1980s and 1990s (and indeed today) called for blood taking and HIV positive person cohort development.

In contrast to the cancer research at the Institute in the 1960s and 1970s, there were no therapeutic bullets on deck, nothing that would magically make HIV related issues disappear. Staff at the UCI did not necessarily need chemotherapy clinical trials for Kaposi’s sarcoma patients or randomized controlled experiments to see if oral morphine makes a difference in end of life care—staff knew what was needed from decades of prior experience and evidence making at the Institute. Saline for rehydration after explosive diarrhea, opiates for crushing pain, antibiotics

\textsuperscript{307} Ibid.
for opportunistic infections—these were the pressing needs on the wards. At the same time, Ugandan physician-researchers like Mbidde (but also many others) found themselves in a hugely challenging situation where ‘cutting edge’ HIV research did not necessarily map on to their work as clinicians. Ugandan physicians were simultaneously principle investigators, hosts to international collaborators, cultural brokers, money transfer managers, ethicists, and above all, physicians on the front lines of a long and protracted social and medical emergency that was the HIV/AIDS epidemic in Uganda in the 1980s and 1990s.

This isn’t to say that research collaborations at the Cancer Institute were moribund in the 1980s, 1990s, and early 2000s or that Ugandan physicians at the Institute simply worked as gatekeepers. The Institute saw many HIV positive patients with Kaposi’s sarcoma and other AIDS related malignancies in the 1980s, 1990s, and early 2000s, but these patient populations did not necessarily bring large scale international investments in the infrastructure of cancer research or care during this period. A collaboration with UCSF physicians did form a Kaposi’s sarcoma study group in the late 1980s and early 1990s that was quite active. At the UCI, patients with HIV related Kaposi’s sarcoma were (and continue to be) remarkably abundant. At the same time, Ugandan bodies and communities provided a tremendous wealth of clinical, serological, and epidemiological evidence on the HIV epidemic in sub-Saharan Africa. In particular, the community of Rakai in southwestern Uganda was turned into a large scale population cohort where one could study HIV—some staff who cut their teeth as medical students at the Cancer
Institute went on to spearhead the Rakai project and also animate some of the largest community based HIV care operations in the country like The AIDS Support Organization (TASO). All of this is to say that clinical staff at the UCI, who were operating under a severely constrained budget after being folded into Mulago hospital, faced the reality that they were now operating under a triple mandate—run a palliative care facility where people were sent to die from lower Mulago Hospital, try to provide cancer care and treatment support to patients who were able to purchase their own drugs, and serve as a hub for collaborations with international medical researchers.

**Rocket Launchers and Toxic Drugs**

In the 1980s and 1990s on the wards of the Uganda Cancer Institute, the violent effects of chemotherapy technologies were equated with the collective experience of violence during the war of liberation in 1979. According to nurses and medical officers who worked on the wards of the Uganda Cancer Institute from the period of 1986 to 1995 or so, chemotherapy treatments were called *saba saba*. *Saba saba* is translated in Swahili as “seven seven.” Colloquially in Tanzania, *saba saba* refers to July 7, 1954, the day that the Tanganyikan African National Union (TANU) political party was founded. In a Ugandan, *oku-saba* means “to ask” in Luganda. Among Protestants, *oku-saba* can also mean “to pray”. *Saba saba* was the

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expression Kampala residents used to describe the Soviet rocket launchers used by Tanzanians and the booming of these rockets during the war of liberation in 1978 and 1979, an allusion to Tanzanian liberation and nationalism politics.

Dr. Margaret Nakaketo, one of Uganda’s only neonatologists, worked at the Uganda Cancer Institute with Mbidde from 1985 to 1993 as the medical officer in charge of the Lymphoma Treatment Center. When Mbidde was out of the country, she often assumed leadership of the whole of the Institute. She imagined that she would become a pediatric oncologist, but irreconcilable differences with Mbidde about the strategies of triage and rationing of drugs at the Institute led to her departure in the early 1990s. Speaking about her memories of working at the UCI in the 1980s and 1990s from behind her desk at the private pediatric clinic she now runs in Rubaga, her “retirement” after creating a hugely successful premature baby survival program at Mulago, she recalled the relationship between chemotherapy and the war:

When there was the war in Uganda, the Tanzanians, when they came for this liberation they had this big gun, which used to throw the bombs. And we called it saba saba. And so the patients had named this drug saba saba. The chemotherapy. It would hit them [snapping fingers]. The hair goes out [snapping fingers]. The next day they are anemic. They are weak. Some would vomit when hit by the drug so
they called it *saba saba*. Nobody told you? They would come for their
*saba saba* and it would really hit them.\(^{309}\)

As Nakaketo recalled this story, she emphatically and rhythmically snapped her
fingers to punctuate the way that chemotherapy treatments violently hit the body.
Administered through a push injection, the drugs feel like a thunderous clap. The
blood counts crash. The eruptive vomiting comes. Eyebrows, eyelashes, pubic hair,
and the hair on one’s head comes out in clumps. For those living in Kampala during
the time of the Tanzanian invasion, *saba saba* hit buildings, farming land, roads, and
radio towers. Those who remember *saba saba* remember the rockets were different
colors. Pinks, greens, blues, and smoky greys painted evening skies. When *saba saba*
was fired, it let out a terrifying, tearing, screeching sound.\(^{310}\) Germans called these
rocket launchers “Stalin’s Organ” because of this particularly harsh and terrible
sound in World War II.\(^{311}\)

Chemotherapy treatments as *saba saba* connected the booming of bodies on
the wards of the Uganda Cancer Institute to the broader experiences of the body
politic in the 1980s and 1990s in Uganda. Bombing a targeted area with devastating
effect and little precision—what *katyusha* rockets are made for—can also be

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\(^{309}\) Interview: Margaret Nakaketo, June 2012.

\(^{310}\) This discussion of devastation and rockets in technicolor is drawn from
conversations with older UCI staff about what they remember about the war with
Tanzania and *saba saba*. My description of the sound of *saba saba* is derived from
watching a series of World War II videos of *katyusha* rockets in action.

\(^{311}\) Steven Zaloga and James Grandsen, *Soviet Tanks and Combat Vehicles of World
extended to describe, in general, the style of oncology practice at the UCI from the mid 1980s onwards. The end of randomized trials and regular drug supplies meant that nurses and oncologists were left to bombard the body with whatever happened to be sporadically available. This practice worked directly against the logic and findings of approximately a decade and a half of research conducted at the Institute. As Dr. Nakaketo remembers: “The drugs were never available. So most of the time we had to think of combinations. You would give a combination and one drug would be missing. These days at least I know they are available in the market. But those days, it was not in the country if it was not a the Institute.”  

The shift from researching chemotherapy combinations and their effects to using whatever was available in the “armamentarium” of the oncologist that particular month or week to alleviate suffering was debated and contested in the period where Dr. Nakaketo worked at the UCI from 1986 to 1993. Most of the patients at the Solid Tumor Center came with fulminating, AIDS related Kaposi’s sarcoma. Wound cleaning, fluid administration, making patients comfortable, and providing palliative care made up the majority of the nursing work on the STC side. The occasional patient would come with advanced stage hepatocellular carcinoma, and there would be negotiations with pharmacies and families to try to put together the funds to purchase Adriamycin to debulk the tumor. On the Lymphoma Treatment Center side, children with Burkitt’s lymphoma still came to the wards, as did patients with leukemia and other kinds of lymphomas. HIV positive children

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312 Interview: Margaret Nakaketo, June 2012.
came to the wards with Kaposi’s sarcoma. Their blood and biopsies were taken for ongoing research studies in collaboration with German scientists on pediatric Kaposi’s sarcoma, but a treatment program was not part of the research agenda.\textsuperscript{313}

Under these circumstances, “We would get a lot of terminal stage [patients] with huge tumors. I remember I would take a lot of risks. Dr. Mbidde would say you cannot put drugs in that one. And the patient would just die,”\textsuperscript{314} said Dr. Nakaketo. When she was able to act on her own (that is, when Mbidde was out of the country), she often took “risks” during her work at the UCI from 1986 to 1993. At one point, a lymphoma patient with a huge abdominal tumor came to the Lymphoma Treatment Center and “Mbidde said that one is going to die. But he was so uncomfortable. He was going to die anyway but maybe there is a 1\% chance that we’ll reduce the tumor a bit so he’ll be more comfortable.”\textsuperscript{315} Nakaketo had the patient sign a consent form saying that he understood that he was taking a highly toxic drug that might not have any benefit. His tumor significantly reduced over the course of several rounds of treatment, before he eventually passed away. This sort of administration of chemotherapy at late stages of illness brought Nakaketo into active conflict with Mbidde, who did not want her “taking risks with these patients,”\textsuperscript{316} and in the process squandering the scant supplies of drugs on patients who were certainly

\textsuperscript{313} This account is derived from conversations with nurses and staff who worked on the wards during this period, and is corroborated by patient records in the 1980s and the 1990s.
\textsuperscript{314} Interview: Margaret Nakaketo, June 2012.
\textsuperscript{315} Ibid.
\textsuperscript{316} Ibid.
going to die of their cancers or the complications of the drugs. The patchily available

drugs needed to be saved for conditions that might actually bring about a “durable
remission,” like Burkitt’s lymphoma patients who still came to the Institute for care.

In 1993, Nakaketo submitted her resignation and went on to specialize in pediatric

neonatology. Today at her clinic, she still treats the families of some of the patients

she treated for cancer in the 1980s and 1990s. The children with leukemia are long
deceased, but she is still in touch with a few Burkitt’s lymphoma patients in long-
term recovery. They still remember arriving at the Lymphoma Treatment Center

clinic no later than seven in the morning to get their blood work done before

treatment.

What does it mean that on the wards of the UCI chemotherapy treatments

became synonymous with saba saba? It was a joke on the wards to a certain extent.

Patients would come for their rounds of poisoning. After arriving early in the

morning for blood work to ensure that their white cell counts were adequate and

that their livers were in working order, patients would either be admitted onto a

bed and receive their drugs, or they would sit on a hard wooden chair in the

“outpatient” areas of the Solid Tumor Center and Lymphoma Treatment Center,

which doubled as reception areas and nursing break areas. “It’s time for your saba

saba!” was a moment of levity, as nurses would look for veins on the hands of
patients to insert cannulas and then push in vincristine, cyclophosphamide, and methotrexate.\footnote{317 Interview: Mary Kalinaki, March 2012.}

Although I worked in interviews and on the wards to elicit greater reflection on what calling chemotherapy treatments \textit{saba saba} meant for cancer patients and their care providers in the 1980s and 1990s at the UCI, the conversations stopped after confirming that cancer chemotherapy treatments were equated with rocket launchers, and that the war of liberation continued and exacerbated instability and violence in everyday life in Kampala. In one such conversation about chemotherapy administration, Sister Mary Kalinaki, the long term nursing sister in charge who worked at the UCI starting in 1977/78 and recently “retired” to work as a study nurse for the Uganda Program with the Fred Hutchinson Cancer Center, grabbed my left hand and said, “oh! This is so nice!” I thought she was referring to my wedding rings, and I said, “Thank you! This one is for my engagement and this one is for my wedding,” pointing out the simple band. “No, no dear, I am admiring your veins. These are so nice,” said Sister Kalinaki as she peered through her glasses and pointed out the prominent blue veins that I have on the tops of my hands. Apparently they are perfect for inserting a line for chemotherapy administration.\footnote{318 Fieldnotes, 2012.} It was easier to discuss practices of administration than to speak directly to the experience of the war.
I think calling chemotherapy *saba saba* in the 1980s and 1990s was a way to talk about what it means to live through catastrophe and disorder. Chemotherapy as *saba saba* suggests a sudden, explosive moment of chaos. The body under the power of chemotherapy is ungovernable, eruptive, and impossible to reign in. But this is also a fleeting moment of chaos, a punctuated catastrophe, an episode of violence. *Saba saba* hits. And then it passes. I think calling chemotherapy *saba saba* provided an additional cue for patients. If they could survive the Tanzanian invasion, they could surely survive six rounds of poisoning. Cancer patients in the 1980s and 1990s survived a war. They lived through the years of misrule under Idi Amin. They could also survive cancer if they just held out through the “booms” of *saba saba* injections.

Calling chemotherapy treatments *saba saba* is historically contingent, and an evocative analogy which connects the somatic experience of chemotherapy drugs to the devastation and booming of bombs that blew out villages, markets, and raised churches to the ground in 1979. The analogy expresses the memories of the experiences of war, the circulation of healing and harming technologies, and practices of providing cancer care in the 1980s and 1990s. The analogy provides a way of characterizing the experiences of a generation of cancer patients and their biomedical care providers during a time of protracted war and violence brought about by the departure of Idi Amin in 1979.

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Technologies of Harming: Chemotherapy and Katyushas

The broader history of the development of cancer chemotherapy is intimately intertwined with the history of chemical weapons research in World War I and World War II. Mustard gas (sulfur mustard) was developed as a tool of warfare. Krumbhaar was one of the first to describe the ravaging effects of mustard gas on the body in 1919. When bodies were exposed to mustard gas, within ten to twelve hours, their skin and mucosa would begin to painfully blister. Eyes burned. Lungs burned. Skin burned. Nausea, vomiting, and diarrhea occurred. Internal effects of exposure to mustard gas came afterwards. Those who survived the initial physical symptoms of the gas would develop acute bone marrow suppression. That is, their bone marrow would cease to produce red and white blood cells, leaving the body vulnerable to infections due to immunosuppression, and crashing fatigue from the lack of red blood cells and consequential anemia. Other tissues, especially lymphoid and testicular tissues, atrophied after exposure.320

Researchers initially assumed that mustard gas exposure was carcinogenic, but a decade later Berenblum and Riley-Smith published results showing that the application of mustard gas on tumors had an anti-carcinogenic effect. World War II renewed both an interest in chemical warfare, as well as the long-term repercussions for soldiers. Researchers at a variety of medical and government

institutions were called upon to investigate the relationship between mustard gas and its possible role in treating neoplasms. At Yale University, Gilman, Goodman, Philips, and Allen discovered the anti-tumor properties of nitrogen mustard in 1942, which was kept secret until after the end of World War II. Also at Yale in May 1942, Dr. Gustav E. Lindskog carried out a trial using nitrogen mustard treatments on a 48 year old man with x-ray resistant lymphosarcoma who was in his terminal stages of illness. The man experienced a temporary regression of his tumors after being given a daily dose of 0.1 nitrogen mustard mg/kg over a 10 day period. This patient showed astonishing tumor regression in the short term, “by the last day of treatment, all signs and symptoms of his disease were gone.” He died after a relapse several months later.321

The military secrecy surrounding researching the effects of nitrogen mustard as chemotherapy for cancer during World War II meant that the promise of the drug did not become fully apparent until after the war among the nascent community of medical oncologists. Nitrogen mustard became, one of many alkylating agents, which work by directly destroying DNA, in the oncology arsenal. In the 1950s and 1960s, how to create “durable remissions” with nitrogen mustard and other agents, such as folate antagonists like methotrexate, and powerful antibiotics that had anti-tumor properties like actinomycin-D, was a major goal in pediatric leukemia research. In 1955, the Cancer Chemotherapy National Service Center was

established as part of a national program for cancer drug development under the auspices of the National Cancer Institute and directed by Kenneth Endicott. A decade later, it was folded into the NCI’s Chemotherapy Program directed by Gordon Zubrod. Cyclophosphamide, a nitrogen mustard derivative, came to east Africa in the 1950s and 1960s largely through informal connections between British colonial medical officers and staff at the American National Cancer Institute.

Nitrogen mustards are by all means a clunky chemotherapy technology. It is not a targeted therapy that discriminates against the DNA of cancerous cells and the DNA of healthy cells. For a rapidly dividing liquid tumor like Burkitt’s lymphoma, which can double in size in a 24-48 period, the demolition of the DNA of rapidly growing cells is a boon. For slower growing solid tumors, nitrogen mustard derivatives do not pack the same tumor destroying punch—they are too indiscriminating in the cells they destroy.

The Katyusha rocket launcher is a Soviet manufactured multiple-rocket launching system mounted on a heavily armed truck. They are designed to blanket target areas with explosives in a quick and devastating manner. They are not particularly accurate and take a longer time to load than some other forms of artillery. But their mobility and ability to cause mass havoc made them a weapon of choice for the Soviets in World War II. Over 10,000 units were manufactured for the war. After the end of World War II, Soviets continued to manufacture multiple rocket launchers. New generations of multiple rocket launching systems, modeled
after the *katyusha*, such as BM-13s and BM-21s, circulated to customers in Libya, Syria, Algeria, India, and elsewhere.\textsuperscript{322}

Military sales of Soviet weapons in the 1970s were shaped largely by the politics of supporting oil producers in the Middle East and Africa. In Africa, sales of Soviet arms and equipment were largely concentrated in Libya, the Horn of Africa, and Algeria. In 1973, Egypt ended relations with the Soviets and Libya became Moscow's top military customer. In 1976, after the Soviets shifted their support from Somalia to Ethiopia, $2 billion worth of weapons were sold to Ethiopia, which "provided a class of sophistication new to the region and far beyond the capabilities of the Ethiopian military establishment to operate or maintain,"\textsuperscript{323} and consequently led to an extensive training program. Tanzania remained on the margins of these Soviet military purchase packages. Tanzania trained its troops and built its military reserves by drawing upon both communist and capitalist expertise. Canadians and Chinese both had a hand in training soldiers.\textsuperscript{324} Uganda's military might under Amin

\textsuperscript{322} Scholarship in the history of the development of *katyusha* is squarely situated in the camp of World War II military history buffs. It is easier to purchase a *katyusha* model kit on the Internet than it is to find a comprehensive historical overview of this durable and highly mobile rocket launching system. For the history of the *katyusha* within the broader context of Soviet Rocket Science initiatives, see A.B. Tokaty, "Soviet Rocket Technology," *Technology and Culture*, Vol. 4 No.4, 1963, pp. 515-528. On the circulation of Soviet arms and assistance during the Cold War, see Orah Cooper and Carol Fogarty, "Soviet Economic and Military Aid to the Less Developed Countries, 1954-78," *Soviet and Eastern European Foreign Trade*, Vol. 2, No. 1/2/3, East-South Trade: Economics and Political Economics, 1985, pp. 54-73.  
\textsuperscript{324} But NB the Tanzanian role in the Rhodesian Bush war. . .
came largely from relationship with Libya, which funneled Soviet arms and military support and expertise. Unfortunately, from the records available, it is unclear how many katyusha style rocket launchers, be they BM-21s or BM-13s, the Tanzanian army procured in the 1970s and how widely they were used during the war of liberation in 1978 and 1979 in Uganda.

Chemotherapy and rocket launching technologies are both products of secret wartime research and development during World War I and II. Both chemotherapy and rocket launchers came to east Africa in the 1960s and 1970s through circuitous routes, and on the far margins of the broader geopolitics and cleavages of the Cold War. The meaning and to some extent the purpose of these relatively old military technologies were refashioned by east African users on cancer wards and liberation fronts alike.

Dr. F’s Story

At the time of Dr. Nakaketo’s departure from the UCI in 1993, immediate memories of the collective experience of the decimation of war in Kampala were fading. By the early 1990s in Uganda, President Yoweri Museveni and the National Resistance Movement government brought relative peace and stability to Kampala and the surrounding central, western, and eastern regions of the country. North of

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326 For a fascinating discussion of the idea of refashioning the history of technology as a “history of technology-in-use” and the way that allows us to make previously invisible contexts of technology utilization and innovation, see David Edgerton, *The Shock of the Old*, (Oxford University Press, 2007), xi.
Lake Kyoga, where the Nile cuts the country in two at Karuma Falls, an ongoing insurgency known as the Lord’s Resistance Army went on throughout much of northern Uganda. This war would continue for nearly two decades. Violence and war in Uganda did not come to a close with Museveni’s government, but the geographical locus of unrest markedly shifted to the north. Infrastructural violence, on the other hand, that is, the ongoing fall out of structural adjustment policies, the under-funding of basic health services, and the procurement politics which shut the UCI out of any sort of reliable drug supply pipeline, endured in the 1990s and 2000s and shaped hope and senselessness at the “Museum”.

Here, I focus on the story of Dr. F to explore what it meant to work at the UCI in what Kris Peterson would call a hollowed out or empty space, after the long term experiments in cost sharing and minimal financial or administrative support to the Institute.327 Dr. F first started working at the UCI in the early 2000s. He is one of the original four physicians trained through an oncology training grant set up to increase cancer care and research capacity at the UCI sponsored by UPCID, and completed his studies in Seattle from 2009 to 2010.328

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328 Incidentally, I first met Dr. Fred on a chilly November morning in Bethesda in 2011. We were both attending the International Conference on Malignancies in AIDS and Other Acquired Immunodeficiences conference, where the emerging problem and epidemiology of HIV related cancers in sub-Saharan Africa took center stage during the plenary session. Dr. F was at the conference along with his team to
Chances are, if you are on a ward round at the UCI and are in need of a translator for a little known Ugandan language, you will look for Dr. F. Dr. F grew up near Busia, a vibrant border town and main thoroughfare between Kenya and Uganda. The son of an accountant and home-maker whose family had historic ties to the cattle selling market and butcheries, Dr. F was the first of his family members to go into a life in medicine and first started working at the UCI as a medical student in the early 2000s. He speaks many of Uganda’s 40 widely known languages and has a reputation on the wards for smoothing out issues of end of life care or ways forward for dealing with late stage cancers with a deft, humane, and educational touch.

When he first started at the UCI as a third year medical student in 2001, he was one of two students on the ward who slept over in the evenings to attend to giving blood and medications.\textsuperscript{329} This was a longstanding arrangement at the Institute, going back to the 1960s, where bright and energetic medical students were given the opportunity to learn how to do lumbar punctures and blood type matching as well as a roof over their heads and tea in exchange for managing emergencies and being a first line of contact for crises at night.\textsuperscript{330} Despite being a present a poster of data on the applicability of AIDS Clinical Trials Group staging criteria for Kaposi’s sarcoma in Uganda in an era of highly active anti-retroviral therapy.

\textsuperscript{329} The following discussion is based on fieldnotes from that meeting in November 2011, a subsequent formal interview with Dr. F Okuku in March 2012, and many hours of participant observation on the Solid Tumor Center and outpatient units shadowing Dr. F’s work, as well as conversations in “down time” at the UPCID office on the UCI’s campus.

\textsuperscript{330} Many internationally recognized Ugandan physician-researchers initially started their careers as third year medical student residents at the UCI, including Professor
“sad place” where “whenever a patient came with a diagnosis of cancer, there would be no hope for them. Next would be death,” Dr. F still wanted to work at the UCI, largely because of ongoing mentorship from Dr. Orem and Dr. Mbidde. “It was a really interesting opportunity to learn.” There were no other wards at Mulago where a third year medical student would be charged with tasks like: “getting transfusions done. Clerking for people coming late in the evening because we always had Burkitt’s kids coming late, like after 5pm. And those kids needed some kind of care.” Dr. Mbidde, famous for being challenging to work with because of his exacting and high standards, taught Dr. F how to do a “meticulous examination of the patient,” as well as how to manage tumor lysis syndrome through administering adequate fluids. Dr. F also learned how to manage pain, prescribe complicated regimens of antibiotics, and even manage some chemotherapy administration.

Dr. F continued to work at the UCI for his fourth year medical school elective and continued to learn. “I started doing [more] procedures. All these procedures we do on kids with Burkitt’s like bone marrows. I became very efficient. I taught many post grads. Of course LPs [lumbar punctures] was like daily bread. I did so many lumbar punctures on BL kids. I would do like 20 in a day. I became an expert, really. It was unique to the cancer institute. Whoever went through there learned so much.”

David Serwadda, now the head of the School of Public Health and one of the first physicians to publish about the SLIM syndrome that would eventually be identified as AIDS in the early 1980s, and Dr. Alex Coutinho, head of the Infectious Diseases Institute. Dr. Robert Comis, an American breast cancer specialist who now heads up ECOG, was one of the first medical students to do this rotation in 1970.
In the 2000s, the institutional lore is that staff would receive one shipment of chemotherapy a year, and would run out of it within a month. They were rarely stocked with morphine. When Dr. F was asked to describe what they were doing at the UCI when he worked there as a medical student and volunteer medical officer he said, “I’m not sure what kind of care we were providing,” he said, but we “weren’t doing medicine”. Were you doing palliation, I asked? “There was nothing to palliate with. The work went on, but we had serious issues at that point.” But at the same time, there were moments of reprieve and patients who did survive and greatly improve. “I personally developed interest in oncology because after working with the patients and seeing some very challenging situations where people died, I was also seeing some success stories.”

Dr. F finished medical school in 2003 and went directly to the UCI as a volunteer medical officer. He was paid no salary. “No salary. Nothing.” Mulago was still responsible for “all sundries,” at the UCI, whose budget was about 20 million Ugandan shillings a year. Or roughly $7,940. A full chemotherapy cycle of COM for a Burkitt’s lymphoma patient was about $300 at that time.

But the UCI continued to offer a real education, not just in terms of learning new procedures and improvising under circumstances of profound scarcity. Working at the UCI also offered an up close and often disturbingly intimate look at the reality of poverty facing many of the patients and caretakers who came to this place, the only place offering oncology goods, such as they were, to the public in
Uganda. As Dr. F put it, “we never saw high clientele come over here for treatment. It was usually this local, rural flock. I guess people who had the money went elsewhere.” Destitution and death commingled in unsettling ways. Take the story of Dr. F’s “worst experience” working at the UCI in the early 2000s:

FO: We had a situation where there were so many dead, but this was a unique one, where you have a grandmother who brings in a child with HIV and Burkitt’s lymphoma. The disease was advanced. There were no drugs at that time [for either BL or HIV]. We knew the child would die. And indeed the child died without receiving any medicines then. And then what happened next was this grandmother didn’t have any money to take back the body, like to hire a van or a truck.

So she did what all of us would not imagine. Before the body became stiff she folded the knees of this child and forced the body in to a bag. We had left the child lying on the bed, usually in the area where we do procedures. And I came back and asked, “eh! Where is the body?” And she showed me the bag. And I said, “What do you mean?” ‘The boy’s in the bag.’ And I said “what? How did you fit him in this short bag this small? And she said, ‘Well, I broke his knees and pushed him in there.’

So in shock I called Angus Robinson [a visiting British hem-onc who worked at the Lymphoma Treatment Center from 2000-2003] to come and experience for himself. We opened the bag because we
couldn’t believe he [the boy] was in the bag. That was the worst. It traumatized both of us.

We saw that we were working in a place where there was so much poverty that people were forced to do some extra ordinary things. Out of this world. To make life easy for them. If it meant hiring a truck, it would have cost lots of money.

MM: But this way she could go on a bus.

FO: She would just go on the bus with a bag. [...] It is still fresh in my mind.331

In the 2000s, Dr. F and his nursing colleagues worked in a context where death was a common occurrence. With the advent of chemotherapy, syringes, and more reliable morphine stocks since institutional autonomy in 2009, staff at the UCI still work at a site where caring for late stage cancers means that many of their patients will die, either on the wards or back in villages and homes. This particular story of the granny and the boy in the bag has become something of an institutional legend, a way to hearken back to the “dark days” of the UCI. In her work on end of life care in hospitalizations in the United States, anthropologist Sharon Kaufman writes about the challenges of trying to usher in a “good death” for patients, and also for their loved ones. This involves a progression of rituals, in which the medical staff subtly perform for families that they have done everything that they can, while it is

331 Interview: Dr. F, March 2012.
the family’s job to “let go” of the patient so the medical staff feel free to “move things along” and usher in a good death for the patient by ending life support or avoiding heroic medical procedures.332

At the Uganda Cancer Institute in the 2000s, indeed for the three decades that the Institute was under the administration of Mulago, the staff at the UCI were often stripped of their ability to do “everything,” be it debulking a late stage liver tumor with chemotherapy to ease pain or administering antibiotic ointment on KS lesions to prevent fetid infections. They were left to work within a different set of ritual practices that signaled doing everything—a meticulous ward round, a careful diagnostic work up of cancer stage and histopathological diagnosis (even if the pathology department itself was out of important reagents and that diagnosis languished for six months), writing letters to pharmacists to request cutting the price of cyclophosphamide for this one promising case of early stage Burkitt’s lymphoma. For patients and their caretakers, participating in this set of rituals necessitated coming to chemotherapy treatments with regularity, and buying coffins and organizing transport when there would be a death on the ward. But as the story of the granny and the bag shows, the realities of impoverishment often dictated that these rituals of moving things along to a good death were compromised.

As Dr. F sees it, money and the ability of a family to purchase the necessary chemotherapy cycles were what brought the “few success stories” during the early

332 Sharon Kaufman, And a Time to Die... (Chicago: University of Chicago Press, 2005).
2000s. For most patients, they would receive one cycle of chemotherapy, and then collect the phone numbers of nursing staff and wait for a call that a new shipment of chemotherapy had arrived.333 “So then you would have one guy receiving chemo today and then he doesn’t come back because he doesn’t have money. And he comes back after two months for chemo or another five months. And he gets one injection and goes back again home. So it was senseless. You wouldn’t talk about doing any research. Or treatment research to see the outcomes. […] it was a horrible place.” But nonetheless the staff worked and staff worked tirelessly and professionally. Dr. Mbidde would do a daily “cleanliness round” in which he would walk into the wards and run his finger along the window ledges looking for dirt, and chided nurses if the toilets smelled. Patients were given tea and two meals a day. As “horrible” as the UCI was, according to Dr. F, work continued on.

**Chemotherapy after 2009**

As I discussed in the introduction, circumstances at the Institute began to shift in the mid 2000s with the advent of the partnership between the Fred Hutch and the UCI to study infectious diseases and cancers. In the interlude that follows, I discuss the history of the partnership between the Uganda Cancer Institute and the Fred Hutchinson Cancer Research Center in Seattle and how and in what ways

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333 Claims about how many chemotherapy shipments the UCI actually received a year in the early 2000s vary across and within accounts. Some say once a year. Some say quarterly. Some say every month.
research initiatives helped to bring about a profound renaissance at the Institute, including institutional autonomy from Mulago.

During ethnographic fieldwork on the wards of the Uganda Cancer Institute between 2010 and 2015, I could hear, see, and smell the violent effects that chemotherapy renders on the body as drugs destroy DNA, disrupt folic acid reception, and promote cell death. Between 2010 and 2015, I found that chemotherapy treatments are generally called “the drugs” or keemo, the closest Luganda approximation to “chemo,” or empiso mukaaga or “six shots” in Luganda. When I asked nurses who had worked at the UCI in the 1980s and 1990s if they remembered saba saba, they would laugh, clap their hands together for emphasis, and say “yes, saba saba, the war”. These older nurses also confirmed that they called the drugs saba saba in the past. But even though bodies boom and erupt in the chemotherapy administration room today, chemotherapy is no longer called saba saba among this generation of doctors, nurses, or patients. Younger nurses, most of whom were born in the 1980s, have no visceral, embodied memory of the war, and were hired only in the late 2000s, they would say chemotherapy is simply “the drugs” or “chemo.”334 In patient consultations, this is often what Dr. F will explain when he is sketching out a course of treatment for cancer at the UCI—“you will come back for keemo six times. This is six shots. You must come back for empiso mukaaga even if it makes you sick.” He counts it out on his hands as a gesture in consultations with patients and their families.

When I talked about *saba saba* with patients who were treated at the UCI in the 2000s, some of them remembered the invasion of 1979, but were keen to point out that chemotherapy is no longer *saba saba*. As they remembered, in the 1980s and 1990s, *saba saba* was related to the violence of administering the drugs through push injections rather than intravenous drips. As one breast cancer survivor M put it, “They called it *saba saba* because they would push it into you. Not like they do today on the wards with the drip.” Intravenous drips here are seen as more “gentle,” and less violent on the body.

Since 2009, the chemotherapy procurement budget for the UCI shifted from less than 20 million Ugandan Shillings a year to approximately 7 billion Ugandan Shillings a year.\(^{335}\) This has meant more reliable chemotherapy supplies, although there are still shortages, and many, many more patients. The Institute has grown from 20 to 200 employees in a few short years as well, leading to issues about how to transform practice and build institutional cohesion at the “Museum”. How to redefine the practice of administering chemotherapy has become a major issue. It is no longer a viable option to run a makeshift outpatient unit for patients trickling in with their own drugs in the UCI’s reception area. There are now upwards of 100

\(^{335}\) This has not changed the fact that there are still shortages and stock outs of necessary drugs. During the longest continuous period of fieldwork from January 2012 to October 2012 at the UCI, supplies were remarkably consistent. The week leading up to my departure, it became clear that there was going to be a major stock out of chemotherapy and other sundries on the wards because of budgetary shortsightedness on the part of the Parliament to release enough funds to the UCI. Since October 2012, periodic stock outs of essentials are ongoing.
outpatients a day coming for their infusions, and this has led to several investments—in additional treatment space, in a chemotherapy reconstitution hood, and in the dedicated training of pharmacists. While conducting fieldwork in 2012, these practices were still being defined and redefined, and on the pediatric wards, chemotherapy was still being reconstituted in the reception area.

The mixing of chemotherapy in the general entry area of the Lymphoma Treatment Center under the shadow of the plaque put up in 1967 to honor Denis Burkitt and his contributions to chemotherapy research was a point of contestation throughout much of 2012. There were ongoing concerns about safety, toxicity, and the violence of these chemicals in a setting where the number of patients and the volume of orders always exceeded human capability. And the nurses were managing the sheer volume of these patients at considerable risk and hazard to themselves, working in a place without good ventilation or reliable protective gear. One day, in mid June 2012, this suddenly changed when World Vision dumped 1000 pieces of chemotherapy protective suits on the door of the UCI as a “gift.” Here are my fieldnotes from that day:

*I went to the LTC, took tea, and chatted with the nurses. Benjamin received a big donation of protective chemotherapy gear, which Susan and Rose were sporting out in the chemotherapy reconstitution area of the LTC, also known as the general entry.*
I spent a lot of time watching Rose and Susan work--I've watched them work before--but what really struck me about their work was how much they talked about the danger of the toxicity of the drugs this morning and afternoon. It was as if this new get up had opened up a space in which you could talk about the very real challenges and problems of giving cytotoxic drugs in a "low income" or "resource poor" setting. Rose talked about the fact that she's been doing this for five years but has never had an accident. Sister Allen came in and chided me for not wearing anything protective--PLEASE. Put on a mask. These are toxic drugs. And some of them are quite pretty. Doxorubicin has the color of red Koolaid. Vincristine is a simple push, and is called "vinc." Because they get saline packs in such large bottles, there is also the work done of emptying out the saline so that you can get the right ratio for the normal saline to the chemical. I also followed Susan as she went and administered chemotherapy and explained the sequence of events that would happen with regards to treatment over the next few weeks, months. So much math involved. And counting.

By the end of the afternoon, after the chemo had been administered, the ward was filled with the sounds of retching and the shuffle of parents walking in and out of the ward, with buckets full of sickness to be deposited into the toilets. Whether called saba saba or keemo, cytotoxic drugs are still excruciatingly violent on the body.

Why were nurses mixing “dangerous drugs” in a public area with minimal ventilation and risk of spillage and contamination, especially now that the Institute had a new chemotherapy hood in place? Nurses were reluctant to add to the amount
of time spent going to and from bench to bedside, which would be part of the fall out of increasing the amount of distance between where chemo would be mixed and where it would be administered. But nurses were also worried about the fall out of having pharmacists take full control of the mixing process. The pharmacists were entirely disconnected from the everyday care for patients receiving chemo on the wards and lacked the intimate familiarity with these kids. A lack of familiarity with the kids and their regimens, as well as double and triple checking with overwhelmed parents that the proper drugs were in order, could bring mixing mistakes. And then there was the fact that mixing for the LTC would significantly add to the pharmacists’ already strained workload.

It took a few weeks, but by the time I left the UCI in October 2012, Collins, Rose, Miriam, and other chemotherapy nurses were running back and forth between the Lymphoma Treatment Center and the chemotherapy mixing center in the outpatient building every afternoon with trays holding IV bottles with names of patients scribbled across in black marker. There was quiet grumbling—orders did get mixed with one another or they would not get filled in time. There were delays in getting pre-chemo hydration started because it was uncertain when the drugs would actually be ready for the “dripping”. And meanwhile, Godfrey, the pharmacist primarily responsible for mixing chemotherapy for the outpatients saw his workload more than double, and the surface area of his available workspace under the hood shrink appreciably, taken up by the new requests from the LTC. The reception table area continued to be used as anything but a reception area, however.
Patients still slept behind the desk on mattresses. Nurses used the space for overflowing medical supplies, as the wooden chair for blood draws still sat by the entry door. And on ward rounding mornings, dozens of patient files would fan out onto the table, a reminder of the sheer volume of patients waiting to be seen on the wards.336

Over the six years that I actively conducted research at the Institute, chemotherapy clinical trials were still on the relatively distant horizon, waiting for new buildings and infrastructure. And in the more than 30 years that chemotherapy clinical trials had been conducted at the UCI, international standards of medical research, sample size calculation, adverse events reporting, confidentiality, and the specificity of cancer drugs themselves have changed dramatically. Accommodating these changes in technology and research practices meant that long-term practices of drug administration needed to change too.

Part of this was accomplished by suggesting to older nurses that they may want to consider retirement, and many newly appointed chemotherapy nurses were brought on to the staff. But at the same time, the deeply artisanal skills which long time nursing sisters had acquired over decades of patiently, methodically inserting cannulas into dehydrated hands and ensuring that they didn’t slip the vein and let the toxic drugs leak into the skin, creating painful burning and necrosis, were not

336 When the Lymphoma Treatment Center was torn down, the reception table was not demolished. It now sits outside of the LTC Two, where patients and caretakers sit around it and take shelter from the sun or lean up against the heavy, dark wooden sides.
skills that could be acquired through any number of new “human subjects research” trainings. Several of these nurses near the retirement age simply crossed over to work with the Fred Hutchinson Cancer Research Center Uganda Project, bringing their skills of working with patients to blood draws, collecting oral and anal swabs, doing HIV testing, and operating consent taking, and in the process leaving their chemotherapy administration days behind.

Transforming the Uganda Cancer Institute from “the place where you were sent to die” to a “Center of Excellence” from 2009 onwards relied both on invoking the history of professionalism at the Institute and calling for a new era. Newly available drugs were often at the center of these transformations. “Culture change” required discarding these old ways of administering chemotherapy and providing supportive care, which were shaped by these decades of triage, rather than a nascent culture of research center excellence.

_Coda: August 2012_

Sister K stands in the corridor of the men’s side of the Solid Tumor Center, which is a essentially a corridor of ten or so beds that are lined up against the wall of windows with tattered screens. It is surprisingly still. There is no breeze. She wears a simple black skirt and a brightly colored Hawaiian shirt. The festive hibiscus flowers are overwhelmingly cheerful. We may be on the Equator and there may be monkeys and jack fruit trees on Mulago hill, but tropical paradise seems so far away from this ward on what seems like a particularly bleak afternoon. Family members
sit on colorful woven mats on the floor next to the beds, periodically shifting to make room for nurses who are checking the fluid levels in IV bottles. A skeletal mzee carefully sips the porridge his relatives have given him. The doctor from Mulago’s palliative care department fills out a referral form for hospice care for a woman withered and wasted by her breast cancer. She shows the wound to the doctor, gingerly pulling an old and tired wrap cloth away from her chest.

Sister K is quick to point out the bright blue mosquito nets dangling from the ceiling. “This is new!” When she worked here in the early 2000s as a nurse on the STC, they would have frequent malaria outbreaks on the wards because patients who were coming in from villages with malaria mixed and commingled with patients from Kampala, where the exhaust fumes have seemed to killed all the mosquitoes. “We deal with cancer, but we also deal with everything else,” she said.

Sister K worked as a chemotherapy nurse at the UCI from 2002 to 2006 after spending a long career at Mulago Hospital. She worked on the wards of the STC at a time when, “Sometimes there would only be two of us on the wards. One of us would administer chemotherapy and one of us would be attending to the patients. With the drugs, what really matters is time. You have to give the drugs on time,” and in combination, or the drugs would have little effect. In an era when government supplied little chemotherapy, most of this attention to ensuring that drugs came on time would fall on the family. “The patients would buy the drugs. The relatives would help to buy drugs.” Relatives sold goats, pooled finances, and organized
transport to ensure that their patients would not die, or at least that everything that could be done, would be done.

In 2006, Sister K left chemotherapy nursing because of her own breast cancer diagnosis. She brought her drugs to the Uganda Cancer Institute to be administered in a small room that is now used as the nurse’s breakroom on the STC.

“Were you ever admitted on this ward?” I asked as we stood in the STC. “No, thankfully no,” she responded. “The chemo, though. Ah. I don’t want to talk about it. The chemo. The chemo, that was Hell,” she said as she raised her hands up to the sky, and shook them as if she were in a moment of ecstatic prayer. We spoke nothing more of her time as a patient at the UCI.

In August 2012, watching Sister K giving Dr. F a gigantic bear hug upon seeing him in the doorway of the newly built private wing at the UCI could have seemed so out of place in Kampala where personal space is honored even in matatu taxis. But here she was, a breast cancer survivor, still in remission six years later, and quite round and healthy. Of course she was going to hug her doctor and her friend. They survived at the Institute even when it was a “place without hope.”
INTERLUDE: The Rise of Global Oncology

The first three chapters of this dissertation offered an account of the founding of the Uganda Cancer Institute and the ways in which national politics, scientific research priorities, economic transformations, and epidemics all transformed this experimental infrastructure. I have also shown how generations of committed Ugandan medical practitioners navigated these challenges and extended the mandate of the UCI to provide cancer care. The next two chapters of this dissertation are more concerned with the ways in which the transfer of oncology’s tools and technologies shaped public cancer care in Uganda from 2004 onwards. This interlude offers a contextual snapshot of the rise of “global oncology” in Uganda and some further background on the Fred Hutchinson Cancer Research Center and Uganda Cancer Institute partnership.

Let us return to 2004 and American researcher Corey Casper’s tour of the Uganda Cancer Institute, which culminated in a visit to the Uganda Cancer Institute’s freezer graveyard. Remember that this room was a graveyard for forgotten research partnerships dating back to the 1960s. Individual study acronyms were painstakingly etched into the sides of the freezers—partners included institutions in the United States, the United Kingdom, Sweden, and France. Some freezers had once housed biopsied tissue samples. Many of the old refrigerators used to contain chemotherapy drugs and antibiotics for clinical research studies. Mbidde turned to Casper and asked him if this would be the fate of his proposed research venture on
HIV related malignancies at the Uganda Cancer Institute. Mbidde’s question, while a bit prickly, was not meant to be rude. Mbidde spoke from four decades of personal experiences at the Uganda Cancer Institute where partnerships, equipment, drugs, and friendships come and go.

To avoid leaving another abandoned freezer in a dilapidated building, over the past ten years the Fred Hutchinson Cancer Research Center has poured over ten million US dollars into infrastructure improvement. As of 2012, the freezer room no longer exists. It now houses a functioning outpatient center that has a new roof and approximately 120 patients receive chemotherapy daily. To give you a sense of other numbers—in 2000, there was one oncologist practicing in Uganda. In 2012, were eleven. Patients increased from less than 500 a year to more than 30,000 a year. The collaboration with the Fred Hutch that started with a pilot study in 2004 on HHV-8 viral shedding now includes over 20 different research projects and approximately 40 staff members in Uganda engaged in cancer research. The crown jewel in this collaboration, a new research and outpatient care center, opened in May 2015: the UCI-Fred Hutch Cancer Centre. The facility is a “strategic investment” to help “the UCI grow from a small facility with limited resources—including one oncologist—to a the state-of-the-art UCI–Fred Hutch Cancer Centre, that can treat up to 20,000 patients a year.” Incidentally, this facility stands on the footprint of the

original ward of the Uganda Cancer Institute, the Lymphoma Treatment Center, which was bulldozed to the ground in 2013 to make room for the Hutch’s “strategic investment.” 338

Capacity building for cancer research has had synergistic effects. At the same time as the Fred Hutch helped to expand the number of oncologists in the country from one to eleven in less than a decade, cancer also became a more visible and political problem for the Ugandan government. In the early 2000s, one Member of Parliament, Yefusa Okullo Epak, beloved and respected by many, died of lung cancer in a protracted and horrible way, spending many months in and out of care facilities in South Africa and the Uganda Cancer Institute undergoing palliative chemotherapy. He was struck by the profound differences between resources between South Africa and Uganda. Receiving chemotherapy in a soft chair with some privacy and strong anti-emetics was very different from sitting on a hard wooden bench lined up with other patients in a building without a roof. It was Epak’s dying wish that his colleagues in the Ugandan government take cancer more seriously and allocate funds and resources accordingly. He worked to pass a bill through parliament that granted the UCI financial and administrative autonomy from Mulago Hospital. 339 The combination of more Ministers of Parliament getting

338 Fred Hutch Global Oncology Reducing the Cancer Burden Worldwide  
cancer and the visibility of the Fred Hutch partnership politicized oncology in Uganda in the early 2000s. At the same time, Dr. Mbidde moved on after nearly 40 years at the UCI, and his successor, Dr. Jackson Orem, took the helm with a relentless dedication to expanding oncology services for the public in Uganda. In the past ten years, the UCI shifted from a place where you were “sent to die” to a site where cancer services are provided to the general public with funding from the Ministry of Health. It is perhaps no wonder then that the UCI’s current motto is “Research is Our Resource.”

As we saw in the last chapter, Edward Mbidde kept the Institute going in the 1980s, 1990s, and 2000s despite severely limited resources and palpable absences by maintaining high standards. While Mbidde ran the Uganda Cancer Institute as the lone oncologist, Jackson Orem delegates the tasks of daily ward rounds to create more time for advocacy and exerting careful pressure on the Ugandan government to allocate more resources to cancer. Both are brilliant, caring physicians, but their leadership styles are in a way broader reflections of their personalities. Corey Casper has been another a charismatic force in Uganda oncology. He took the problem of freezer graveyards seriously and shaped a research program that went


Fieldnotes October 2011. At the groundbreaking ceremony for the UCI-Fred Hutch Cancer Centre in October 2011, a Hutch colleague commented on Orem’s evolution from oncologist to politically savvy cancer advocate in just a few short years. Colleagues at the UCI also corroborate this gloss on Orem’s leadership style, Fieldnotes March 2015, Global Oncology Symposium at the Fred Hutchinson Cancer Research Center in Seattle, Washington.
beyond mere extraction and sample collection. This is a man who took the challenge of the gaps between Seattle and Kampala seriously and was not afraid to dig deep into the Fred Hutch budget coffers as needed. As he noted to me one afternoon during a particularly charged conversation about the ethics of biomedical research in Uganda, “We spend $40,000 a year to keep biopsy samples in Uganda because it’s the right thing to do.” But while the alchemy of people and the charismatic forces of personality help us to understand why a closed institution under Mbidde transformed into a far more open one under Orem, it still offers only a partial explanation for the profound changes at the Institute in the past decade.

We can best understand why the Uganda Cancer Institute shifted from where you were “sent to die” to one of the shining examples of the rise of “global oncology” over the past thirty years by situating these transformations within the broader history of HIV/AIDS research and the rise of global health. Increased access to free or almost free antiretroviral therapy transformed the landscape of HIV in Uganda over the past decade from a death sentence to chronic illness, although the realities of living on antiretroviral therapy can be quite complicated. In Botswana, Livingston notes that the roll out of antiretroviral therapy renders cancer all the more visible, as people live longer with HIV and develop HIV related malignancies. The trend is similar in Uganda, and the Fred Hutch may be seen as

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341 Fieldnotes, June 2012.
343 Livingston, Improvising Medicine, 29-51
the first in a much longer line of international research collaborations who are
“scrambling for Africa” as a place to do research on patients with HIV related
malignancies.344

Like many other first generation global health physicians, Dr. Corey Casper
came to work between Seattle and Kampala largely through experiences with the
American HIV-AIDS epidemic.345 As a medical student on the wards of major
teaching hospitals in New York, and then as an infectious diseases resident at the
University of California, San Francisco, Casper observed the transformation of AIDS
from a death sentence to a pharmaceutically managed chronic illness over the
course of the 1990s and early 2000s. He remembers first seeing Kaposi’s sarcoma
(KS) as a medical student in New York. This motivated him to pursue a career in
infectious diseases and Kaposi’s sarcoma epidemiology and etiology. In the late
1990s and early 2000s, KS cases were declining across the United States, thanks to
better patient management and access to long-term anti-retroviral therapy. When
Casper took a position at the Fred Hutch in Seattle in the early 2000s, he came with
the hopes of building a research cohort of KS patients in the Pacific Northwest. What
Casper had not realized was that the year before he arrived Seattle saw its last KS
patient.

344 Crane, Scrambling for Africa
345 The following account is based on several conversations between Casper and
myself, as well as several publicly available profiles of Casper. See fieldnotes June
2012, May 2013, and Mary Engel, “Building a legacy of hope,” Joanne Silberner
Casper turned to sub-Saharan Africa under the advice and mentorship of Dr. Merle Sande. Sande who was a venerable AIDS physician at UCSF who was instrumental in setting up a major HIV research institute in Uganda. He was also convinced that cancer research in Africa was going to be “the next big thing” after the HIV/AIDS epidemic. The UCI had patients—many of whom in the 1980s, 1990s and 2000s were suffering from HIV related malignancies. And thanks to the remarkable prescience of the British government and the tremendous care of Raphael Owor, Henry Wabinga and others, there was also a functioning cancer registry in Kampala, Uganda dating back to 1954. As we have seen this registry was and remains pretty much the only of its kind in Africa and provides population based data on a variety of cancers, including Kaposi’s sarcoma.

Ten years ago when Casper and his colleagues first started working in Uganda, the term “global oncology” did not exist. “Global oncology,” like “global health” is a capacious, malleable, and relatively new term to describe what may or may not be a “new” thing. Like global health, global oncology is more of an idea than a discipline. In some circles, global oncology connotes a medical humanitarian agenda for mitigating the vast global inequalities surrounding the prevention, treatment, and palliation of cancers. These inequalities are described as the global cancer divide:

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346 Discussion with Corey Casper, Fieldnotes 2012.
There are glaring disparities between rich and poor in incidence and
death from preventable cancers and death from treatable cancers, as
well as in the pain, suffering, and stigma associated with the disease.
These disparities constitute a cancer divide and demonstrate that
increasing access to cancer care and control is also an issue of
equity.\(^{347}\)

Numbers tell a stark story about these disparities. According to the World Health
Organization: 8.2 million people died from cancer worldwide in 2012; 60% of the
total new annual cases of cancer occur in Asia, Africa, and Latin America; 30% of
cancers could be prevented.\(^{348}\) Julio Frenk, one of the architects of the global oncology movement, argues: “[…] To correct this situation we must address the staggering ‘5/80 cancer disequilibrium’, that is, the fact that low- and middle-income countries account for almost 80 percent of the burden of disease due to cancer yet receive only 5 percent of global resources devoted to deal with this emerging challenge.”\(^{349}\)

Although cancer kills more every year in the developing world than the holy trinity of HIV, tuberculosis, and malaria combined, financial support for addressing the cancer burden outside the west remains low. In low and middle income

\(^{347}\) Closing the Global Cancer Divide, 3
countries, it is estimated that there are 4.8 million deaths annually from cancer. It is estimated that there are about 2.1 million deaths from HIV/AIDS annually in the Global South. About 1.1 million deaths from tuberculosis occur in low and middle income countries annually. Malaria claims 0.7 million lives annually. Global funding for HIV/AIDS treatment and prevention is $6.2 billion annually. Funding for malaria treatment and prevention receives about $1.3 billion. Tuberculosis prevention and treatment programs receive $903 million annually. Annual global health funding for cancer in low and middle income countries is approximately $168 million.  

In other words, the global funding resources allocated for treating and preventing cancer in low and middle income countries annually is much, much lower than the global funding that is allocated for treating HIV, tuberculosis, and malaria.

The American National Cancer Institute only established a Center for Global Health in 2011 with the mandate to “help reduce the global burden of cancer.” The first annual global oncology symposium was held at Harvard in 2014, arranged in part by a group of fellows in Hematology/Oncology at Harvard Medical School who founded the Global Oncology volunteer community in 2012. Their mission was to: “seek to alleviate suffering and make it possible to provide the highest quality cancer care to people in resource-limited settings by building partnerships between

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350 Fred Hutch Global Oncology Brochure, (Seattle: Fred Hutchinson Cancer Research Center, 2015).
skilled professional volunteers and global partners.”

Building on the momentum of Partners in Health, the focus of this symposium was largely on defining the scope of the global cancer burden, but also potential essential therapies for cancers in low and middle income settings. And true to the Partners in Health style of setting up rural hospitals of excellence driven largely by community health workers, PIH already has established a working model for their brand of “global oncology,” the cancer ward at Butaro Hospital in rural Rwanda. As described on the website:

Patients seeking treatment at the Butaro Cancer Center receive the full spectrum of care, including screening, diagnosis, chemotherapy, surgery, patient follow-up, palliative care, a pathology lab, mental health and social work services, and socioeconomic support, such as food, transportation, home visits, and community health worker accompaniment. Patients needing radiology treatment are referred to Mulago Hospital in Uganda. The Center also is an accredited national referral site for cancer.

The Partners in Health global oncology model is a bold call to use tools of oncology that are already readily available. Writing about their priorities and experiences in Rwanda so far, Harvard global health specialist Larry Schulman says:

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To have a major impact on cancer mortality worldwide, we do not need more scientific discoveries but rather the resources, organizational infrastructure and political will to bring currently available diagnostics and potentially curative treatments to the largest proportion of the world’s population who do not currently have access. Without these, a young person with Hodgkin’s lymphoma will continue to be denied the chance for a cure because of the place he or she was born. This reality is thrown into stark relief when we consider that a cure for Hodgkin’s lymphoma normally requires a simple incisional or excisional biopsy, the ability to process the tissue and make a pathologic diagnosis, and the administration of four old and inexpensive generic drugs (doxorubicin, bleomycin, vinblastine, and dacarbazine).  

However, all the material goods included in this simple recipe for a potential cure are anything but straightforward. Global oncology needs hospitals built from scratch, pathology expertise, committed health workers, and political will.

The Fred Hutch model for global oncology draws similarly on the language of remediating global inequalities in cancer and optimism that certain cancers, particularly Burkitt’s lymphoma, are curable, and that “Where you live should not

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determine whether you will survive cancer.” To address this burden, the Hutch identified three key areas of intervention over the past decade: improving diagnostic capabilities, optimizing treatment protocols, and also laying the groundwork for better prevention mechanisms for cancers that are caused in one way or another by infectious diseases. Vaccines exist for hepatitis B, which is linked to liver cancer, and HPV, which is linked to cervical cancer. And as the Hutch notes, “Infection-related cancers offer an especially promising target for cancer prevention and treatment efforts. Nearly a quarter of the world’s cancers are caused by infectious diseases that are preventable or treatable—diseases such as viral hepatitis, Epstein-Barr virus, HIV and human papillomavirus (HPV). In parts of the developing world, up to 60 percent of all cancers are associated with infectious diseases.” The Hutch is already the administrative and scientific home of the HIV Trials Network. It is the institution that laid much of the groundwork on the linkages between HPV and cervical cancer which contributed to HPV vaccine development, and the Hutch is looking for the next big Gardasil-like breakthrough in treating Kaposi’s sarcoma and Burkitt’s lymphoma.

The Partners in Health model uses “implementation research,” which “includes the prospective collection of diagnostic, treatment, toxicity and outcomes data in a particular setting, within a defined care delivery system,” and guides the knowledge making agenda at Butaro. In contrast, the UCI and Fred Hutch collaboration endeavors not only to do research that benefits treatment outcomes

355 Fred Hutch Global Oncology Reducing the Cancer Burden Worldwide
on the ground, but exists largely to do infection related malignancies research in a setting where access to a large cohort patients with infection related cancers more concentrated than it would be anywhere in the United States.

In order to conduct this research in Uganda, the Fred Hutch took infrastructure seriously and pledged to not leave another abandoned freezer among the ruins of the UCI. Between 2004 and 2015, the Fred Hutch worked to transfer the tools of contemporary oncology research and care in Uganda through investing in infrastructure, training, and research programs. The UCI-Fred Hutch collaboration was and is serious about building out local oncology capacity and ensuring that every staff member in Seattle works with an “analog” (their words, not mine) in Kampala. These Ugandan physicians are what historian Nancy Rose Hunt would call “middle figures”—in this case mediators between the worlds of metropolitan oncology research in Seattle and the frontier space of an increasingly visible cancer epidemic in Kampala. They are also seen as the key to the longevity of research efforts in Uganda. “Our goal is to make ourselves redundant,” one Seattle based program operative noted to me. Dr. F, whom we met in the last chapter as a volunteer medical student at the UCI in the early 2000s, is one of these middle figures. He was one of the original promising Ugandan physicians sent to Seattle for training in oncology. People like Dr. F, who remember what the UCI was like before institutional autonomy and the collaboration with the Hutch, are relatively rare.

For Dr. F, the biggest difference between medical practice in Uganda and medical practice in the United States was not necessarily greater access to MRI machines or the latest cancer drugs. What surprised Dr. Fred the most was a "team based approach to care" and the emphasis placed on spending time with patients and their families. He was struck by a work culture shaped largely by information and knowledge, and a technology as basic as a “white board,” as opposed to scarcity, emergency, and triage. He was amazed by the “family room” approach, which he describes as follows:

There is a board and the physician is explaining the disease and risk factors and how this all came about. [He discusses] what forms of treatment are available, including survival patterns on different regimens of treatment. That’s how detailed! And the guys [patients and family members] come and they have all these data downloaded from the net about different treatments. They are asking very scientific questions and engaging the doctor to the limits. Asking serious questions about side effects. That kind of professionalism wowed me. And I’ve tried it with patients [here in Uganda] and they love it.357

Since returning to the UCI in 2010 as a full time oncologist, Dr. F negotiates how to integrate knowledge and practices he assimilated in Seattle into his daily work in

357 Interview: Dr. F, March 2012.
Uganda. He wants to make “contributions to science,” as he puts it, by finding time to publish and write grant applications. He works to balance this with clinical duties. These include getting through 80 to 100 out patients every other day as a senior consultant physician. He is responsible for running and overseeing the Solid Tumor Center, which has about 20 beds for 40 to 60 in patients at any given time, many of whom are in very late stages of cancer. The Ministry of Health and the National Drug Store Authority in Uganda have proven to be inconsistent financial and drug stocking partners. So there are still plenty of days when there is no doxorubicin or vincristine on the shelves and no oral morphine on hand. Dr. F works to publish his research on Kaposi’s sarcoma staging in international medical journals, but also tries to find the time to work with the Ministry of Health to improve referral guidelines. Patients are still financially impoverished. And there are far more of them than there used to be.

The Ugandan oncologists who see over 40,000 patients a year are brilliant, caring, and fantastic people. The vast majority of them also spent a grueling year in Seattle absorbing the ins and outs of how oncology clinics run at the Seattle Cancer Care Alliance while also taking numerous courses in HIV and cancer epidemiology, biology, and biostatistics at the University of Washington. The emphasis of this training program was to create physician-researcher leaders who would then return to the UCI and become publishing scientists.³⁵⁸ At the Hutch, 90% of a physician-research scientist’s time is devoted to research. At the UCI, as a colleague noted,

³⁵⁸ Conversation with Jason Barrett, Fieldnotes, February 2014.
most of these Ugandan practitioners are operating at 200% on every level. An oncologist is expected to be able to consult with a leukemic child’s family, screen for breast cancer, palliate pancreatic cancer, and keep on top of the latest HIV related malignancy data coming out of sub-Saharan Africa. They are expected to be polymaths, stunningly versatile, and seamlessly negotiating back and forth between children and adults, solid tumors and blood cancers. It is a lot to ask. At the Hutch, being on top of the oncology game means being thoroughly engrossed and specialized in a particular kind of cancer.

The Hutch has very strategically and practically bounded what constitutes their activities and obligations at the UCI. Building patient cohorts, doing HHV-8 shedding studies, and doing some translational research on improving Burkitt’s lymphoma outcomes comprise the bulk of their activities. Although the offices are located at the UCI, many of the late stage cancer patients who are at the site seeking care will never interact with a research program. This means that the sort of work that Dr. Fred does for the Hutch on KS staging is often separated from his actual care for KS patients on the wards of the Solid Tumor Center. In other words, these latest attempts to transfer the socio-technological system of oncology for conducting research on cancer in Uganda inadvertently create divides between the patients who have cancers that are of interest to research programs and those who come seeking care who may not have cancers of interest to international researchers. Closing the global cancer divide both mitigates and entrenches inequalities. The next two chapters offer two case studies in how Ugandan physician-researchers
address these inequalities and keep experimental infrastructures going in Museveni's Uganda.
CHAPTER FOUR: Cobalt Blues—the Half-life of Radiotherapy and Other Transferred Technologies

Radiotherapy in Uganda Today

In the mid 1990s, Mulago National Referral Hospital opened Kampala’s first radiotherapy unit. The GWGP80, a used Cobalt-60 machine manufactured in China and newly refurbished, was procured through a partnership with the International Atomic Energy Agency (IAEA). The machine was seen as “rugged,” “simple,” “affordable,” and capable of quickly and cost-effectively treating cancer patients.³⁵⁹ Nearly 20 years later, the same Chinese GWGP80 Cobalt-60 machine continues to operate at Mulago and has a reputation for frequent disruptions of service due to breakdowns large and small. The machine’s radioactive source is in dire need of replacement. Technically, the radioactive Cobalt-60 source in the unit should have been replaced in 2005.³⁶⁰

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³⁶⁰ Cobalt-60 is a radioactive form of cobalt that is commercially manufactured through linear acceleration to be used either for medical services, where it is frequently used for radiotherapy, or industry, where it is commonly used to sterilize food. Cobalt-60 can also be formed as a byproduct from nuclear reactors. The source has a half-life of 5.27 years, which means that it takes 5.27 years for the radioactivity of this source to decrease by half. Radiotherapy machines use the gamma rays emitted from Cobalt-60 sources to irradiate tumors with the hopes of damaging cancer cells and shrinking or even eliminating tumors. Side effects from radiotherapy treatments can include burns, fatigue, and a host of other long-term issues including infertility and secondary cancers. For more on how Cobalt 60 machines work and the practices of radiation oncology, see E. B. Podgorsak, ed.
Today, despite the weakness of the source and frequent breakdowns, on any given morning at the radiotherapy bunker, 80 to 100 patients line up to be “roasted,” as it is known in Luganda, the local language most widely spoken in Kampala and central Uganda. Approximately 1,850 patients undergo radiotherapy at the unit per year. The Ugandan physician-scientists who have been trained through IAEA partnerships in radiation oncology and medical physics feel that it is their moral and medical obligation to continue to run the unit. They do so by upping exposure times in order to maintain the therapeutic efficacy of the machine, all the while managing a very long waiting list. Given the weakness of the source, it is unclear to what extent longer exposure times simply harm and burn rather than heal or alleviate suffering. But women rotting and bleeding from the inside out from cervical cancer, or men with bone cancer, or children with leukemia and central nervous system involvement still spend time under the “roasting” machine, with the hope that it can provide palliative relief and shrink tumors.

On the one hand, the continued operation of the radiotherapy machine despite its breakdowns and deteriorating source is a remarkable act of creativity in

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361 These estimates come from the head of the radiotherapy department at Mulago Hospital, from an interview conducted by Marissa Mika with Dr. Z in June 2012. The discrepancy in the numbers between patients treated per day and total patients per year is due to the fact that patients come for multiple doses of radiotherapy treatments usually over a 20 to 40 day treatment cycle. By contrast, Nairobi’s Kenyatta Hospital’s radiotherapy unit treats 3,000 patients a year. These yearly estimates of cancer patients seen at Mulago’s and Kenyatta’s radiotherapy units are taken from B. Jeremic et al., “Patterns or practice in palliative radiotherapy in Africa—case revisited,” *Clinical Oncology* 26, no. 6 (Jun 2014): 333-43.
crisis, an extraordinary act of ongoing maintenance and repair. On the other, it’s a tragic situation. Patients face the consequences not only in treatment outcomes, but also in terms of how they will spend their last months of life. As Dr. Z, a long time radiation oncologist at Mulago said:

We continue what we do now, which is palliative. The very early cancers we try to treat aggressively. But for anybody who is very advanced, we are very strict and don’t give long treatments for that. And it kind of denies them some of the palliative care they can receive and as far as pain control is concerned maybe some of the most distressing symptoms we can control reasonably well with the existing machine. Certainly it’s not good, but what can we do where we are working at?\textsuperscript{362}

\textsuperscript{362} Interview conducted by Marissa Mika with Dr. Z, June 2012. The research for this project occurred between 2008 and 2014 and included over 24 months of ethnographic and historical fieldwork at sites in the United States, the United Kingdom, and Uganda. From January to November 2012, I conducted the bulk of the Ugandan historical and ethnographic research for this project and spent the vast majority of my time working at the Uganda Cancer Institute. Comparatively speaking, the amount of time I spent at the Radiotherapy Unit at Lower Mulago Hospital as a participant observer was far shorter, about a six weeks total of regular visits between June 2012 and July 2012. Although I spoke with nurses and other radiotherapy staff at the department at some length and field noted these conversations, I found the head of the department at the time, Dr. Z, to be by far the most knowledgeable and historically minded about the research. He was the one who ultimately agreed to be on the record and take time to represent his unit to me. In addition to speaking on the record with Dr. Z, I also met with his former boss, who now runs a private hospital in Kampala, and who was responsible for building radiotherapy services at Mulago and mentoring Dr. Z. I also fact checked Dr. Z’s account with Uganda Cancer Institute staff and followed up on available sources in
There is a terribly sad human cost to all of this. Although the work at the unit is mainy to palliate, and the majority of treatments are not aimed at providing cures or even necessarily long term remissions, that is not always what patients are coming for, whether they are referred from the Uganda Cancer Institute or the Obstetrics and Gynecology ward of Mulago. As Dr. Z puts it, this unit is primarily a “Lady’s Unit,” and the vast majority of patients who are waiting to get their turn under the weak gamma rays are women with advanced cervical cancer and breast cancer.363

Yes, these “lady” patients are coming for pain management, but they are also coming to the unit from remote distances and camping out on the verandahs for months at a time in hopes of renewing biologically and socially reproductive futures. Women with cervical cancer are coming not only to mitigate incessant bleeding. They come with the hope that these beams will restore the possibility of having a child, and of returning to a sexual life with a partner. And the staff keeps these hopes alive, counseling women on how to use their fingers to keep their vaginal walls from

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363 A range of solid tumors, most commonly head and neck cancers, are also treated at the unit, as are some patients with lymphoma and leukemia with central nervous system involvement.
collapsing from the treatments and how soon they can return to sexual intercourse.\textsuperscript{364} Caring for these hopes of returning to social and biological reproduction, to an ordinary intimate life, is as important a part of the work of the nurses at the radiotherapy unit as administering chemotherapy and tracking down oral morphine.

Other patients come to the unit after several years of being in remission from cancer. Take the story of Joy.\textsuperscript{365} Joy was one of the breast cancer survivors who spent her Friday mornings at the cancer screening clinic educating patients about how to do breast self-exams.\textsuperscript{366} She felt a new lump in her remaining breast in 2012, and she was devastated. But, she followed up with her oncologist right away who prescribed a new and punishing regimen of chemotherapy and radiotherapy. While undergoing chemo, Joy tripled her attendance at her Born Again church, in large part to ask God to ensure that the radiotherapy machine would be operational when her name was finally called off the waiting list. “I pray that the machine will be working,” she said. The radiotherapy’s long-term mechanic, Mr. T, was able to scrounge a new electrical component that had been failing, just in time for Joy to get her time with the machine. Her appointment slot was late at night—ten pm—

\textsuperscript{364} Fieldnotes from conversations with nurses at the radiotherapy unit, June 2012.
\textsuperscript{365} Joy is a pseudonym. All patient names are pseudonyms and some identifying features of illness progression and where they are from have been altered to preserve patient privacy.
\textsuperscript{366} Breast cancer activism is a small but growing community in Kampala, Uganda and is spearheaded by the inspirational and courageous women at the Uganda Women’s Cancer Support Organization. They do weekly breast cancer education at the Friday Screening Clinic at the Uganda Cancer Institute headed by Dr. N.
because the machine operates 20 hours a day. But after her treatments, Joy did not improve, although her charred skin from the “roasting” and vanished eyebrows remained a reminder of the treatments. She became more and more ill. She melted away at her home in Ntinda, a suburb of Kampala. Regular hospice attendants managed her pain with oral morphine and kind words until the day of her death.

Was it the fact that Joy’s cancer was simply too advanced to be treated? Or was it the fact that the radiotherapy machine was operating with a radioactive source that should have been replaced in 2005, and that therefore her radiotherapy treatments were performative rather than efficacious? We will never know.

In this chapter, my aim is not to untangle the ambiguity and uncertainty of diagnosis and therapeutic efficacy in Joy’s cancer treatments or those of others coming to Mulago National Referral Hospital for relief from malignancies. It is also not my intention to undermine or call into question the daily efforts of staff and caretakers at the radiotherapy unit to alleviate suffering and to use the tools available for palliation and care. These issues are, of course, tremendously important.


368 As we know, therapeutic efficacy has long occupied the interests of historians and anthropologists of medicine, and is particularly salient in the history and anthropology of cancer. On issues of therapeutic and efficacy in the history of medicine in general, see Allan Brandt, No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880, (Oxford: Oxford University Press, 1987); Jeremy Greene, Prescribing By Numbers, (Baltimore: Johns Hopkins University Press, 2007); Charles Rosenberg, “The Therapeutic Revolution: Medicine, meaning and
Institute, uncertainty around the efficacy of treatments, as I discuss elsewhere, is a major topic of concern for medical staff as they try to determine who should be sent home to die and who should undergo a new round of induction therapy. Oncology is an ambivalent constellation of healing technologies under the best of circumstances, where the unholy trinity of practices—poisoning, cutting, and burning—constantly raise concerns about futility, efficacy, and harming. And in Uganda, the grimness of oncology’s violent healing is often rendered in Technicolor.

Here, I am more concerned with untangling the historical, sociotechnical, and political stakes that shape this present day reality. I want to chart the ways in which we can understand why it was possible in the first place for Joy to pray for her time under the weak gamma rays of a radiotherapy machine that, for all intents and purposes, was not “working.” In all likelihood did not have the ability to effectively

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369 See my discussion of “game over” in the next chapter.

370 Of course, I am not the first nor unfortunately will I be the last person to make this point. On healing and harming in oncology, see: Aronowitz, Unnatural History; Jain, Malignant; Livingston, Improvising Medicine; Lowy, Preventive Strikes; and Mukherjee, Emperor of All Maladies. For a general discussion of this tension in African healing, see Steven Feierman, Peasant Intellectuals: Anthropology and History in Tanzania, (Madison: University of Wisconsin Press, 1990).
treat her cancer. Every year there are over a thousand patients like Joy who seek treatment, relief, and the possibility to continue life and living at the radiotherapy unit. What are the circumstances that explain why an ostensibly broken machine is being used over twenty hours a day, seven days a week? Why hasn't the machine been decommissioned? Why is it so difficult to procure a new radioactive source?

These questions about the material, technological, and political basis of therapeutics and diagnostics are part of the core challenges facing oncology care in Uganda. Take the technological challenges of Burkitt's lymphoma treatment for example, where treatment outcomes are poorer in the present than they were during Idi Amin's Uganda. Research suggests that this discrepancy may be a reflection of atrophied pathology services in the country. Currently on the wards of the UCI, the agreement between clinical diagnosis on the wards and pathological diagnosis for Burkitt's lymphoma is very low. According to a recent study of diagnosis of childhood lymphoma, the agreement between pathological diagnoses made in Uganda and a reference laboratory in the Netherlands was only 36% [95% CI 28-46]. Agreement between Ugandan pathologists and pathologists from the

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371 Even with a weak Cobalt-60 source, you can still treat patients, but you must do so by treating patients for longer and longer periods of time, which means that patients must lie still for very long periods of time and also experience more severe burns. If the source is very old, as it is in this case for the machine at Mulago, then it is also possible that treatment efficacy is reduced because of the ability of tumors to repair themselves. All of this is to say, while radiotherapists at Mulago are doing their best and following the general logic of Cobalt-60 decay, the source is so old at this point that it is nearly impossible to gauge whether or not the treatments offered have much efficacy. Personal communication, Dr. Charles Simone, October 3, 2014.

Netherlands on a Burkitt’s lymphoma diagnosis occurred only 52% of the time. If we take the Netherlands diagnosis to be the “right” diagnosis, (and to be fair, it most likely is given the limited access to the reagents and laboratory techniques in Uganda), this means that only half the children with Burkitt’s lymphoma are being correctly diagnosed. The consequences of this can be devastating. For patients who clinically present with Burkitt’s like symptoms and get an injection of chemotherapy drugs, this could very well create drug resistance if it is later decided that the patient actually has a rhabdomyosarcoma.

Untangling why it is so hard to get pathologists to agree on a diagnosis takes us into a thorny briar patch of questions. Why is it so hard to retrofit the pathology laboratory at Makerere? Why is it such a huge challenge to conduct a biopsy properly and get tissues encased in paraffin with alacrity? Is the responsiveness of Burkitt’s lymphoma to a long established treatment regimen itself changing?

Julie Livingston has argued that improvisation is a fundamental aspect of the practice and provision of biomedicine in Africa. In a context where drugs are constantly in and out of stock, where blood transfusion services are erratic, and where vital reagents for pathology diagnoses are missing, the striking unpredictability of what may or may not be available profoundly shapes medical

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practice.\textsuperscript{375} I agree with Livingston and would say that similar issues are in play in oncology services and virtually any biomedical services at Mulago and elsewhere in Uganda. My aim here is to step back and interrogate the techno-political constellations that make this so.\textsuperscript{376}

The history of neoliberal economic reforms that punished and gutted the budgets of African health systems in the 1980s and 1990s is an obvious factor in shaping episodic stock outs or dilapidated health infrastructures.\textsuperscript{377} But scarcity is a necessary but not sufficient factor in explaining this culture of improvisation. I suggest that one way we can understand this story of the radiotherapy machine is if we contextualize it as a key example of the ramifications of oncology care as a

\textsuperscript{375} Livingston, Improvising Medicine, 6-7.


transferred socio-technical system.\textsuperscript{378} The situation where Dr. Z works is the product of a longer history of radiotherapy technology transfer and what it takes to keep technical objects \textit{going} in Uganda. It is but one example of the ways in which transferred technologies are reshaped by a local culture of managing the vagaries of cheap equipment and frequent breakdowns. In Uganda, this logic of care grew at least partially out of experiences of civil war in the 1980s, and it privileges providing \textit{something} to patients, even if it is simply the performance of \textit{doing something}.\textsuperscript{379} This desire to give \textit{something} to patients, be it palliation or long term treatments, is part of what keeps the waiting lists long and the machine operating 20 hours a day. Keeping the radiotherapy machine open and operational is shaped also by a local culture of repair and maintaining machines that is reminiscent of the Uganda’s automobile repair market. Mechanics, spare parts, and a willingness to

\textsuperscript{378} See Wiebe E. Bijker, Thomas P. Hughes, and Trevor Pinch, eds, \textit{The Social Construction of Technological Systems} (Cambridge: MIT Press, 2001). I first heard of this conceptualization from Steve Feierman in his Comparative Medicine course where I was a teaching assistant in 2009 at the University of Pennsylvania. I have found this to be a helpful way of framing the fragmentations and limitations of biomedicine in sub-Saharan Africa since this initial suggestion.

\textsuperscript{379} Uganda’s postcolonial history of violence is a bleak one. While Idi Amin’s tenure from 1972 to 1979 was economically, politically, and socially violent and devastating, the Tanzanian War of Liberation or the Tanzanian Invasion War (the name depends on who you talk to) of 1979-1981 was also catastrophic. On the history of violence in Uganda, see A. B. K. Kasozi, Nakanyike Musisi, and James Mukooza Sejjengo, \textit{The Social Origins of Violence in Uganda, 1964-1985} (Montreal: McGill-Queen’s University Press, 1994). For an account of the Tanzanian war, see Tony Avirgan and Martha Honey, \textit{War In Uganda: The Legacy of Idi Amin} (Lawrence Hill and Co., 1983). For an account of the toll of the war on Mulago Hospital, see John Iliffe, \textit{East African Doctors: A History of the Modern Profession} (Kampala: Fountain Press, 2002), 136-168.
ignore the check engine light keep vehicles going, but repairing roads or filling potholes is a different story.

In the pages that follow, I show how the techno-politics of eroded infrastructures, an under-funded health care sector, international partnerships, anti-corruption measures around procurement, and, weirdly enough, the Global War on Terror and East African military and security concerns, shape the efficacy, practice, and technology of “roasting.” This is not a unique story, either at the Uganda Cancer Institute or in Museveni’s Uganda, but it is an extreme one. I tell this story by briefly discussing oncology as a transferred socio-technical system, contextualizing it within the broader field of the anthropology of biomedicine and science and technology studies. From there, I offer a historical overview of radiotherapy services in Uganda and then offer an account of the ways in which this machine has been maintained and cared for in a style reminiscent of the ways in which vehicles are repaired in Kampala. After providing this context, I unpack the broader techno-political circumstances of procurement and disposal, which have made it so challenging to upgrade radiotherapy services. I conclude the article by discussing some of the implications of technology transfer for the broader arena of oncology services in Uganda.

Oncology as a Transferred Socio-Technical System
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, and say:

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.\(^{380}\)

Oncology, as an arena of biomedicine, can be thought of similarly as a constellation of technologies that are embedded in a broader socio-technical system. The borders of oncology’s socio-technical system are murky and culturally embedded, of course. In contemporary America, everything from cancer screening, to pathology laboratory reagents, to breast cancer awareness campaigns, and to pharmaceutical companies conducting cancer clinical trials could be theorized as an assemblage making up oncology technologies.\(^{381}\) Lochlann Jain calls this tangle of markets,


medical practitioners, politics, and indeed patients the cancer-corporate care nexus.  

What happens when biomedicine travels as a set of technologies? Adriana Petryna has demonstrated that the pharmaceutical industry’s hunger for research subjects for clinical trials has led to a proliferation of experimental sites across the globe, where cutting edge biomedical research enclaves are established alongside atrophied or nonexistent public health care facilities. The Uganda Cancer Institute is a unique historical case study of this phenomenon. At the Institute, we can see the long-term repercussions of what happens when oncology’s technologies travel. When the Institute 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.” But these materials goods were not the only things they brought with them. They also brought a set of practices from their training in medical oncology from US hospitals—ward rounding, the proper way to write up a chart, protocols for doing complete blood workups before deeming it safe to administer chemotherapy. And they learned how to improvise in their new setting—makeshift dialysis units for kidney failure, treating entire families for malaria and parasites, ensuring that there was a big scoop of pungent, nutrient rich greens on plates of local food for pediatric patients. All of these measures made it possible to transfer

382 Jain, Malignant, 68.
383 See Petryna, When Experiments Travel.
384 Interview: John Ziegler, June 2012.
oncological practices from the United States and tailor them to a relatively under-resourced setting like 1960s Uganda.

The concentration of cancer services in Kampala at the Institute has meant that Uganda’s cancer nexus, in comparison to the United States or Europe or indeed other parts of the Global South, is infrastructurally shallow. The Institute was not established with the intention of providing comprehensive oncology services to the Ugandan masses, even when the population was less than ten million. It was, and in many ways still is, an enclave established to do research on African bodies. Since it was founded in 1967, the Uganda Cancer Institute’s mandate has grown in part due to international research collaborations and partnerships, which brought the study tools and new biomedical technologies for examining new populations such as HIV positive children with malignancies.\textsuperscript{385} And Hospice Uganda, founded in 2000, brought greater attention to the problem of pain and palliative care for cancer patients. But the Uganda Cancer Institute, for the most part, has remained a chemotherapy experimentation and treatment facility rooted in the socio-technical practices of oncology as they were in the 1960s and 1970s. It was never a comprehensive cancer hospital with everything from pathology services to a surgical theatre under one roof.\textsuperscript{386}


\textsuperscript{386} Ibid. The construction and opening of the new Uganda Cancer Institute building, a six-story unit which includes laboratory space and a surgical theatre, is designed to remedy this historical artifact and integrate cancer services.
Historically, cancer care and research at the Uganda Cancer Institute were in part shaped by the absence of radiotherapy technologies at Mulago Hospital from the 1960s to the 1990s. In 1967, when the Institute was founded, there was no radiotherapy machine available in Uganda. The lack of radiotherapy services created a research environment where chemotherapy combinations or surgical interventions were the only standard of care available unless patients went to Nairobi, Kenya. In the late 1970s and early 1980s, Charles Olweny, then the director of the Uganda Cancer Institute, planned with his colleagues to build a large cancer hospital at Mulago which would include radiotherapy services, but civil war and exile politics foiled those plans for several decades.\textsuperscript{387} Radiotherapy services in Uganda did not grow out of research partnerships at the Uganda Cancer Institute, and remained institutionally and physically separated from services provided at the Institute. Radiotherapy technology and expertise came to Uganda through channels of donations, partnerships and trainings in two separate geographical and cultural regions in Uganda, rather than being embedded in the historically situated cancer research infrastructure in the country. In the north, at Lacor Hospital in Gulu, radiotherapy services and a surgical oncology unit opened in the 1970s with the help of an Italian donation. These services were seen as a way to meet the needs of the community in the surrounding area of northern Uganda. At Mulago, radiotherapy services were established in the 1990s independently of the Cancer Institute through a partnership with the IAEA. The bigger picture then, of oncology

\textsuperscript{387} Interview conducted by Marissa Mika with Charles Olweny, May 2012.
and its therapeutic arsenal in Uganda, is that of a patchwork of historically contingent transferred technologies and limited systems. These systems, which are bureaucratically fragmented, arrive and are integrated at different times under a variety of political, economic, and epidemiological circumstances in the country.

A Brief History of Radiotherapy Services in Uganda: A Demonstration Project

The radiotherapy unit at Mulago is commonly referred to as “the bunker,” and it was a school of radiography for many years before being converted and reinforced in the early 1990s to house the Cobalt-60 machine. The head of the unit from 1994 to 2014 was the country’s first radiation oncologist, Dr. Z, an amiable middle-aged Muganda man with a boisterous laugh and big glasses. The bunker itself is hot and airless, and when we met, he was wearing a short-sleeved dress shirt to provide some relief from the heat, along with a carefully selected tie. Dr. Z is a busy man, and was not afraid to interrupt our interview on a few occasions to follow up on a consultation for a patient.

The story of Mulago’s radiotherapy department intimately intertwines with Dr. Z’s personal story and the broader history of the hospital’s collapse during the Tanzanian war in 1979, its slow restoration in the wake of neoliberal reforms, and an ongoing bush war in the 1980s and 1990s. Dr. Z first came to Mulago in the late 1970s, and became a doctor in 1981 during the throes of instability and violence. He remembers these times as ones where:
We were sitting exams. Bombs were going off. A lot of war trauma. And there were no immunizations, so measles were everywhere. Children were dying like anything. We had lost years because things weren’t well planned. Programming and prevention and so on. No paper. You would write on some gloves. You would detach the gloves and write clinical notes on the paper. It was really impossible. It was a crazy time. It was a military camp kind of thing. But that’s the time we graduated. Very difficult times. Very difficult years. And there was a problem with funding, which has really not improved very much. It’s better than it was before, but percentage wise in the national budget, it’s a very small percentage.\footnote{Interview: Dr. Z, June 2012.}

In the wake of Idi Amin’s “disintegrating state”\footnote{Iliffe, \textit{East African Doctors}, 136.} and the uncertainty of war, Dr. Z trained as a radiologist at Mulago, but also spent a year and a half doing further studies in Germany. When he returned in the mid 1980s, he was put in charge of operating an x-ray machine, which was used to remove superficial tumors. “I wanted to be a radiologist. I only wanted to become a radiation oncologist after seeing the need.”\footnote{Interview: Dr. Z, June 2012. Emphasis on the \textit{need} is from Dr. Z.} In the late 1980s and early 1990s, as Dr. Z was seeing the need for radiation oncology on the wards of Mulago National Hospital, the International Atomic Energy Association started to recognize a growing cancer burden in the
developing world, particularly in Africa. Spearheaded in part by Emeritus Professor of Radiotherapy at Cairo University in Egypt, Dr. M. M. Mahfouz, the IAEA presented an agenda for ameliorating the “rather disastrous state of radiation therapy in Africa.” Writing in the early 1990s, he described the situation: “Only about 35% of the countries in Africa have any facilities for radiation therapy, and in many cases these are grossly ill-equipped and understaffed. There are shortages of radiation oncologists, medical physicists, dosimetrists, radiation technologists, radiotherapy nurses, and other technicians.”

A number of factors shaped the absence of radiotherapy services in the majority of sub-Saharan Africa. The relative invisibility of cancer as a public health priority and the tremendous capital and human investments necessary in installing and maintaining radiotherapy services put radiotherapy facilities at the bottom of the chain of health priorities for African governments. As the IAEA noted, “The

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393 Keep in mind that during the 1980s and the 1990s, African health systems were undergoing an extraordinarily devastating and eviscerating set of neoliberal economic reforms that would make it impossible for countries to reasonably
high cost of developing the basic infrastructure, and buying equipment for
establishing a medium-sized radiotherapy centre, is probably beyond the means of
many African countries. The cost of setting up a unit capable of treating up to 2000
cases per years is about US $2.5 million."394

In the early 1990s, the IAEA’s leadership decided to address these capital and
training costs by establishing programs to transfer radiotherapy technology to sub-
Saharan African countries along with a package of training fellowships and
maintenance contracts meant to facilitate the establishment of radiotherapy centers
at various national referral hospitals across the continent. This was a demonstration
project. For the IAEA, they would show that radiotherapy technologies could be
established and used in the developing world safely. For African radiotherapy care
providers, they would demonstrate to reluctant ministries of health that indeed if
they built radiotherapy bunkers, patients would indeed come from far, far away to
the capital in search of relief for their cancers. These investments in radiotherapy
equipment and training technologies were meant to establish the first but not the
only radiotherapy facilities across these countries in Africa.

Creating African radiation oncology experts, medical physicists, technicians,
and nurses was at the heart of these collaborations, but at least in Uganda, IAEA
technocrats and Ministry of Health officials did not create these experts from
purchase radiotherapy technologies or to tackle cancer as a serious public health
problem. For more on this issue, see Turshen, *Privatizing Health Services in Africa.*
394 F.A. Durosinmi-Etti, M. Nofal, and M. M. Mahfouz, “Radiotherapy in Africa:
scratch. Rather, they searched for local talent like Dr. Z, who already had a promising career as a radiologist and was already mentored by the head of the radiology department of Mulago, to send for further training. In Dr. Z’s case, he went to train in radiation oncology in Cairo from 1991 to 1993 and returned to Uganda to oversee the operations of Mulago’s newly acquired but already used Cobalt-60 machine.

Mulago’s second hand machine was not unique. When the IAEA spearheaded its radiotherapy capacity building in the early 1990s to bring radiotherapy treatments to sub-Saharan Africa, most of the machines transferred to sub-Saharan Africa were refurbished Cobalt-60 units. These machines were cheaper than the ones usually purchased in the Global North and procured as a way to contain costs. As the IAEA noted:

It becomes obvious, therefore, that the capital outlay has to be reduced to make the units affordable to many countries in Africa. This can be done by encouraging manufacturers of radiotherapy equipment to design cheaper models devoid of costly electronic and mechanical parts, but which will still maintain the same beam quality and optimum radiation safety standards as the more expensive designs. Such a machine will be simple, rugged, and more mechanical than electrical. It is also more likely to withstand damage to electronic
parts from fluctuations in electric power supply, and the humid, warm, and dusty climate common in Africa.\textsuperscript{395}

In other words, the IAEA was looking for the radiotherapy machine equivalent of the Zimbabwe bush pump—rugged, affordable, simple, health promoting. But as you may recall from the seminal piece by De Laet and Mol, the Zimbabwe bush pump is a “good” technology not only because it promotes community health and builds the nation, but also because “good technologies […] incorporate the possibility of their own break-down, which have the flexibility to deploy alternative components, and which continue to work to some extent even if some bolt falls out or the user community changes.”\textsuperscript{396} The Cobalt-60 machine is similarly flexible and open to tinkering, but what makes a “good” technology can make a bad radiotherapy unit. In the Ugandan case, the machine they received was, well, junk. A cast-off unit made and used in China, it was retrofitted for use in Uganda in the name of cutting costs.

Interestingly, there is no equivalent to the word “junk” in Luganda. Things are old, \textit{enkadde}, or very old, \textit{enkadde nnyo}. In deep Luganda, the sort of Luganda that is rarely spoken among younger generations in Kampala, the phrase \textit{mugangatika} describes that which is very old and only just pushing along. \textit{Enmotoka enmugangatika} would be a real jalopy, a piece of junk that was in a dangerous mechanical condition. In English, while colloquially “junk” is defined as useless or

\textsuperscript{395} Ibid, 26.
worthless stuff, essentially trash, it also refers more generally to material that can be repurposed and is salvageable for recycling and re-use. Furthermore “to junk” means to discard or scrap a piece of material that is considered useful. Junk, in all of its multiple uses and interpretations here, is I think an apt and useful way of theorizing the quality of the equipment. But I want to be clear here that Ugandan colleagues interviewed for this project did not describe the radiotherapy machine in this way. This is my gloss—not the way they would talk about the machine, although the word brought up laughter rather than defensiveness, when I offered up in conversation that it seemed like the machine was a piece of junk. As we will see, the closest equivalent to “junk” used by Ugandans for the unit is “Chinese equipment”.397

Made in China, Maintained in Uganda

Over a decade ago, an informant of Dr. Paul Farmer398 summed up the problem of technology transfer to the developing world in a few sentences. This priest said: “Do you know what ‘appropriate’ technology means? It means good things for rich people and shit for the poor.”399 And even from the first days of its installation and use, the Cobalt-60 machine operated like ‘appropriate’ technology.397

397 For more on joking about the quality of broken things in postcolonial Africa, see Damien Droney, “Ironies of Laboratory Work during Ghana’s Second Age of Optimism,” Cultural Anthropology 29, no. 2 (May 2014). 398 Butaro Hospital’s cancer services, which are sponsored by Farmer’s organization Partners in Health Rwanda, actually refers patients in need of radiotherapy to Mulago on occasion, despite the known weaknesses of the source. It is seen as better than nothing. Fieldnotes, 2012. 399 Paul Farmer, Infections and Inequalities (Berkeley: UC Press, 1999), 21.
It was prone to breakdown and required vigilant care, attention, maintenance and small repairs. Within the first several months of being used, a “pilferage of the control panel and TV monitor” late one evening led to the shuttering of the unit for two months while replacement parts were procured from overseas. At other times, issues with Uganda’s electricity grid and “minor” problems such as “cleaning or replacing control switches and fuses or replacing indicator lamps” led to frequent service interruptions of one or two hours at a time.

More dramatic downtimes were caused by the machine’s force back system, which was simply poorly designed. A Cobalt-60 machine’s radioactive source is housed in a storage casing of heavy lead and moves into position during treatment, where gamma rays irradiate a small surface area on the body. The source is then sucked back by a vacuum into the storage position in the machine after treatment. On one occasion, the motor for the compressor that makes this vacuum possible failed, and the source “had to be hammered back into the safe position,” no doubt exposing the mechanic to excess radiation. On another occasion, “the fault was due to a worn-out piston ring” which “could not be obtained locally and an oil seal from a car engine was improvised as a replacement which has been working quite effectively.” Today, the improvised oil seal is still in place. The joke at the bunker

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401 Ibid.
402 Ibid.
403 Ibid.
goes that if Mr. T, the unit’s mechanic, is sick for some reason, the machine will be out of commission until he returns.⁴⁰⁴

At the radiotherapy unit, “Chinese equipment” is a semi-polite euphemism for describing the quality of the machine. As Dr. Z says, “This machine I think we have the oldest machine of this type working in the world after 17 years. It’s Chinese equipment. And the thing about Chinese equipment is that they are not very strong. I think they are an advantage in numbers. You get this, you get a new one. We’ve had this one for 17 years. It has many frequent breakdowns [. . .].”⁴⁰⁵ The Cobalt-60 machine, manufactured and refurbished by the Chinese, is like so many other goods in Uganda. It’s a second hand piece of equipment that in another context would have been junked and disposed of, but here it’s been given a second chance at life.⁴⁰⁶

Maintenance and service guidelines shaped in the metropolitan spaces of conference rooms in Vienna certainly travelled to Uganda. IAEA technocrats knew that the Cobalt-60 machine would be impacted by the dust and the uncertainty of power supplies. Mr. T was even sent to China for a couple of months in the 1990s to learn how to keep the refurbished GWGP80 machine operating and well lubricated.

⁴⁰⁵ Interview with Dr. Z, June 2012.
But the IAEA could not anticipate the ways in which the Cobalt-60 machine would be incorporated into the broader maintenance logic that shapes everyday practices of keeping transferred technologies going in Uganda, where things often break and the spare parts necessary to keep things going must be radically improvised. Nor could the IAEA imagine that this would be the only working radiotherapy machine in Uganda 17 years after this initial demonstration project began. This is a context that Steven Jackson would define as a “broken world,” where “erosion, breakdown, and decay, rather than novelty, growth, and progress, [are] our starting points in thinking through the nature, use, and effects [of technology].” In the case of the radiotherapy unit’s technology transfer, we can see that the IAEA was not taking a “broken world” as its starting point. Furthermore, the IAEA’s technocratic imagination did not allow for the conceptualization of what Jackson calls “repair work”, which he defines as, the “subtle acts of care by which order and meaning in complex sociotechnical systems are maintained and transformed, human value is preserved and extended, and the complicated work of fitting to the varied circumstances of organizations, systems, and lives is accomplished.”⁴⁰⁷

Coping with the quality of “Chinese equipment,” which is cheap and easy to come by, but not necessarily robust or high quality, is part of everyday life in Uganda, and dovetails more generally with a local culture of repair. The way that many in Uganda manage transferred technologies and eroding infrastructures, from

automobiles to electronics to medical equipment to roads is twofold. One is to engage with experts—find the person with the most extraordinary technical acumen available for the task at hand through a long and complicated set of networks and friendships. Two is to find reliable spare parts as quickly and cheaply as possible, which is a challenge in a parts market where materials are often used, and possibly counterfeit.\textsuperscript{408}

The radiotherapy machine is cared for and maintained on a day-to-day basis in Uganda much like a vehicle that must \textit{keep going no matter what}. When I posed this possible analogy between the \textit{matatu} (a bush taxi) and the Cobalt 60 machine to Dr. Z, he laughed and said, “Haha, exactly. You are moving and moving and you get out and put in something. But you get to where you need to go eventually.”\textsuperscript{409}

Allow me to extend out this analogy for a moment and invite you to consider the politics of the road. Second hand Toyotas run on interchangeable parts reverse engineered and then mass manufactured in Taiwan. These parts are shipped by container on the high seas to ports in Mombasa and eventually find their way into

\textsuperscript{408} This description is derived from field notes about the harrowing and hilarious personal experience of trying to purchase a car in Uganda in 2011 as well as numerous discussions with Ugandan colleagues about how they navigate the precariousness of infrastructure and goods of dubious quality in everyday life in Kampala. On everyday corruption in Uganda, see Godfrey Asiimwe, “Of Extensive and Elusive Corruption in Uganda: Neo-Patronage, Power, and Narrow Interests,” \textit{African Studies Review} (2013): 129-144. In addition, some of the most evocative writing about these issues comes from scholars of Nigeria. See Brian Larkin, \textit{Signal and Noise} (Durham: Duke University Press, 2008), and Daniel Smith, \textit{A Culture of Corruption: Everyday Deception and Popular Discontent in Nigeria} (Princeton: Princeton University Press, 2007).

\textsuperscript{409} Interview with Dr. Z, June 2012.
engines and differentials, installed with care by trusted mechanics.\textsuperscript{410} In the markets of Kampala, counterfeit shocks filled with sawdust and painted to look new and fresh, car batteries full of repurposed acid, and recycled cooling filters “from Japan” are as present as fake pharmaceuticals and expired anti-malarials which have been repacked to look like the real thing. Mechanics navigate these markets, find spare parts, and keep vehicles running, even if the oil pressure light is illuminated or the transmission in first gear is completely worn out, ensuring that you must always start in second gear or not at all. Drivers find their mechanics through complex networks built on trust, driver’s associations, garage collectives, and luck.\textsuperscript{411}

Commuters traveling along the circuits of Kampala’s intricate minibus taxi systems entrust their lives to drivers every time they enter into one of these takksiis or matatus. They are also entrusting their bones, their babies, and their backs to the largely invisible labor of the mechanics who may have checked oil, replaced gaskets, or installed brake pads at the garage earlier that week. Or the mechanics they may have lied about the repairs and pocketed the cash.

For anyone who has ever sat through “The Jam,” Kampala’s notorious rush hour traffic, or who has been stranded on the side of the road on an up country

\textsuperscript{410} For a wonderful discussion of cultures of mechanics and repair in Tanzania, see Joshua Grace, “Modernization Bubu: cars, roads, and the politics of development in Tanzania, 1870s to 1980s,” (PhD dissertation, Michigan State University, 2013).

\textsuperscript{411} Again, this account is derived from field notes about contemporary life and the cultures of the road by the author in 2011 and 2012. For broader accounts of the culture and politics of the road in East Africa, see Kenda Mutongi, “Thugs or Entrepreneurs: Perceptions of Matatu Operators in Nairobi, 1970 to the Present,” \textit{Africa} 76, no. 4 (2006): 549-568.
travel expedition because of a blown tire or running out of gas or a bad battery, one must uphold the faith that you will get to where you need to go eventually. Passengers may quietly suck at their teeth, or mutter under their breaths in exasperation, but for the most part, the response is *bibawo*, roughly translated from the Luganda as “that’s life.” And even under circumstances of breakdown and crisis, politesse and patience must be upheld.

Given the politics of the road, is it at all surprising that the maintenance and operations of the radiotherapy unit would be that different? Perhaps you, like me, find this story of keeping the radiotherapy unit going for the nearly the last 20 years with a rickety Cobalt-60 machine to be on some level a triumphant story of local cultures of repair. On the other hand, you may also find it to be appalling that the machine has not been upgraded and that it’s been so difficult to replace the machine’s radioactive source, which is severely depleted, yet still “roasting” bodies on a daily basis. The assumption driving the IAEA’s transfer of Cobalt 60 technology to Uganda was that the machine and radiotherapy services would shape a culture of cancer care and demonstrate that more such services were needed. But there were consequences to transferring a piece of “Chinese equipment” that would have otherwise been scrapped rather than salvaged. And the technocratic imagination of the IAEA did not account for how local cultures of repair and maintenance would

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412 I am grateful to Walaabyeki Magoba for teaching me this phrase, and for generous instruction in Luganda.
shape, transform, and integrate the machine into Uganda’s own elaborate socio-technical approaches to coping with unreliable but repairable technologies.

Ongoing crises around electricity power outs or “load shedding,” as well as interruptions in Kampala’s water supply are other immediate examples of crisis and broken worlds that come to mind. But for a radiotherapy unit, there is not a generator that can be bought at the market, no inverter that can be installed, no reserve water tank that can be purchased, no child to go down and fetch more water in a jerry can from a burst pipe. If the machine isn’t working, you must pray or go to Nairobi or India for care. What are people to do when they cannot improvise at a scale beyond the repair of the matatu or Mr. T’s ongoing efforts to keep the machine going? Why is it so hard to repair a road or buy a new machine? In the next section, I discuss the bureaucratic constellations that constrain the repair of infrastructure beyond the scale of the matatu and allow this situation to continue.

The Politics and Practicalities of Procurement and Disposal

It seems simple enough to “fix” the problem of an expired Cobalt-60 source. All that needs to be done is to purchase a new source from a reliable contractor, ship the material according to international safety standards to the port of Mombasa, move it via truck or train in a hermetically sealed lead box to Kampala, install the source in the machine, and dispose of the old radioactive material. After all, this is what was done in years past with great success through the partnership between
the Ugandan government and the International Atomic Energy Agency at Mulago up until the early 2000s.

The geopolitics of the war on terror and the fear of “dirty bombs” since the 9-11 World Trade Center terrorist attacks have led to tightened regulations on how radioactive materials may be procured and disposed of. For Mulago staff like Dr. Z, the war on terror is seen as one of the major obstacles to the timely procurement and mobility of new Cobalt-60. As the current director of Mulago Hospital noted on the record on Ugandan radio, “The cobalt machine is not an equipment you can buy ordinarily. You need International Atomic Energy Association [sic] regulations so that actually people don’t hijack it and use it for like Shabab or Al Quaeda.”\(^\text{413}\) The head of Mulago was not speculating. Since the World Trade Center attack in 2001, the refusal of airlines to transport radioactive materials has greatly reduced the mobility of Cobalt-60 and other radioactive sources. According to a 2003 report commissioned by the IAEA’s transport safety unit to investigate the reduced mobility of radioactive sources:

> The shipment of equipment including a sealed source, radioactive material and toxic/hazardous chemicals has become increasingly difficult lately. Although it is unfortunately impossible to quantify the

net adverse effect of Sept 11 terror, much more stringent control has been exercised by all airlines ever since. Many airlines do not accept radioactive material and high surcharges to carry dangerous goods have been applied. It may be worthwhile to note, however, that the difficulty to transport radioactive material and hazardous items has been sharply increasing over several years already.

[. . .] we are facing an enormous difficulty as the suppliers cannot find a way to ship these items and some examples are provided below.

ETH5012 and SUD5026 (24,000Ci blood irradiator for tsetse fly eradication project in Ethiopia and 10,000Ci food/crop irradiator for Sudan): Although the contract was awarded to Nordion/Canada (largest manufacturer of irradiators) in October and November 2001 respectively, Nordion has not found a way to ship the irradiators despite a number and variety of attempts so far made. [. . .]

NIC6007: The head of a Co-60 teletherapy unit must be returned to the original supplier in France. According to General Electric design, the head contains the source and is used as transport container as well. As the Nicaraguan counterpart could not find an airline to take it, CIS Bio sent an approved cask (over-pack) to Nicaragua. However, after the Sept 11 terror, neither CIS Bio nor Nicaraguan counterpart
can find a flight taking the cask (with head inside) back to France.414

In addition to the challenges of transporting radioactive materials, new and evolving procurement policies for purchasing materials over $1,000 (US), instituted by the Ugandan government to mitigate corruption and graft similarly shape and constrain the purchase and movement of new Cobalt-60. The procurement process involves seven steps of complex bidding, soliciting tenders, and weighing contracts, all which have to be done according to the cycle of the fiscal year.415 In addition, the manufacture of Cobalt-60 itself is on the decline, as more and more radiotherapy facilities in the Global North shift their technology to linear acceleration. And there have been changes in the partnership between the IAEA and the Ugandan government since the early days of the radiotherapy unit. Personal relationships, which were so important to setting up and operating machines in the first place, shifted and changed as people retired, got promoted, or lost their energy and willingness to keep one-time technology transfers maintained and viable.

Procurement politics are also shaped by the realities of the challenges of disposal. What do you do with old sources if a new one comes? On the disposal side,

415 Ugandan Government, “The Public Procurement and Disposal of Public Assets (Contracts) Regulations 2014.” This analysis is also based on multiple conversations with staff at the Uganda Cancer Institute about the challenges they face in the procurement process. In particular, I would like to thank the Institute’s head pharmacist for being so generous with his time.
while the IAEA remains ultimately in charge of managing radioactive waste, the everyday responsibility for safe source disposal of radiotherapy sources often falls on partner governments across the Global South.\textsuperscript{416} Despite concerns regarding the mobility and management of radioactive materials like spent Cobalt-60 sources, countries are still left to deal with these materials largely on their own and in locally specific ways. Incineration, by far one of the most common methods of dealing with medical waste at Mulago, does not work for disposing of Cobalt-60. In the past, according to memories, spent sources were taken by the IAEA and dumped out on “the high seas,” usually off the coast of Somalia. But due to the challenges associated with moving these materials to the standards of international regulations, the spent sources remained on Mulago’s campus. For much of the 2000s, depleted cobalt-60 sources were kept in a small 3 foot by 4 foot storage facility on Mulago’s campus, secured with a padlock and not kept under particularly close surveillance.\textsuperscript{417}

According to U.S. government wires made public by WikiLeaks, in July 2007, a group of thieves broke into the storage area and stole the radioactive materials from the unit, unaware of its value or what exactly it even was.\textsuperscript{418} Officials from the

U.S. National Nuclear Security Administration visited Kampala shortly thereafter to assess the situation and demonstrate a “joint US-Ugandan response to the theft of radiological material from a storage area at Mulago Hospital.” (Incidentally, the U.S. ambassador to Uganda responsible for bringing the thefts to the U.S.’s attention, Mr. Jerry Lanier, went on to work at the State Department as the director of the Counter-Terrorism unit.) But on paper, the International Atomic Energy Agency is, for all intents and purposes, still responsible for signing off on the way radioactive materials are stored in Uganda. As the Mulago Hospital spokesman, Dan Kimosho said when this story broke in September 2011, “International Atomic Energy Agency clears us for procurement, storage and whatever we do. It’s up to them to clear us.”

Finally in addition to the politics of disposal, while the Cobalt-60 source loses its potency, the radiotherapy machine itself continues to break and atrophy, moving from enkadde (old) to enkaade nnyo (very old), so old that it is increasingly apparent to staff that the machine should also be replaced. And so an ongoing debate has led to a stalemate of sorts. Is it worth buying a new radioactive source and installing it in an old machine that is about to be decommissioned anyway? Isn’t it just better to wait until the next fiscal year and see if a new machine can actually be procured? In the meantime, isn’t it just best to house the spent sources on site rather than spend

419 Ibid.
huge amounts of money to truly dispose of it properly? In the meantime, the “roasting” continues.\textsuperscript{420}

**Ebola: What it takes to close a unit?**

So why not just shutter the unit until a new radiotherapy machine is procured or a new Cobalt-60 source is acquired? Dr. Z and many of his colleagues learned how to keep things going and provide care in the midst of civil war. They are used to working creatively in crisis, writing out lab report requests on recycled paper from gloves packaging if need be. In addition, Dr. Z’s professional identity is intimately tied to the continued operations of the radiotherapy unit. Dr. Z is an expert, invited to meetings in Geneva and Cape Town. He publishes in international medical journals and has made a better living than most as a department head at Mulago. He and his colleagues have a professional stake in keeping the unit open as long as possible.

To shut something like the radiotherapy unit down would probably require a catastrophe. And indeed, catastrophe is what shuttered Uganda’s only other

radiotherapy unit. Until this point, I’ve focused mainly on the history of Mulago Hospital’s radiotherapy politics, and have only discussed Lacor Hospital’s radiotherapy unit in passing. In contrast to Mulago’s unit, Lacor Hospital’s Cobalt-60 machine was procured through the channels of Italian Catholic donors. The secondhand machine was made in Germany by Siemens. It arrived at Lacor Hospital in the mid 1970s via train to Gulu and was assembled on site with the help of several Italians, including an X-ray technician and mechanic. The machine was installed in a bunker in the middle of the hospital campus, and, with a surgical oncology unit, provided cancer care to those living in northern Uganda.\footnote{This account of the history of the radiotherapy unit at Lacor Hospital is derived from fieldnotes from a research trip to the site in September 2012, as well as conversations with the X-ray technician and Dr. Y, who ran the radiotherapy unit for many years and is currently one of three directors of the hospital. For more on the history of Lacor Hospital itself, see \textit{To Make a Dream Come True: Letters from Lacor Hospital Uganda} (Milano: Fondazione Piero e Lucille Corti, 2009).}

But in 2000, the unit closed due to a series of unfortunate circumstances. The Lord’s Resistance Army brought havoc to northern Uganda. Lacor Hospital became a war hospital and a space of refuge for nighttime residents fearing kidnappings.\footnote{For more on the history of the war in northern Uganda, see Tim Allen and Koen Vlassentoot, eds, \textit{The Lord’s Resistance Army: Myth and Reality} (London: Zed Books, 2010); Adam Branch, \textit{Displacing Human Rights} (Oxford: Oxford University Press, 2011); Sverker Finnstrom, \textit{Living With Bad Surroundings} (Durham: Duke University Press, 2008).} The radioactive source needed to be replaced, and it was going to be extremely challenging to move a new Cobalt-60 source in northern Uganda during a time of war. The official story of what shuttered the unit, however, was a horrible Ebola outbreak that claimed the lives of over 200 people, including the hospital’s director,
Dr. Matthew Lukwiya. His colleague, Dr. Y, who was responsible for running the radiation oncology services at Lacor, suddenly found himself in the position of running the hospital. As Dr. Z put it, “he had a weak source and too much administration. He was doing radiology apart from radiotherapy and said, ‘well, radiotherapy. I think it is what? It’s Closed.’”

At the hospital, the stories about why the radiotherapy unit itself was closed contradict one another. Some have said that it had much more to do with jealousy on the part of Mulago, which was irritated that Lacor was doing such a good job managing cancer patients, and put together a list of specifications for keeping a radiotherapy unit open safely that Lacor was simply unable to meet—a physicist, etc. Somewhere between these two explanations is the version that Dr. Y himself gave me, that the Cobalt-60 machine was old and outdated, that the company that had supplied them the source from the UK had gone out of business, and even though the cobalt wasn’t completely useless, the amount of time they had to expose patients to the source for it to have any effect was simply becoming too much. And so they shuttered the unit.

Every morning at Lacor Hospital, a siren sounds at 8am. Imported from Italy, it is both a call for hospital workers to get to work and a haunting reminder of both air raids in Italy during World War II and of the war in Northern Uganda. Many used to retreat into the radiotherapy bunker to escape the gunfire from soldiers and

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423 Interview: Dr. Z, June 2012.
424 Today, many towns in Italy still test their Air Raid sirens daily, a grim reminder in the soundscape of World War II.
rebels when they would come into the hospital to loot, steal, pillage, and terrorize in
the wake of Amin’s departure in 1979 and 1980. Today, activity at the hospital
buzzes around the now abandoned bunker, where the machine still sits entombed in
1.2 meters of reinforced concrete. If you peer through the windows, you can see
some of the old control panels. The door itself is shuttered. There are cobwebs
growing up around the windows, and patches of old long abandoned screens sag
and blow in the afternoon breeze, a reminder that at some point later on the
heavens will open and dump rain for an hour or so. A plaque is mounted to the
building and honors Professor Belladina, the Italian radiographer/radiotherapist
who came to Lacor and established the radiotherapy unit after his retirement from
work in Italy. Today, the radiotherapy unit stands as more of a monument than the
intentional one which honors the graves of the hospital’s past directors: Matthew
Lukwiya, dead from Ebola, Lucille Teasdale, dead from AIDS, and Piero Corti, dead
from a heart attack or heartbreak.

There is no longer a cancer ward. It was converted into a tuberculosis unit. At
Lacor Hospital community meetings, people ask when cancer services will come
back to the hospital. While the hospital still sees cancer patients and refers them to
Mulago for care, most melt away into their respective northern villages to rot, never
to be seen in Kampala. The Cobalt-60 itself is still entombed in its lead chamber,
slowly losing its radioactivity as it retreats into its half-life, and irradiating all of the
old radiotherapy patient records in the process. Ironically, the fallout shelter went
nuclear.
With this story, we see what would it take to shut down Mulago’s radiotherapy unit or at least shutter it until a new Cobalt-60 source is procured and installed in the machine. Quite frankly, it would probably require something comparable to the synergy of the Ebola catastrophe, guerilla war, and administrative shortfalls that plagued Lacor in the early 2000s. Similar circumstances shuttered Liberia’s Cobalt-60 machine in Monrovia during the civil war, as did the full scale atrophy of Zimbabwe’s health services in the wake of the economic meltdown following Robert Mugabe’s cynical efforts to redistribute land to “war veterans” and hang on to power. Medical staff, as we’ve seen at Mulago, elsewhere in Uganda, and indeed across Africa, are incredibly adept at acting creatively in times of crisis. But some circumstances are simply too much.

**Returning to the Freezer Graveyard and the Half-Life of Research Partnerships**

The stories of Uganda’s radiotherapy units, one still running on an expired source, the other officially shuttered by an Ebola outbreak and guerilla war, are just two examples among many of a prominent feature of global health partnerships or international development initiatives. Partnerships often fortuitously inject pieces of technology into circumstances where there is little infrastructural or technological redundancy to begin with. A catastrophe like Ebola can close a hospital ward, or a more gradual shift in the top echelons of leadership can lead to the atrophy of a gift that has long outlasted its usefulness.
From the freezer graveyard to the entombed radiotherapy unit of Lacor, the debris of past health improvement measures, whether from the colonial era or the remnants of medical research and experiments, litter the terrain of biomedicine across sub-Saharan Africa. In some ways, the case study of the radiotherapy unit's technology transfer is benevolent in contrast to many of the original transferred technologies of biomedicine to sub-Saharan Africa that were deeply and inextricably tied to colonial conquest and 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 medical experiments and treatment interventions today. Many anthropologists

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425 Hunt, A Colonial Lexicon; Stoler “Imperial Debris”.
are examining how medical experiments and treatment interventions shape access to health care, and the ramifications of disseminating technological solutions, be they mosquito nets or antiretroviral therapies, independent of the broader social and technological infrastructures where they were originally designed for across the Global South. These sites of research create “experimental fields,” as Adriana Petryna calls them. They are sites where corporate drug development research brings biomedicine in the form of drugs and care to places where there are minimal state services in exchange for research subjects.

Ethnographies of humanitarian

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projects similarly theorize and argue that a disaster relief zone or an internationally funded AIDS clinic can become a zone akin to an “experimental field” for accessing health care in a context where neoliberal policies have severely crippled health care systems. In Uganda, where so many development projects in the Museveni era happen under public-private partnerships and through collaborations with NGOs, these zones of accessing care and services beyond the state are fast becoming many people’s principal, if not sole, site of care.

But in the story of the radiotherapy unit, and indeed in the history of the Uganda Cancer Institute, we can see the constellation of forces that embed these experiments in broader infrastructures and within the politics of the Ugandan state. Freezer graveyards and radiotherapy bunkers turned radioactive also remind us that there is a fundamental dynamism to the creation and dissolution of health interventions and experimental fields in sub-Saharan Africa. As Thomas Gieryn suggests, built environments and their material resources shift over time. They can fall into ruin. They can be radically modified. Infrastructures are fluid, consistently being transformed and tinkered with, often through collaboration or political negotiation, even if they are theoretically fixed in mortar and concrete. We can also see that within the context of Uganda, transferred pieces of heavy equipment are often donated secondhand machines, that once embedded in local maintenance

and care logics, they are very difficult to junk or discard. They are more often than not repurposed, or used until they break, and then carefully stowed. Recently, the Uganda Cancer Institute was given two mammography vans through international partnerships. The vans themselves often didn’t have working batteries and the mammography screening machines did not work, but nevertheless these vans are used in cancer community outreaches because they look impressive and attract interest when they roll into towns around Uganda. They also consume a huge amount of fuel. It seems that the metaphor of the half-life, be it the deterioration of radioactive potency over time, or long standing relationships, or material infrastructure, is an apt metaphor for describing this process and characterizing the precariousness and long term ramifications of transferring technologies.

**Some Provisional Conclusions**

In one of Uganda’s daily newspapers, there used to be a column entitled “WHO IS RESPONSIBLE?” which ran photographs of infrastructural crisis: an image of a terrible road with flooded potholes, a run down medical clinic, or a gigantic pile of festering trash and a request that the responsible person, usually a government agency or wealthy businessman, come forward and patch the road, renovate the clinic, or move the debris. If a photograph of Mulago’s radiotherapy unit were to run in the “WHO IS RESPONSIBLE?” column, and if they were to ask why it is that the radiotherapy unit remains open and operating with a source that needed to be

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431 Interestingly enough, this column ran in the Ugandan government sponsored *New Vision.*
replaced in 2005, the public would argue that responsibility most likely falls on the “government.” It would be the latest demonstration of a lack of commitment to investing in healthcare and infrastructure. This is a story that is repeated time and time again in Museveni's Uganda.⁴³²

But the story of the “roasting machine” is more than simply another case of techno-politics as usual in present day Uganda. It is a grim and representative tale regarding the long-term repercussions of demonstration projects that are shaped to control costs, transfer technology, and build capacity. It is also a story about the long-term repercussions of treatment enclaves and sites of medical experimentation that echo broader histories of medical technology transfer in sub-Saharan Africa. The Cobalt-60 machine currently at Mulago was never supposed to be the only radiotherapy service in Uganda. It was supposed to be the first among several government-sponsored facilities. Seeking a rugged and simple machine that was affordable, the IAEA transferred a piece of junk that was miraculously maintained by the wits and extraordinary talent of a dedicated group of radiation oncologists, physicists, technicians, and nurses. It is these people, and these people alone, who continue to keep things going long after interest from the IAEA and the Ugandan government has waned and the half-life of transferred technology has passed.

CHAPTER FIVE: “It’s not a village. It’s a camp,” 2010-2015
Experimental Infrastructures in Transition

My retelling of the Uganda Cancer Institute’s history concludes with a discussion of the profound physical and institutional transformations of this experimental infrastructure from 2004 to 2015. Experimental infrastructure is my term for the constellation of physical facilities, research questions, care practices, data collection procedures, and human labor that make up the biomedical research enterprise. I have argued that cancer care looks, smells, and feels the way it does in Uganda because of the histories of oncology research in this country. I have traced how this site, which was designed to do highly specific research on the response of cancers to chemotherapy, shaped the scope and practices of public cancer care in the country. Biomedical cancer care is concentrated at the Uganda Cancer Institute at the top of Mulago Hill in Kampala because oncology’s technologies and practices came to the country in the 1960s as part of an internationally supported research enterprise. The concentration of cancer research at the Uganda Cancer Institute shaped this singular silo of cancer expertise in the country. 40 beds were never supposed to comprehensively serve the needs of a population catchment of 100

million living in the Great Lakes region of Africa, but that, effectively, is the Institute's mandate today. In addition to Uganda, this catchment includes residents from Burundi, Rwanda, Congo, Sudan, Kenya, and Tanzania.

This is not to say that the Uganda Cancer Institute has remained stagnant or unchanging. This site has had multiple meanings and purposes over time—a combination chemotherapy/clinical trials site, a place of politically visible Africanized research, and a ward where you were sent to die from complications associated with HIV. And I have emphasized the creativity in crisis that African physicians, nurses, laboratory technicians, patient outreach workers, administrators, family caretakers, and cancer patients themselves employ as they struggled against malignancies on the wards, the malignant violence of war and political unrest. Their labor kept this experimental infrastructure alive for the past fifty years, long after their initial international partner’s interests shifted from combination chemotherapy trials to oncogenes and targeted cancer therapies.

Today, in the Institute’s latest instantiation, Jackson Orem and his Ugandan colleagues aim to capitalize on the rich history of this Institute and resurrect it as a site of hope for oncological excellence and cancer research in the Great Lakes region of Africa. As I’ve discussed elsewhere, part of the Institute’s renaissance relies on

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434 The actual estimated population catchment served by the Uganda Cancer Institute has expanded and contracted. Colleagues at the Fred Hutch give the figure 100 million and colleagues at the Uganda Cancer Institute often give the figure of 40 million, Mika Fieldnotes May 2015.
the strategy of appealing to national anxieties regarding the rise of non-communicable diseases such as diabetes, heart disease, and cancer in Uganda. But the UCI’s other strategy is to resurrect its importance as an experimental infrastructure for doing research on cancers in Africa. This mission is captured in the Institute’s slogan, “Research is Our Resource.” Practically, this means selling the Uganda Cancer Institute as an attractive site for doing cancer research in partnership with internationally-based biomedical institutions and reanimating the Institute’s experimental infrastructure. The Fred Hutch partnership, which began in 2004, is predicated on addressing many of the infrastructural and human capacity shortfalls at the Institute. The cornerstone of this partnership is a new UCI-Fred Hutch Cancer Centre, an outpatient and laboratory research facility, which opened in May 2015. In 2013, the Lymphoma Treatment Center, the original ward of the Uganda Cancer Institute, was bulldozed to make space for this internationally sponsored outpatient care and research facility. Pediatric patients and adults with a Return to Greatness,” Journal National Cancer Institute, (2007) 99 (15): 1144-1151.


blood and lymphatic cancers were moved into a temporary, improvised space, with
the intention that they would eventually be moved into the new Uganda Cancer
Institute six-story in patient hospital, which was completed in early 2013 with
Ugandan government funds. At the time of this writing, this hospital is still largely
unfurnished and occupied only by private patients and pediatric patients. The
Institute estimates that approximately $6.8 million are needed to fully furnish and
equip the building.\footnote{Fieldnotes, May 2015. These estimates come from Institute staff, including the
Public Relations Officer and the Institute’s director.}

These infrastructural transformations do not occur in a vacuum. Since 2009,
there has been a dramatic policy shift at the Institute, which is to welcome anyone
and everyone with a cancer diagnosis to receive care, no matter how late the tumor
stage, no matter how many X-ray films Mr. K has in stock, no matter whether or not
the National Medical Stores has filled the latest order for more doxorubicin, and no
matter if the ward is completely full. This decision, which accompanied the
Institute’s administrative and budgetary autonomy from Mulago, is a dramatic
departure from policies of the past, which, in the 1960s and 1970s, were mainly
triaged according to the research protocols on the wards, and, from the mid 1980s
to 2009, oriented largely around conserving very thin resources and stretching
them to care for patients who stood a solid chance at survival. During those 30 years
where there was “nothing,” when patients were responsible for bringing their own
syringes and gloves, and when caretakers had to go down the Mulago blood bank
and bribe someone in order to get platelets, the wards were still incredibly full and
packed. Still, opinions and numbers converge. There has been an unprecedented rise in the number of patients coming to the Institute since autonomy in 2009. Estimates suggest that patients have gone from less than 1000 a year to over 40,000 in just half a decade between 2009 and 2015.

The partnership between the Uganda Cancer Institute and the Fred Hutch has, over the past decade, valiantly attempted to address the profound structural inequalities that render Seattle and Kampala incommensurable. Hence the investments in training Ugandans as oncology fellows in Seattle and in building a laboratory facility so research can be done “in house” on the UCI campus. But these investments in infrastructure and even in staff training hold the possibility of inadvertently cementing inequalities in mortar and concrete on the Institute’s campus. The UCI-Fred Hutch Cancer Centre’s disease-specific research agenda is written into the design of the building, and so, too, whose bodies and cancers will be seen and treated in this space. Closing the “global cancer divide” through infrastructure improvements like the UCI-Fred Hutch Cancer Centre widens the gaps between “government medicine” and “doing a research.” These divides, which were somewhat tempered over the past decade by being housed under the

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439 This account is derived from interviews conducted by the author and informal conversations between 2010 and 2015. Informal conversations with Dr. Fred Okuku, Dr. Noleb Mugisha, Sister Mary Kalinaki, (2012) and Dr. Edward Mbidde (2014) were particularly helpful. These accounts are corroborated by a systematic sampling of former patient records from the 1960s to the late 1990s.

440 Mika Fieldnotes, May 2015. These estimates come from the Institute’s director, Jackson Orem.

441 “Government medicine” and “doing a research” is the way Ugandan colleagues describe the differences between what it means to work on the wards of the UCI as a clinician and with the UCI-Fred Hutch partnership as a research-scientist.
same metal roofs, are now much more visible and jarring, especially given the contrasts between the government built in-patient hospital, which is still not fully equipped, and the USAID sponsored outpatient treatment center and laboratory, which is brimming with top shelf equipment. Over the next decade, it will be fascinating to see how exactly these differences in research cultures and priorities at the Uganda Cancer Institute and the UCI-Fred Hutch Cancer Centre both recreate and one hopes transcend the politics of global cancer inequalities. But that is a different project.

In this chapter, I focus on the unintended yet profound violence that has come along with trying to transform the Uganda Cancer Institute from a dilapidated place “where you are sent to die” to a site of public oncological excellence in the Great Lakes region of Africa.442 Cancer treatments, as we know and have seen, radically harm and uncertainly heal. They are ambivalent technologies at their best and devastating at their worst. Opening the doors of the UCI wide—turning the site into a place of hope as well as death, and restructuring the infrastructure of the Institute to accommodate this explosion of patients—also walks the fine line between healing and harming. Current patients navigate both the liminality of cancer’s uncertain prognostication and violent treatments, and receive care in an similarly liminal treatment environment, somewhere between a bulldozed past, an unfurnished present, and a hopeful future, particularly if their cancers are of

particular interest to the growing number of research programs on site that can offer access to better resources.

This chapter uses the analogy of the “camp” as a starting point for discussing the shape of everyday life at the Uganda Cancer Institute as I encountered it over five years of fieldwork between 2010 and 2015. In particular, I use the category of the “internally displaced person” to think through how patients have been displaced both by illness and by new oncology research and care initiatives. In the next section, I discuss the cycle of being internally displaced by illness which eventually becomes “cancer,” through the process of diagnosis, taking up uncertain residency at the camp, engaging in the long work of waiting, the ebb and flow of crisis, and then repatriation, be it through remission, “game over,” running away, or another kind of departure, such as leaving in a coffin. The chapter then discusses the process of displacement through infrastructural shifts at the Uganda Cancer Institute between 2012 and 2014, which accompanied the demolition of the Lymphoma Treatment Center in April 2013.

“It’s not a village. It’s a camp.”

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 very 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, 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 an hour every morning before he distributed x-ray reports to patients snoozing on benches. *Boda bodos* would blast into the parking lot, dropping off patients and supplies. Quotidian Kampala pastoral at its best.

Beyond the appearance of village life, there were also complicated kinship networks and inter-generational relations. Some of the older nurses who worked on the wards for three or four decades were sisters in everything but blood. 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. Ssalongo, who was responsible for running orders for blood and platelets back and forth between the UCI and Nakaserro 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 in 2010, scarcely more than a month into fieldwork and energized by this easy analogy, I remarked to a physician colleague that the Institute
seemed to me to be a lot like 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. Looking at the bed rolls, the washing basins, and one young patient with a case of fulminating Kaposi’s sarcoma on his foot who 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. The Institute looked, smelled, and sounded a lot like a refugee camp.

When my colleague called the Uganda Cancer Institute a “camp,” he was not talking about life and death at the concentration camps of the Holocaust in the style of Georgio Agamben, a theoretical intervention that has led over the last decade to a virtual cottage industry of ethnographies of bare life. My colleague was talking about the camp in a vernacular sense, as it most commonly manifests itself in Uganda—a refugee camp or an internally displaced persons camp. In a sense, my colleague is invoking the idea of malignant politics. There is a parallel between the violence of the state on its own social body and the violence of cancer on the bodies of individuals. There is a sense that the state is violently attacking itself at select

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moments in Uganda since independence. The symptoms appear in many forms, from
guerilla war to the failure of the state to provide basic services and care to its
citizens.

Some further political context: Since assuming power in 1986, Yoweri
Museveni’s National Resistance Movement (NRM) government and the Ugandan
Police Defense Force (UPDF) has been in an ongoing conflict with the Lord’s
Resistance Army (LRA) in Northern Uganda. In the mid 2000s, after more than a
decade of war, nearly a million northern villagers were moved into refugee camp
cities around Gulu and elsewhere in Acholiland for several years. Internal
displacement came both from ongoing fears of violence and child abductions from
the LRA, and also the urging of the UPDF that safety could only be guaranteed in
these encampments. The encampments themselves were buttressed by a
tremendous amount of humanitarian and foreign aid, which ebbed and flowed
according to surges of violence in Northern Uganda. When my colleague made his
comment in July 2011, the camps in Acholiland had been disbanded for several
years, and Joseph Kony’s LRA had been driven out of Uganda and into the Central
African Republic, where it continues to wreak havoc in the country’s tropical forests.
But the idiom of the camp and the category of the internally displaced person, a
national uprooted from his or her home and forced into a long temporary
encampment, remains a powerful analogy in Uganda.444

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444 This is a rudimentary gloss of a long and complicated war and the history of the
IDP camps. For a primer on the history of Acholiland, northern Uganda, and the
Lord’s Resistance Army, see: Tim Allen and Koen Vlassentoot, eds, The Lord’s
Those coming to the UCI are not fleeing violent events *per se*. But given the residential requirements of chemotherapy cycles, the long distances to be travelled, the expenses of transportation, and general poverty, a considerable number of patients take up residence at the UCI for months on end. It becomes a long temporary home. These long-term residents at the UCI are internally displaced, in a sense, by the violence of debilitating tumors. The founders of the Uganda Cancer Institute understood that they would only be able to take the need for long-term residence on the cancer ward seriously. As we’ve seen, in the 1960s and 1970s the Lymphoma Treatment Center operated largely as a residential treatment facility, with attention to subtle social innovations, such as a playground, a teacher, a dedicated cook, and extra mattresses for parents, which made it easier for patients to stay over at the Institute and receive care. Today, patients are still coming in from

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*Resistance Army: Myth and Reality*, Adam Branch, *Displacing Human Rights*, Oxford: Oxford University Press, 2011, Sverker Finnstrom, *Living With Bad Surroundings*, Durham: Duke University Press, 2008. There was ongoing controversy over whether those moving into the camps in Acholiland fell into the category of refugee or internally displaced person. Here I find anthropologist Sverker Finnstrom’s discussion of this tension to be helpful for contextualization and definitions: “In international and humanitarian jargon, most of these people are ‘internally displaced persons’ rather than refugees. To say that they are internally displaced obviously indicates that they have moved but remain in their country of origin. The term ‘refugee,’ in contrast, is usually restricted to a people who have fled their country of origin. Their refugee status is acknowledged by international law, but also, the refugee becomes a ‘disquieting element’ who ‘brings the originary fiction of sovereignty to crisis’ (Agamben quoted in Oxford 2003: 2010-2011). Internally displaced families do not pose such an explicit threat to Uganda’s sovereignty. [...] The internally displaced persons in Acholiland, I hold, are refugees in their own country, uprooted and scattered families. Unlike most other refugees, however, they have not fled the crisis that caused their predicament. They are thus not refugees in the sense that they have found a safe haven.” in Finnstrom, *Living with Bad Surroundings*, 133-4.
all corners of the country, but without much of the institutionally provided expansive supportive care that the LTC provided in the past, which made residential life marginally comfortable. Instead, patients and their caretakers rely on an expansive network of relatives. Those relatives living in Kampala can offer accommodation, support with food, and part of their urban paycheck to help buy drugs. Relatives and support systems who stay in the village tend to crops, provide child care, and the like.

Residential life at the UCI is not easy. The homestead’s daily rituals of cooking, washing, sending children to school, and the seasonal rhythms of planting, harvesting, and selling are warped by the timing of chemotherapy injections, clinic visits, and the exhaustion that comes with waiting to be permanently discharged to go home and live or die. Similar dynamics of internal displacement, oscillations between crisis and boredom, and long temporary residence characterized the experiences of those living in Acholiland during the war, as did the uncertain possibility of repatriation.

Refugee camps also connote a profound concentration of resources, goods and services, which may be impossible to access elsewhere in times of crisis or vulnerability. And in this sense, the UCI is also a “camp” because it is the key point of concentrated oncology goods and services available to the public in Uganda. Uganda’s hospital referral network system is crafted like a giant storm drainage system, with cancer at the last final filtering point. Invariably patients come to the UCI through long and circuitous routes, and are often only caught at this last point.
on the referral chain. This is the historical legacy of the UCI as an experimental cancer research enclave—resources for treating cancer remain concentrated in the capital.

Since its founding in 1967, the UCI strategically provided cancer care to patients who fit the criteria for research programs, rather than extending comprehensive oncology services to everyone in need. In the 1960s and 1970s, triage by research agenda shaped who would be given a bed at the UCI. In the 1980s and 1990s, triage on the wards continued even in the absence of robust cancer care.

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445 This storm drain analogy comes from colleagues at the Uganda Cancer Institute. The “quest for therapy,” that is, the complicated, heterogeneous routes to seeking therapeutic relief for bodily and mental afflictions, has occupied Africanist scholars of health and healing for several decades. See Janzen, The Quest for Therapy, 193-222 especially for a discussion of how different therapeutic systems interact with one another in contemporary Zaire. See also Langwick, Bodies, Politics and African Healing; Livingston, Debility and the Moral Imagination; Whyte, Questioning Misfortune. The rich landscape of therapeutic pluralism (spiritual healing shrines, traditional healers, private pharmacies, government health facilities, public-private partnerships for HIV care) that characterizes much of the contemporary landscape of illness relief in Uganda (and elsewhere in East Africa) is often minimized on the wards of the UCI. Patients are seen as coming “late” rather than as carefully weighing their options with the input of a large family decision making unit behind them. There is a small but growing public health literature specific to tracking “treatment delays” for cancer patients in Uganda, and the richness of the therapeutic landscape and the social concerns of families are de-emphasized. See Buckle et. al., “Factors influencing time to diagnosis and initiation of treatment of endemic Burkitt Lymphoma among children in Uganda and Western Kenya: a cross-sectional survey,” Infectious Agent Cancer (2013) 8: 36, Galukande et. al., “Patient Delay in Accessing Breast Cancer Care in a Sub Saharan African Country: Uganda,” British Journal Medicine Medical Research (2014) 3(13): 2599-2610.

446 My use of the “enclave,” comes from David Arnold, Colonizing the Body (Berkeley: University of California Press, 1993), 61-115.

447 On the problem of triage in global health, see Nguyen, The Republic of Therapy, 89-110, Redfield, Life in Crisis, 155-178, Biehl, Will to Live, 53-105. On health access, triage and its relationship to pharmaceutical research, see Petryna, When Experiments Travel, 89-138. On triage and the cancer ward, see Livingston, Improvising Medicine, 152-158.
chemotherapy trials. Patients received oncology services on the wards if they could produce the funds to pay for their drugs, or, in all too rare cases, if the Institute could appeal for drugs and make a strong case that the patient would benefit from treatment.448 Today, the research focus of the UCI-Fred Hutch alliance is to examine the synergy between infections and cancers. Kaposi’s sarcoma and Burkitt’s lymphoma are the key targets of inquiry for UCI-Fred Hutch alliance, much as they were in the past during the early days of collaboration between the American National Cancer Institute, Makerere’s Department of Surgery, and the British Empire Cancer Campaign.

But this research focus operates alongside the contemporary mandate that the Institute provide oncology services as a public good, despite all of the financial, infrastructural, and staff constraints that come along with being part of the machinery of Ugandan government health services. This enlargement of scale is a radical departure for the Uganda Cancer Institute. The public Uganda Cancer Institute now serves technically includes any and all Ugandans seeking oncology relief. The policy shift, that this is a place of hope, not simply palliation, has meant that patients who would typically remained home to die—or would have been told that there is no hope and then sent directly home after reaching Mulago—now come to the UCI seeking relief from the violence of a body in late-stage cancer and the ramifications of that bodily state. The new breed of UCI patient includes bodies wracked by the rot of late stage breast cancer, such as a beloved matriarch brought

448 “Letter requesting chemotherapy,” Uganda Cancer Institute Archives.
to the Institute by a family who can no longer bear her smell or cries, or a five-year-old child with loose teeth from Burkitt’s lymphoma whose parents have exhausted the question of witchcraft after several long consultations with healers at shrines and courses of herbs and turned to the Institute.

Ugandan oncologists often say, “cancer is a disease of the poor.” One part of the public in mind here is the one that cannot afford care within private hospitals or treatment outside of the country—hence the need for either free, or close to free, cancer drugs, which are otherwise prohibitively expensive. The Institute also hopes to cater to the upper middle class publics, and “VIPs”. The plan is that strategic investments in infrastructure, such as the government built six story in-patient cancer hospital at the top of Mulago hill, will make it possible to treat Ugandans in Uganda rather than sending them overseas to India or across the border to Kenya for care.449 As the US Ambassador put it at the grand opening of the UCI-Fred Hutch Cancer Centre in 2015, we want “real life saving care for real people,” and a way to

mitigate the practice of spending large amounts of money to send people abroad when they can be treated in the country.\textsuperscript{450} This expansion of the Uganda Cancer Institute’s mandate is unprecedented, although it was certainly discussed in the early 1980s before Charles Olweny went into exile.\textsuperscript{451} The mission to be a center of research excellence in the Great Lakes Region of Africa operates alongside the reality that many of the patients seen at the Institute come in the throes of late stage illness, and while many of them do have Kaposi’s sarcoma and Burkitt’s lymphoma, many of them do not.\textsuperscript{452} This crush of “very sick” patients shapes the immediate concerns of UCI oncologists as they provide “government medicine.”

\textsuperscript{450} Fieldnotes, May 2015.
\textsuperscript{451} “Comprehensive plan for cancer hospital in the early 1980s,” Uganda Cancer Institute archives.
\textsuperscript{452} The Uganda Cancer Institute is still in the process of setting up a formal surveillance system, and so I am drawing upon evidence from the Kampala Cancer Registry. According to data from the Kampala Cancer Registry, the number of Kaposi Sarcoma cancer cases reported between 1991 and 2010 for Kyaddondo county was 6,003. The total number of prostate cancer cases as 1,158 and the total number of breast cancer cases was 1,572. Age standard rates per 100,000 for KS in men from 1991 to 1995 was 39.7. For 2006-2010, it was 29.3. In other words, KS age standard rates have declined from the height of the HIV/AIDS epidemic. Prostate cancer age standard rates have increased. From 1991-1995, the age standard rate for prostate cancer was 25.7. In 2006-2010, the age standard rate was 58.0. Breast cancer age standard rates in women have similarly gone up over time. From 1991-1995, the age standard rate for breast cancer (in women) was 18.0. From 2006-2010, it was 31.2. This isn’t to say that “HIV related malignancies” are suddenly no longer a problem. The implication here is that the need for better cancer screening programs and targeted inquiry into how to best provide care to patients who come to the Uganda Cancer Institute with advanced cancers that wouldn’t benefit from aggressive treatment. See Wabinga et. al, “Trends in the incidence of cancer in Kampala, Uganda 1991-2010,” \textit{International Journal of Cancer}, 2014 135: 432-439.
Displacement by Illness—the Lymphoma Treatment Center in 2012

The Uganda Cancer Institute, in its latest iteration, is an institution in flux. As I worked at the UCI as the “historian” in 2012, I spent much of my time observing how cancer services were being reshaped on the ground—chemotherapy administration protocols, the purpose of the “oncologist” now that there were eleven rather than one, and means of capitalizing upon the newfound availability of drugs, syringes, gloves, and other sundries for the greatest good. I concentrated my ethnographic focus on these issues at the Lymphoma Treatment Center. In the oldest facility at the Cancer Institute, these challenges were particularly dramatic as Dr. J and her team worked to build a dedicated pediatric oncology service. This specialized focus on pediatrics was something that the Institute had not seen since Burkitt’s lymphoma chemotherapy clinical trials in the 1960s and the 1970s. Dr. J was charged not only with managing Burkitt’s lymphoma patients, but also with treating a steady stream of leukemia patients and other pediatric cancers. She often had 40-60 ‘in-patients’ and approximately 25 beds available. At the LTC in 2012, many of the innovations to address the long course of residency at the Institute were long gone, but nevertheless, patients and their caretakers arrived at the Uganda Cancer Institute, displaced by illness, carrying buckets and sheets and thermoses, waiting to take up long term residence and camp out in search of relief.

453 The following discussion is derived from Fieldnotes, February 2012 to October 2012.
and hope. The task fell on Dr. J and her staff to manage pediatric cancers at this “camp”. In the section that follows, I discuss how patients, caretakers, and medical staff navigated displacement by illness at the Lymphoma Treatment Center in 2012.

On arrival at the UCI, it can take a while to set up residency at the camp—most patients and caretakers will spend some time in limbo sleeping on verandahs, waiting for biopsy results, and waiting for a patient to be discharged or die so they can clean off the bed with a bottle of bleach and make it anew with sheets either brought from home or purchased at a Kampala market. Ties to village homes remain, although relationships with spouses, elders, and siblings can be fraught. Home and family life beyond the space of the UCI continue to matter, both as a source of financial resources and also of caretakers.

The Process of Getting a Bed...and keeping it

Baby Winnie, an 18 month old who suffered from bladder cancer, was a permanent fixture at the UCI along with her mother for most of 2012. Mama Winnie,

454 All patient and caretaker names are pseudonyms. Interviews were conducted with patient caretakers in June, July, and August 2012 in Luganda by Irene Nassozi and the author, Marissa Mika, who 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 Marissa Mika relatively well. Approximately 20 interviews were conducted with caretakers. We followed an informed consent taking procedure approved by both a local Ugandan IRB and an American university IRB. While I’ve done my best to preserve the anonymity of the patient caretakers by using pseudonyms, some patients and their caretakers may be recognizable to the Uganda Cancer Institute staff who provided their care during 2012.
a peasant farmer from central region whose main source of income is 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 was 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.455

455 Interview: Mama W, conducted and translated with Irene Nassozi in June 2012.
Mama Winnie hung onto 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 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 have Mama and Baby Winnie come back only for treatment cycles. Mama Winnie refused in subtle and stubborn 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.

Lost Biopsy Results and Clandestine Groundnuts

Patients and family members arrive at a cancer diagnosis through deep conflicts, often about money, regarding the 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, as was the case with 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 came to the UCI after several months of questing for therapy. 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 1 week before an operation and a biopsy was taken. We were discharged and told to return after 1 month for the results. When I went back I did not find him on several occasions. After 2 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.

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.

I had cultivated my ground nuts 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 bed ridden. 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.

I did not inform my husband about my plan as he indicated that he does not have any more money for this case.\textsuperscript{456}

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. Paperwork is another. At the UCI in 2012, a referral note and a biopsy result must be in hand or at the very least in motion in order to be admitted onto the wards of the UCI. In the 1960s and early 1970s, centralized pathology services at Mulago that cooperated with referral hospitals throughout the country and corresponded via the post office made the project of remote diagnosis take about a week.\textsuperscript{457} When the UCI was under serious duress, this referral structure helped to conserve scarce resources from

\textsuperscript{456} Interview: Mama P, conducted and translated with Irene Nassozi in June 2012.
\textsuperscript{457} Interview: Raphael Owor, June 2012.
being spent on “hopeless cases,” or patients without diagnoses. It was a triage mechanism at the UCI during the 1980s, 1990s and 2000s, when the staff was less than ten. In 2012, a lost biopsy result means salvage chemotherapy.

The Ward’s Chairman

For nearly the entirety of 2012, Baby Angel resided in crib number 24, right at the entrance of the pediatric side of the Lymphoma Treatment Center, with a big blue mosquito net, stuffed animals, and a puffy cheeked doll that mirrored her own cheeks 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, and who knew more about the vagaries of rains and planting seasons than 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 onto 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*, or sesame paste, via bus, to be cooked up with sorghum porridge. In the central region, home of the Baganda, 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 became the “Ward Chairman” of the LTC. In Uganda, the “chairman” is a revered and often invoked figure. They preside over anything
requiring meetings or social organization from *boda boda* stage self governance, to routine UCI general purpose meetings, 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. They are an indispensable part of ward life, and in Tata Angel’s case, he took on this social function even though he felt and voiced the fact that the UCI was a “place of great suffering.”

“Game Over”—the point of getting a bed is to give up the bed

There are fundamental differences between an internally displaced person’s camp and the UCI. The violence that accompanied much of the day-to-day living in encampments in Acholiland at the height of the war has a decidedly different texture than the embodied experience of a particularly bad day of chemotherapy and its side effects. Consider anthropologist Sverker Finnstrom’s eloquent account of violence and uncertainty in Acholiland:

The conflict in northern Uganda has had its ups and downs, with corresponding fluctuations in the interests and involvement of the international community. During lulls in the fighting, when international attention is turned elsewhere, some people try to walk

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458 Fieldnotes, a fleeting moment with Tata Angel in the LTC corridor, March 2012.
back to their villages. They do this on a daily basis. But peace is illusory. [...]. The Ugandan army often responds to increased rebel activity by ordering rural civilians to return immediately to the camps. People who are found outside the camps are sometimes treated as rebel suspects. [... once] the army announced a 48-hour deadline for people to return to camps, after which the areas surrounding some camps were shelled and bombed.459

Given the volume of patients and shortages of space, for the medical staff at the UCI, the long term goal of admitting a patient—the Luganda translation is giving a bed—is 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 of 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. Although hen patients and caretakers shift to and from home, they are not fleeing bombs or hearing that it is finally ok to go home, there is still a perpetual and violent upheaval that comes with being internally displaced by cancer. 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, being given a verdict that it is “game over.”

“Game over” was the phrase Dr. J, the head pediatric oncologist at the UCI, invoked time and again for residential cases at the UCI who were for all intents and purposes salvage chemotherapy patients. Quite soon upon returning from a year of training in South Africa, Dr. J, who was running a ward with 24 beds and 34-40 more “in-patients” 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 than “standing” ward rounds. Part of this was to reduce the amount of time spent on feet in tight quarters, 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,” Dr. J says. “They are watching, wondering if you are going to give up on them or if it’s game over.” In a setting that was so public—24 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.

On Tuesdays, somewhere around one or two p.m., and usually after staff had taken a fast lunch of local food drowned in meat, fish or groundnut sauce, we piled in to the examination and intake room of the Lymphoma Treatment Center. A wooden table, surrounded by hard chairs, dominated the room. A filing cabinet stood in a corner. I, the social worker, and counselor usually assembled themselves on the slightly ragged examination bench, legs dangling. An old, barely functioning 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 and piles of cotton gauze that would be used for cleaning up veins after blood draws.

Dr. J would usually rush into the room, apologizing for being late, and 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 that they were nearly falling apart. Others were slender, containing only a face sheet and a referral note that were filled out that very morning. Rachel would slip a wad of Ugandan shillings to N, the elderly Muganda nurse who has been working on the wards of the UCI since the 1970s. N would come back several minutes later with black “caverras” (or plastic bags) of sodas. Coke, Fanta, and Stoney Ginger Beer would be distributed along with straws to the 15 or so in attendance, the ward round officially beginning to the sound of bottles being cracked open and the discussion of “very, very sick children,” namely when to discharge them, and whether or not that would be a declaration of “game over”. Here, I share an excerpt from my fieldnotes that help to illuminate the experience of “game over”, once again revisiting the story of Tata and Baby Angel.

September 2012

*Tata Angel found out that he is being discharged from the LTC permanently. There is no chemotherapy combination that can salvage his daughter’s blood cancer. It is time to go back to their village just outside of Lira. It is “Game Over.” We are sitting in silence. He wears dark green trousers and a pale colored short sleeved shirt with a slightly frayed collar. He has deeply 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.”

“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.

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.

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. Rachel 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?

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.

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.460

A refugee camp implies impermanence, a temporary condition, a physical manifestation of crisis that will, over time, come to an end. The image of Baby Angel's bed scrubbed clean of her presence in less than 48 hours is a stark reminder of the impermanence of residence and of life at the Uganda Cancer Institute.

“I'll be eating chicken every day”

Only a handful will remember the day in September 2012 that Kirabo’s parents found out that it was “game over” for their sweet, cherubic, little girl. Kirabo

460 Fieldnotes, September 2012. These notes were edited for legibility and grammar.
had lived off and on at the Lymphoma Treatment Center for months receiving treatments for her leukemia. She was in the care of her fabulous mother, who often wore a blue gomesi the color of the noon-day Kampala sky, hair wrapped in a flowing white head scarf, alternating between carrying her new baby on her back or breast feeding on a straw mat. Her father, who stayed outside of Kampala towards Lugazi, was often at the Institute over the weekend, checking in on his daughter and her progress. A wonderful family, everyone agreed.

But acute refractory leukemia “in our setting,” is not something that can be easily treated in any setting. You would need access to bone marrow transplant technologies to begin to even have a fighting chance, and that’s just not 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 is finally game over. Dr. J said, “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.”461 She made this last point mainly to the medical students who are on her service for the next few weeks and are doing master’s

461 Fieldnotes, September 2012. “Juice boxes, some oral morphine” is a direct quote. All other dialogue was written from memory about an hour after this discussion.
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."\textsuperscript{462}

The next day, I saw that the news had been broken. Maama Kirabo was standing next to a hospice vehicle and chatting with them. Kirabo played with some of my arm bracelets, and was giggling, and laughing, and wearing her mother’s white headscarf like a pirate. She was still cherubic cheeked, 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 was hoping for some sort of optimistic closure—you can see the desperation and resignation in my fieldnotes. But it was a typical day at the Institute. For most of the afternoon, a simple wooden coffin sat open and waiting for the deceased on the adult side of the Lymphoma Treatment Center. 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. Maama Patience looked a little bit exhausted, wearing her faded but smart 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 vomit powerfully. Stevie was out playing on a see-saw with a friend. “What are you doing, Stevie?” We are playing. I can see that. At the end of the sit down ward round for the pediatric patients, little Nakkazi from

\textsuperscript{462} Fieldnotes, September 2012.
Wobulenzi walks in, sobbing terrible deep throaty cries. “Nakkazi, what’s wrong?” asks Dr. J. In between her eruptions of grief, she said, “I want to go home. I want to go home. I want to go home.”

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. I couldn’t help but pine for the technological intervention that could avert this tragic, but in this context highly ordinary, death. So I asked a colleague, as I got into my car, “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.”

Requiem for the Lymphoma Treatment Center

During 2012, the systems of care and triage at the Lymphoma Treatment Center were being shaped and created through trial, error, the limitations of staffing and resources, and the realities of trying to offer cancer care to patients and families

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464 Words from Livingston, Improvising Medicine, x, come to mind: “Any close look at oncology, as so many readers already know, necessarily means contemplating the deep ambiguities of biomedicine and our uncomfortable relationship with technological longing.”
for whom shifting back and forth between the ward and the village was too much. As Dr. J worked to build these systems, she did so within a ward space which had been designed largely as a Burkitt’s lymphoma research and care facility by John Ziegler and colleagues in 1967. The old building, a dilapidated maternity ward infested with rats before it was first renovated, was certainly 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, and 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 designs made it easier for staff to do their work and possible for families to camp out at the Institute for weeks or months at a time, and they were historically established innovations.

The entire time Dr. J and her colleagues worked at the Lymphoma Treatment Center in 2012, they did so with the knowledge that this structure was slated for demolition. As I noted earlier, the Uganda Cancer Institute’s infrastructure itself is undergoing profound transformation in an attempt to be a center of global oncology excellence. This is part of the work to “slowly by slowly” bring better oncology to Uganda. But the consequence of this expansion was the inadvertent creation of a double displacement. On top of the experience of being displaced by illness, tearing down the Lymphoma Treatment Center created a new group of internally displaced patients on the Institute’s campus. In this section, I unpack the layers of that story.
At multiple points in the history of cancer care and research in Uganda, it has been the children—wildly deformed by Burkitt’s lymphoma or fabulously playing with a blown up latex glove in between chemo cycles—that have given the Cancer Institute its international appeal. In October 2011, when political dignitaries and international health moguls came to the Institute to celebrate the groundbreaking of the new USAID-Fred Hutch-UG sponsored outpatient building that would displace the Lymphoma Treatment Center, 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 forty-four year old 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 25 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 with ports 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.”

Even after it was slated for demolition, the Lymphoma Treatment Center remained the apex of generating international attention and was seen as the showpiece of the Institute, used in part to try to martial further support and donations to furnish the new inpatient cancer hospital. On one such occasion, the Prince of Saudi Arabia announced he was making a visit to the Uganda Cancer Institute to see the important work being done on non-communicable diseases in the country. The staff had approximately 24 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 Saudi government would make a gift and contribution towards $4 million worth of medical equipment needed to furnish the not yet open five story Ministry of Health sponsored cancer in-patient facility at the Institute.

That Saturday morning in June 2012, patients and their caretakers were up and out of the Lymphoma Treatment Center 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

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466 Fieldnotes, October 2011.
dressed in their best and cleanest outfits. Medical records were stacked neatly onto 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. On that morning, the ward, painted in that unmistakable industrial sea foam green so characteristic of hospitals in the developing world, sparkled. The under the sea mural of starfish, sea horses and bobbing fish looked cheerful, rather than dreary. All traces of residential life—the cook stoves, cardboard shelters, mats, bed rolls, suitcases, crutches, buckets, donated stuffed animals clearly loved to death—were erased from the public space of the verandah and the wards and shoved back behind the Lymphoma Treatment Center for the day. Nurses in sparkling white, freshly pressed government uniforms came to start the morning ward round early, around eight in the morning, ensuring they would finish before the “VIPs” arrived at eleven.

I arrived at the UCI at around ten in the morning with my camera and notebook, to find plenty of police forces standing around in blue security forces uniforms, but 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 Baganda introduction ceremony, or kwanjula, 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 mylogenous 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 six children, plus 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, belly distended, wasted in his arms and legs. 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, Dr. Rachel 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?” I poked Oliver’s belly and tried to get a smile. “He is not fine,” said Tata Oliver. “And how are you doing?” I asked. “I am not ok,” 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. Morgan deftly took Oliver’s blood pressure as Tata Oliver continued. “I am not ok. We were told this muzungu is visiting today and that we must put on clean clothes and make the sheets. I am happy he is visiting, but,” and here Tata Oliver began to get angrier, louder, and more animated, “But I CLEAN. I keep my child clean. I make the bed!” 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. Dr. Rachel 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 Dr. Rachel 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? There’s dancing. And there’s dying,” he said. “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.”

And then we waited. And we waited. And we waited some more. A Ministry of Health vehicle drove up to the gate. A Ministry official stepped out and went to

467 Fieldnotes, June 2012. “Dancing and dying” is verbatim.
talk to the UCI’s director. The Saudi 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 Uganda Cancer Institute’s director, Dr. Jackson Orem, 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 National Anthem. Patients and staff mingled under the tents and ate the box lunches, including Tata Oliver, who cajoled his son to take another sip of Fanta. I took my leave, shook hands with Dr. Jackson, and told him 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,” said Dr. Jackson, “it is ok that the Prince did not come.” The money never came.  

More than a year later, it only took half a day to bulldoze the Lymphoma Treatment Center. It came down easily. The bricks and the plaster and the dreary fish mural, of cartoon seahorses swimming in the sea and anthropomorphic starfish, crumbled into fine powdery dust. The windows and the doors and the iron gates were salvaged and piled up back behind the Institute’s generator. Staff were kindly reminded in internal memos sticky taped on the wall that they were not allowed to reuse these old materials for their own construction needs. Nurses quietly cried and took photographs of their old, decrepit, beloved LTC. “The heart and soul of the Institute,” said Sister Allen. Patients and their caretakers watched the building

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468 Fieldnotes, June 2012.
crunch and crumble from their newly improvised temporary space—a refurbished tuberculosis outpatient facility with three airless rooms where you could shove in about seven full sized beds and a few floor cases apiece, and 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 bed rolls, washing bins, and buckets. This was the temporary fix in April 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.469

I did not witness the fall-out of the demolition until June 2014 when I returned after 57 weeks of being away from Uganda. This was my last trip for the foreseeable future. The ongoing questions—when are you going to start a family? When are you going to finish your book? When will you buy land and settle and build here in Uganda? Where are my chocolates?—remained the same. And I was so thrilled to return, but also appalled by the conditions at the new long temporary Lymphoma Treatment Center. I include my fieldnotes here as they are and uncensored, not to undermine the efforts to transform the Institute, but to pull you into the violent stakes of these improvements:

*The demolition of the Lymphoma Treatment Center is a slow moving disaster. 45 years of carefully worked out practices bulldozed for "the future" chemotherapy clinical trials that will apparently happen at some point. In the meantime, the place is more*

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469 I was not there for the demolition. This account is based on notes and conversations from summer 2014.
and more like a refugee camp, but a disorderly one, where you have to walk through the toilets to get to the X ray department or weave through cooking stoves. I am sure it's only a matter of time before a toddler dies from a bad burn. It is such a disaster. I am truly appalled. And morale on the pediatric ward is way, way down. People in every role from medical officer to family member along for the ride while his or her sibling gets treatment have been put into a pretty impossible situation.

Is any of this surprising? This is the sausage making part of shiny global health initiatives that nobody wants to see or talk about. And it is all there playing out 500 feet from a construction site which is raining fine powdery construction dust all day long onto kids with weepy bulgy eye tumors.

My Ugandan colleagues aren't happy with it, but “bibaawo,” that's life what can we do? And my American colleagues who have so strategically been drawing a line between themselves as researchers and the realities of clinical care at the site are shrugging and saying, "well, that is their problem and besides our new building will be awesome."

I am so appalled. I am keeping my cool and taking notes and trying to gauge the sentiments of my colleagues. They are too polite to say that this is an !&^%#&%#! situation but they all agree that they are basically working under camp conditions and
that this is unsustainable and sad and tragic for the "nationals" who are here seeking care.

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. But in the meantime, I can't help but feel complicit by keeping my mouth shut when I know the field site so well and what was irrevocably lost when they squashed 45 years of history in half a day.470

So let me be clear here. Both my colleagues at the Uganda Cancer Institute and the Fred Hutchinson Cancer Research Center know full well that this long temporary ward—improvised to provide pediatric and liquid tumor care to adults while they wait to move into the new building—is far from an ideal situation.471 They are realistic. They are frustrated. They, too, are appalled. 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 dodge 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 fetid wounds. And, in many ways, the Cancer Institute sounds and looks much as it did in 2012.

And there are silver linings. In the past two years, Dr. Rachel has built a pediatric oncology service that works in “our setting”. There are more antibiotics on

471 It should be noted that colleagues at the Fred Hutch significantly delayed the construction of the new UCI-Fred Hutch Cancer Centre to account for the fact that the Lymphoma Treatment Center patients had nowhere to go and also contributed significant funds to the refurbishment of the temporary LTC II, Mika Fieldnotes, July 2014.
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, fantastic pediatric oncologist. Dr. R 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.

But no one is denying that this is a tough situation. And the questions and comments about this tough situation pour 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.”

“This is government medicine.”

This is government medicine. And government medicine in Uganda means that you must wait and subject yourself to the budgetary allocations of the fiscal year. It could and most likely will take another two to three years for this temporary treatment space to be fully dismantled and for all patients and caretakers to be treated in the government’s new cancer hospital. There are layers of reasons regarding why it has been so difficult to furnish the new in-patient Uganda Cancer

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472 Fieldnotes, June, July, and August 2014.
Institute hospital. In the most basic terms, the total budget for furnishing and equipping the new building will cost about $6.8 million US dollars, and the Ugandan government has opted to dole out those funds slowly over a several year period as their budget is not liquid enough to put up that sort of money at once. Then there is the bidding system—in order to procure equipment, one must go through a seven step procurement system which involves advertising for bids for supplies and equipment, and a third party then goes with the most economical bid, often at the expense of quality.473 One wonders why some hospital in the United States or the United Kingdom hasn’t partnered with the Uganda Cancer Institute to simply donate essential equipment, but the UCI technically does not currently have independent legal standing, and therefore no freestanding Cancer Institute bank account. All funds and all gifts are released through government financial and administrative channels, which makes it challenging to develop direct relationships with donors.474

In the past two years since the new UCI outpatient hospital was completed, in a very drawn out and protracted way, so too has the administration gone through a drawn out and protracted process to achieve full legal and financial autonomy. Divorcing Mulago Hospital was not enough. The Parliament is currently reviewing a bill that would establish the Uganda Cancer Institute as a free-standing entity within the Ministry of Health and therefore make it easier for the Institute to directly procure drugs, engage with donors, and equip and outfit the building. Some funds

474 This analysis is based upon multiple conversations with colleagues at the Uganda Cancer Institute in 2014 and 2015.
from the government have finally been released, and the first step will be to hire a consultant so the equipment and furnishings are purchased wisely and strategically. Creativity in crisis continues.

But in the meantime, why aren’t there relief tents and multiple hand washing stations and an army of crisis workers? Where is Doctors Without Borders when you need them? Why is there only one water spigot for 100 plus people and a cooking area that is a huge accident waiting to happen? This shit stinks—you can literally smell it while chatting with Mr. K at the X-ray department as a human cadaver using a sheet to hide his face, and heavily distorted by a festering naso-gastric tube, hobbles walks past us to relieve himself in the gutter. The sad and terrible fact of all of this is that this scene, this refugee camp, is one of the few remaining political tools the staff at the Institute have left to shame the government into action. How well can this work when it appears, for all intents and purposes, that his Excellency is long past the point of shame and is much more concerned with distributing 1000 Ugandan shilling notes (about $0.40 US dollars), across the countryside in an effort to build NRM solidarity in advance of the 2016 elections?475

Of course, one could easily flip the narrative I have recounted here and tell an optimistic story of an institution that has defied all odds and miraculously pressured the Ugandan government to take cancer seriously in the country. One could argue that the investment both from the international community and the local

government in oncology goods in Uganda in this past decade 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 continue to provide tireless care and engage in the political work of making cancer visible to the Ugandan government. No doubt in five years the landscape of cancer care in Uganda will look wildly different as referral centers open at regional hospitals, as the new buildings become equipped and operational, as patients come to the clinic through cancer screening programs rather than the long cycle of displacement by illness, and as the investments in this team of Ugandan oncology experts begin to publish their translational research. My point here is that these transformations at the Institute occur within the context of profound human cost, of devastating personal loss, and of extreme discomfort not only from bone marrow aspirates but also from sleeping on a mat outside and getting chewed up by mosquitoes all night.

But yet there are surprising moments of survival. In June 2014, while reeling from the changes at the Cancer Institute one hot afternoon, I stumbled across a little boy spinning Ugandan shilling coins like a game of tops on the floor of the verandah space at the new temporary Lymphoma Treatment Center 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, joy. “Greet the muzungu!” said Tata Oliver, pulling him away from his coins and up to his feet. We bumped our fists together, had a wonderful laugh, and poked at bellies, his no
longer distended. 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."
EPILOGUE: Globalizing Oncology and Localizing Inequality, May 2015

When my husband and I returned to Kampala and the Uganda Cancer Institute in May 2015 to attend the celebrations of the opening of the new UCI-Fred Hutch Cancer Centre it was for one week only. Traveling from San Francisco to London and finally Entebbe took over 22 hours. We drove up the Entebbe-Kampala highway in the inky black of the night, past bustling clubs blasting Congolese dance music, and *boda bodas* laden with passengers. When we reached the eerie quiet of downtown Kampala at midnight, I thought back to stories from the 1980s and early 1990s in Uganda where this sort of late night mobility was just not possible due to soldiers, shake downs, and security risks. On our way to the Cancer Institute the following morning, we opted to foot from the hotel rather than deal with the traffic. I pointed out all of the new malls, restaurants, grocery stores, and Kampala beautification schemes to my husband that had mushroomed across the city since we were last in the country together in February 2012.

Economic indicators tell a story of a booming Uganda since the 1990s. According to statistics compiled by the World Bank, Uganda’s GDP was $4.3 billion in 1990, $6.2 billion in 2000, $18.8 billion in 2010, and a staggering $23.7 billion in 2012 when the bulk of this research was conducted. (These figures are in current US dollars. For some reference, in 2014, Uganda’s GDP was $26.3 billion compared to Liberia’s $2.0 billion, Kenya’s $60.9 billion, South Africa’s $349.8 billion, China’s
$10.4 trillion, and the United States’s $17.4 trillion.\textsuperscript{476} Setting aside the problematic issues of using something like GDP as an indicator of economic well being for a moment, just let it sink in that Uganda’s economy has indeed grown substantially in the past 29 years since Museveni assumed the office of the Presidency in Uganda.

The economy is not the only arena of growth. Since 1990, Kampala’s population too has expanded from less than a million residents to approximately three million in the greater metropolitan area. So too has Uganda’s population greatly expanded.

Total fertility in Uganda is estimated to be 6.2.\textsuperscript{477} Roughly 50% of Uganda’s population of 36 million is 15 years of age or younger.\textsuperscript{478} But the bottom line is that incomes in Uganda still remain low. According to a recent Uganda Annual Household Survey, average yearly household income in 2012/2013 in Uganda was approximately 2,676,000 Ugandan Shillings or US $807. GDP per capita in 2012 was estimated to be $652 (US dollars current). Said differently, most living in Uganda are still living on a few dollars a day.\textsuperscript{479}

\textsuperscript{476} These figures are publicly available at the World Bank Online Data Catalog, Accessed June 22, 2015, http://data.worldbank.org/data-catalog/GDP-ranking-table. All data are adjusted to be current US dollars.


Growth and inequality uncomfortably mingle in Uganda. A year before the UCI-Fred Hutch Cancer Centre opened in Uganda, President Museveni attended the grand opening of the Acacia Mall, situated in Kisenyi. The Acacia Mall is a direct response to meeting the demands of growth, according to the mall’s website description:

Kampala, the capital of Uganda is among the fastest growing metros in East and Central Africa. This has been measured at a GDP growth rate of approximately 7% and has resulted in a steadily increasing consumer driven market, a magnitude of people demanding premium offerings from various industry segments including premium residential and commercial properties ranking among those with the highest demand. Hence, the launch of Kampala's premium shopping and leisure destination in the upmarket environs of Kololo …..The Acacia Mall.

A quality development in every aspect, Acacia Mall (35,000 sq.m's) encompasses lifestyle and value with a vibrant mix of home, fashion, fitness, food, service, leisure and entertainment offerings, and will render the shopper spoilt for choice. This splendid property with a spread of more than 35,000 sq metres offering mass and upmarket
merchandise to shoppers, fun, food, fashion and films will easily be the shoppers’ stop of choice in Kampala.\textsuperscript{480}

Knight Frank conducted extensive market research to see if this mall, which includes a Nakumatt (Kenya’s flagship grocery store), a Kentucky Fried Chicken, and air-conditioned movie theatre, would have reliable patronage. Estimates suggest that intended customers have approximately $350-$400 to spend on basic shopping needs per week. These are customers who come from “the so-called “deep pocket” suburbs, which are populated by High Net Worth Individuals (HNWI), mainly in the expatriate community, corporate Ugandan society, high ranking government officials and wealthy individuals.”\textsuperscript{481} This is the Ugandan middle class, as it is imagined by international investors and local developers: “Acacia follows the pattern of malls that represent a golden age. In this case, it is a true a celebration of the sprouting middle-income class and confirms Uganda’s place among the fast-growing countries in the Sub Saharan Africa region that are said to have experienced a surge in economic activity over the last two decades. The money of the mall clientele is local but their tastes and aspirations are foreign.”\textsuperscript{482}

At the same time that malls like Acacia are mushrooming up around Kampala, and with them the promise of bringing “foreign tastes” to the city, the heart of everyday commerce is being excised from the city one bulldozing

\textsuperscript{480} The Acacia Mall, Lifestyle Destination, Accessed July 2, 2015, http://www.theacaciamall.com/about.html
\textsuperscript{482} Ibid.
beautification program at a time. In the bustling neighborhood of Wandegeya, much of the trading center was torn down in October 2014 to make space for a new mall. As the *New Vision* reported, “The area had eateries, motor vehicle garages, mobile money shops, saloons, boutiques and shoe shops among others.” While KCCA said they served eviction notices three months prior, many business owners were caught off guard. The Chairman of Kimwani Zone, Hassan Wasswa said, “The operation was mainly meant to remove containers which were set up illegally. These people were warned.” Some traders moved their businesses into drainage channels to avoid eviction, but were subsequently forcibly removed. Said bystander Jolly Bakuru, “I wish KCCA finds a solution for these people. Iron bar hit men are going to increase.”

The rubble of the demolitions of Wandegeya trading center still litters the entrance to the new mall, being built one story at a time. And in the meantime, “these people” have moved their shops off the main thoroughfares, further into the outskirts of the city where commerce is vibrant, or have joined the ranks of the “iron bar hit men.”

There is a sense that Kampala is eating itself from the inside out.

Like the rest of Kampala, Mulago Hospital’s campus has seen a construction boom over the past ten years especially, to accommodate the infrastructural needs of global health research collaborations with partners from the Global North. When I first started working at the Uganda Cancer Institute five years ago, there were no

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484 Ibid.
easy landmarks that you could follow up the hill from the entrance of Mulago National Referral Hospital. A few old Mulago signs of blue and white pointed towards the Institute. When you arrived at the top of the hill, there was a cluster of dilapidated buildings to greet you and the two donated mammography vans with flat tires, sitting like beached whales in the parking lot. In the intervening years, as the place became more crowded, it was often the spectacle of outpatients under tents and patients distorted from their tumors that signaled arrival at the UCI. As of May 2015, the brand new “UCI-Fred Hutch Cancer Centre” is the first thing you see when you reach the Institute’s gates.

A Grand Opening for a Grand Building

A grand building calls for a grand opening, and on May 21, 2015, nearly three and a half years after the groundbreaking ceremony in October 2011, the UCI-Fred Hutch Cancer Centre officially opened. His Excellency President Yoweri Museveni came as the special guest of honor. The opening was spectacular, and here it is helpful to see it through eyes other than my own. As Mary Engel writes:

People began trickling onto the brick-paved parking lot of the building by 8 a.m. Thursday to go through security set up for the president’s arrival. By 9:30, a crowd of around 300 — nurses in their starched white uniforms, colorful belts and dress caps; physician-researchers; university deans, professors and medical students; hospital administrators, government ministers and members of parliament,
reporters and others — gathered under a giant white, open-sided party tent. And the dancing began.

Colorfully costumed dance troupes from around Uganda performed, and their dances were as varied as Uganda’s nine indigenous communities and 56 tribes. In one, a courtship dance, men outdid themselves with kicks and jumps to win the hand of a village woman. In another, spear-carrying dancers in long straw-colored wigs imitated the crested crane, Uganda’s national symbol. In one dance, men carried big drums on their heads; in another, women with rigid torsos and whirling hips balanced pots on their heads, kneeling to add one at a time until the pots were stacked eight-tall.

Musicians accompanied the dancers on long wood-framed horns covered in cow hide, xylophones, stringed harps, gourd shakers and drums of every size and shape. Singers joined in. It was impossible not to smile. [...]

Despite the entertainment and good cheer, the air was tense with anticipation. Guests grew a bit restless as the hours went by and the Master of Ceremonies assured us that the guest of honor, President Museveni, would be arriving shortly.

Dance after dance from the Ndere Dance Troupe provided proper entertainment for international visitors and local Cancer Institute staff and patients alike, while the MC kept assuring us that His Excellency was on his way. Dr. Jackson Orem, who officially welcomed us all to the “grand commissioning” for the new cancer center said that we “were blessed by the presence of His Excellency”.  

I was nervous that he would not show, that this would be like the failed visit of the Saudi Prince all over again in 2012, or that the Vice President would be asked to come in and pinch hit for the President, as was the case for the groundbreaking ceremony back in October 2011. But surely if Museveni could open the Acacia Mall down the street, which is home to both KFC and a proper gelato place, not to mention a palatial Nakumatt, then surely he could come and preside over the grand opening of an equally palatial and modern facility to address cancers in the developing world.  

There was a collective sigh of relief when His Excellency’s convoy finally arrived. Museveni arrived on the red carpet with a flash of his signature hat of straw, flanked by bodyguards in jungle green army fatigues and sturdy black boots. The booms of welcoming drums and trumpets sounded, as, with a deft flick of the wrist, he unveiled the bronze plaque celebrating the commissioning of the building. Wasting no time, Museveni was joined by Jackson Orem, Corey Casper, Larry Corey,

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486 Fieldnotes, May 2015.
Charles Olweny, Fred Okuku, Joyce Ballagadde, nursing sisters Susan and Miriam, the Minister of Health, and the US Ambassador, among others, for a tour of the building. The rest of the guests sat outside and waited for the next thirty minutes. We were given glasses of juice, and made polite conversation, all the while humming to smooth jazz and Toto’s “Africa.” The usual waiting benches for the X-ray department, which overlook the adult intake space of the new building, were vacant, save a lone special forces operative who was diligently scanning the scene and holding onto his AK-47.

His Excellency and colleagues finally emerged from the building, pausing for a photo opportunity between the Ugandan and American flags in front of the new Centre. The guests of honor then entered the tent, which was decorated in the Fred Hutch colors of green, blue, and silver, rather than the Ugandan national colors of red, black, and yellow, a departure from building opening ceremonies of the past on the UCI’s campus which proudly flew the colors of the nation. The trumpets of the national anthem sounded, we prayed, and were seated.

It was Professor Charles Olweny who first took the podium for the hour and a half of speeches from Corey Casper, Larry Corey, the US Ambassador, the Ugandan Minister of Health, and President Museveni himself. “Thanks delayed is thanks denied,” noted Olweny as he welcomed the honorable guests to the festivities, especially thanking President Museveni for his presence on this “auspicious occasion.” He thanks the tremendous support of the Ugandan and US governments,

the Fred Hutch, and the contractors for completing the building in a timely fashion.

“The keyword that’s driven the Uganda Cancer Institute since its inception is collaboration,” noted Olweny. “We do not take the Hutch for granted.” He then proceeded to tell the story of the history of collaborative cancer research in Uganda, as he saw it, from the 1960s to the present.

As Olweny told it, in 1964, the Union for International Cancer Control held a meeting on the commonest childhood cancer in Africa, which had been identified by Denis Burkitt and colleagues at Mulago. “I take pride because he taught me surgery, and we became colleagues.” Paul Carbone came to Kampala in 1965 to discuss the possibility of a research collaboration on Burkitt’s lymphoma between Uganda and America. By August 1967, the Lymphoma Treatment Center opened under the supervision of Makerere Medical School’s department of surgery. The LTC was part of a broader gift from the Ministry of Health, which donated three buildings at the top of Old Mulago for the cause. At the LTC, 18 beds were available for research on Burkitt’s lymphoma and Hodgkin’s disease. The unit was dedicated to Denis Burkitt. In 1969, the LTC’s sister unit, the Solid Tumor Center was opened to research Kaposi’s sarcoma and other solid tumors. Olweny came and worked extensively with Vogel and Ziegler, doing his master’s in medicine research on the treatment of adult Hodgkin’s disease with chemotherapy alone. In 1971, Olweny left for further training in clinical and laboratory oncology at both the Karolinska Institute in Sweden and the National Cancer Institute in Bethesda, where he worked closely with Carbone and DeVita. With Idi Amin’s economic war, Ian McAdam and the rest
of the American team realized they needed to leave. He received a letter in 1972 saying, “If you do not return immediately, there will be nothing to return to.” As Olweny said, “I alone replaced six Americans and one British.” 489

Olweny went on to tell the story of the survival of the Institute in Idi Amin’s times, and as an earlier chapter in this dissertation went into extraordinary detail on that period, I will not rehash those highlights or scientific contributions here. What was so striking about the rest of Olweny’s speech was his attention to profound continuities over time. The Institute’s four main objectives under his leadership—clinical investigation, postgraduate training, active consulting with up-country hospitals and cancer research—remain the same today. So, too, does the centrality of collaborative partnership: “All we need to do is replace the National Cancer Institute with other cancer centers of repute,” he noted. And this continuity extends also into the centrality of cancers and infections in Africa. As Olweny noted, the key cancers of interest—Burkitt’s lymphoma, Hodgkin’s disease, hepatocellular carcinoma, and Kaposi’s sarcoma—remain the cornerstones of the research and care agenda at the Institute. But one major point of departure for the Uganda Cancer Institute is the question of scale. The pursuit of full institutional autonomy on the part of the UCI is being done to ensure that medical and radiation oncology are housed under the same roof. “Cancer care is a very expensive endeavor,” and will continue to be in the coming decades, Olweny noted, particularly as the UCI expands its mandate to be East Africa’s oncology center of excellence.

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Profoundly moving is probably the best way to describe Olweny’s presentation. There was an unshakable sense that Olweny himself, as well as the Uganda Cancer Institute, was coming full circle. Here was the first, and for a long time the only, Ugandan oncologist who was charged with keeping this research institute alive in the 1970s and whose vision for something more comprehensive was foiled by exile. Olweny’s return to Uganda and assuming this position as Chairman of the Board of the Uganda Cancer Institute marks a powerful second chance to see the vision of comprehensive cancer services in the country realized. Olweny’s speech was storytelling at its best—Museveni joked, “I have benefitted very much from Olweny’s long remarks.” Museveni also explicitly thanked Olweny, saying that there is a superstition that the name influences a person. Olweny in some languages in Uganda means war. This “Professor Warrior” did a remarkable thing in running a cancer center under Idi Amin. He said, “I would not have done that myself.”490 Olweny’s speech also offered some of the necessary context for understanding the history of the UCI for outsiders, both Ugandan and American, who may well be unaware of the Institute’s rich history and see the Hutch collaboration as something entirely new, rather than building on 50 years of collective energy and collaboration.

When Museveni stood to make the final speech of the morning, he thanked the speakers. “I did not mind the unbrief comments because I was just learning,” he said, pointing to the yellow legal pad he had scribbled on the whole time—13 take

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away points on cancer in Uganda. “Our blood inside has all the information if you have the right equipment,” he said. “We’re celebrating that that capacity is now in the laboratory.” He went on, and said that on his tour he had asked, “What else is missing?” and found out that imaging equipment, such as a CT scanner or MRI was still not available. “I don’t see why this should be a problem to acquire. The Ugandan government can find ten million or twenty million dollars.” Applause sounded. Museveni’s speech was gracious—he thanked everyone profusely—the Hutch, the Ugandan government, and the IAEA (which was also in attendance). He also called for a “simple strategy” focusing on cancer prevention and the basket of usual health priorities—tackling malnutrition, improving hygiene, promoting safe water, immunization coverage, malaria prevention, and lifestyle sensitization, especially around alcohol drinking. Infrastructure improvement was also an issue. “The roads are part of health [. . .] where the roads are not you must put them there. The patients need roads [in order to get to the hospital].” “Prevention is better than cure,” he noted, saying that reducing the disease burden should be the priority, rather than spending too much on expensive treatments.491

And just like that, Museveni’s speech was over. Everyone rose again for the national anthem. My husband noted to me afterwards that Olweny was the only one standing with his hand over his heart as the anthem sounded. Drums again sounded and Museveni’s entourage departed. The chair he was sitting on was head loaded out to his convoy. Immediately after he departed, they rolled up the red carpet, so, I

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thought, nobody else could stand on it. The nurses dashed to the tea sandwiches and lukewarm eggrolls catered by the Serena Hotel and filled their plates to the brim. Patients and caretakers lined up at a catering tent behind the festivities. In contrast to the groundbreaking ceremony in October 2011 where only the invited guests were invited to the table, everyone was eating today. The air was electric and exhausted. Had we all just witnessed the gifting of a new CT machine, just as Amin had granted a new X-Ray machine in the 1970s?

We would later find out that the reason the grand tour of the building had lasted such a long time—thirty or forty minutes—was because Museveni had sat down with the stakeholders on the tour and asked, “What are the gaps?” He was so impressed with the facilities and also projected such genuine interest in the subject that his yellow legal pad came empty and left full.492 Apparently, this question about the gaps caught everyone a little off guard. I couldn’t help but think about the parallels from the 1970s when Amin visited the UCI and asked, “What do you need? A new machine? We will get you a new x-ray machine!” When Museveni talked about the relative cheapness of a new imaging machine my jaw dropped to the floor. $10 million or $20 million could easily furnish the relatively empty cancer hospital at the top of the hill. This is power.

While I have lived and worked in Uganda for more than two years over a six year period, it was only after this event that I finally understood the combination of pastoral charm and military menace that has come to characterize Museveni’s long

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tenure as the country’s leader since 1986. In photographs of President Museveni in the popular press, his military apparatus is largely out of sight and he often cultivates the image of the old man in the hat, a benevolent mzee wearing his suit that cannot hide and would not want to hide the visual evidence that he, like the rest of the country, is eating well and prospering. This is a sharp contrast to Idi Amin, who often flanked himself with military personnel, opting for photo opportunities that would depict the weight of military might behind him.\footnote{Elly Rwakoma, \textit{All The Tricks} (Kampala: History in Progress Uganda, 2015).}

At the grand opening, the military presence was everywhere—it surrounded the building; it hid in corridors; it rolled out the bomb-sniffing dogs; it opened the water his Excellency drank and examined it for poison. And at the same time, rather than snoozing or staring off into space, Museveni sat and took detailed notes on a yellow legal pad as the speeches rolled out. He made sure that a select group of Ugandan oncologists came up for a photo opportunity. And he thanked the Americans profusely for the gift of this new building and for their friendship with Uganda. Like any good magnetic politician, we all left energized by his presence, even if only a select few got to shake his hand. This is power.

\textbf{Writing the Research Agenda Into The Walls}

As of May 2015, the UCI-Fred Hutch Cancer Centre rises like a phoenix out of the ashes and rubble of the Lymphoma Treatment Center. It is truly an impressive building. I have argued the ultimate solution to the freezer graveyard was to build a
new building at the Uganda Cancer Institute where an updated infrastructure for doing research and training could operate in Kampala. It is intended to close the distance between Seattle and Kampala, and is built on the site of the old Lymphoma Treatment Center. Specifically tailored for examining the linkages between infectious agents and cancers in Uganda, this building is the new experimental infrastructure and the flagship demonstration project for the Fred Hutchinson Cancer Research Center’s foray into “global oncology.” The Hutch calls this facility a “strategic investment” to help “the UCI grow from a small facility with limited resources—including one oncologist—to a the state-of-the-art UCI –Fred Hutch Cancer Centre, that can treat up to 20,000 patients a year.” But which patients will make the cut? The UCI saw over 40,000 patients in 2014. I wrote in my fieldnotes after touring the building in May 2015:

Walking through the UCI-Fred Hutch Cancer Centre, past the many imported exam tables, the spacious and dare I say inviting chemo bays, the gigantic bathrooms with automatic lights, and the extremely well equipped histopathology laboratory and PCR station, I am in awe.

494 “Global Oncology,” as I’ve already discussed, refers to bringing oncology goods to the Global South in a style similar to other “global health” initiatives, with an emphasis on “cost-effective” treatments, improvement in basic diagnostics, and health care capacity building. The Fred Hutch draws in part on its experiences heading the HIV Vaccine Trials Network as a model for this work. A contrasting example of global oncology can be found in Partners In Health at Butaro Hospital in Rwanda. See Fred Hutch Global Oncology Reducing the Cancer Burden Worldwide, (Seattle: Fred Hutchinson Cancer Research Center), 2015 and Shulman et. al. “Bringing cancer care to the poor: experiences from Rwanda,” Nature Reviews Cancer 2014 14: 815-821.

495 Fred Hutch Global Oncology Reducing the Cancer Burden Worldwide, (Seattle: Fred Hutchinson Cancer Research Center), 2015
But then, standing in the adult intake waiting area, I see a group of patients looking in on our building tour from the LTC II, sitting on the benches, waiting for their X-ray films. My heart sinks a little as we eye each other. This beautiful brand new building cannot possibly see and treat everyone. 496

“When you are in the building you feel that you are in Seattle,” said Dr. James Kafeero, one of Uganda’s new oncologists who has benefitted heavily from the opportunity to train at the Hutch in Seattle. 497 The building is relaxing, air conditioned, clean. Built in a style of brick and glass reminiscent of the Fred Hutch facilities in Seattle, the facility is, in Corey Casper’s words, “audacious and ambitious.” 498

It is also a well-considered building. Months of conversations went into conceptualizing and planning how to create a facility that would meet the essentials for conducting clinical drug trials and keeping the tools of laboratory research and specimen processing within Uganda. These thought experiments about how patients would encounter the building and experience routine examinations, chemotherapy infusions, and blood draws are written into the building, and are at their most visible in the spatial separation of children from adults. It sounds obvious, but adult cancer patients find children with Burkitt’s lymphoma and other large and

496 Fieldnotes, May 2015.
497 Ibid.
distorting tumors to be deeply disturbing. The same goes for pediatric cancer patients, who are turned off by the smells and sights of adults with explosive tumors or cadaverous faces. Built like a gigantic horseshoe, if you’re facing the main steps of the building you can see an Adult Patient Clinic entrance on the left and a Pediatric Patient Clinic entrance on the right. There is also a separate entrance to the Research Clinic, which goes up a simple flight of concrete stairs to the second floor, where sunshine yellow tiles and a smiling receptionist greet research subjects for appointments for consent taking, swabbing, and counseling. On the ground floor, there is a small window for the pharmacy is tucked into the left hand corner of the building, so patients can just walk to a window and pick up necessary prescriptions without heading into the building. There is also a specimen repository center and generator on site. The Centre is three stories, 25,000 square feet, and is designed for 20,000 patient visits a year. 499

The UCI-Fred Hutch Cancer Centre is so much like America that the building was largely imagined as an interior space. In contrast to the pavilions of Old Mulago, with their large outdoor and shady verandahs, or the open air hallways of New Mulago, that invite in the tropical breeze, or the large patient caretaker cooking pavilions of Lacor Hospital, or even the open-air waiting areas of the Infectious Disease Institute, the UCI-Fred Hutch Cancer Center does not utilize outdoor space. The stairs and the entrances to the clinics currently bake in the afternoon sun—in

time I imagine they will put up a tent or awning to help mitigate the heat and shelter relatives waiting for their patients.

This is not a residential facility. At its core, this new building is designed for blood taking and chemo administration and research. It is not equipped to handle in-patient care. Nor can the 20,000 slots for patient visits accommodate the 40,000 patients who come through the UCI annually. So it’s an open question as to how and if this new facility will sediment inequalities in mortar and concrete between those who have cancers that are interesting to international researchers (Burkitt’s lymphoma and Kaposi’s sarcoma) and those who have cancers that are not. This would signal a profound continuity if the focus of the research at the new UCI-Fred Hutch Cancer Center remained solely on these two cancers that captured the imaginations of physician-researchers half a century ago—Burkitt’s lymphoma and Kaposi’s Sarcoma. The spatial divisions that ensure that adult patients make a left into the adult clinic and pediatric patients hang a right into the child cancer clinic—can be read as an accidental nod to the spatial politics separating the Solid Tumor Center to the left and the Lymphoma Treatment Center to the right when they were set up in the late 1960s.

This new building is a sharp contrast to the working environment of the Hutch collaboration over the past ten years, where converted shipping containers, tiny dark office spaces, and a communal working space that was, at one point in time, a dental surgery theatre made up the physical infrastructure of the Hutch collaboration. It used to take a day in an airplane to close the physical and
infrastructural gaps between Seattle and Kampala. Now it takes a five-minute walk and a flight of stairs to get out of the crush of the Institute’s encampments on top of Mulago Hill and to a space more akin to the US than Uganda.

Step down the stairs and cross the brick paved parking area with neat white lines to where the property ends, however, and you are back in a parking lot that is either mud or dust, depending on the rainy season. The overwhelming quality of the “camp” at the Institute remains. As I discussed in the previous chapter, these transformations enacted profound infrastructural violence. The demolition of the Lymphoma Treatment Center and the subsequent makeshift ward that was created to accommodate patients left in between the old ward and the promise of the new inpatient hospital, exacerbated the suffering of pediatric patients and adults with hematological and lymphatic cancers. The Lymphoma Treatment Center II still has only one water spigot for its patients. Patients and family members seek out shade and lie out on mats, waiting for appointments. The most visible (and stinky) divide between the dilapidated UCI facilities and the gleaming Fred Hutch collaborative space is the open gutter of raw sewage that comes down from the LTC II, drawing a line literally in the concrete between the old and the new. Further up the hill at the grey six-story in-patient government-funded cancer hospital, the pediatric patients are now on their own floor; the smell of human urine and bile already unmistakably present. Private patients are now being treated on their own floor as well. But the rest of the building remains ghostly and barely occupied. Last year at this time, the building was vacant, save for the vervet monkey colony that left dirty paw prints all
over the walls as they engaged in their nocturnal monkey business. Today, the furnishings and equipment for this new cancer hospital are trickling in, but it’s still unclear when this shell of a facility will be fully operational.

For me, as the “historian,” with none of the clinical responsibilities of an oncologist or the subjectivity of a Ugandan national or the research questions of an infectious disease specialist, I found this sharp division between the new UCI-Fred Hutch Centre and the Uganda Cancer Institute’s largely vacant hospital to be hugely jarring, upsetting, and dislocating. When I gave another expatriate historian colleague a tour of my field site, his basic reaction was, “Wait, why is there an empty cancer hospital and a fully equipped cancer laboratory? Couldn’t they furnish the hospital at the same time too?”500 For me, this new facility has not closed the cancer divide so much as its brought into relief, more starkly than ever, the sharp divisions between the raft of oncology goods that are offered to patients in America, and those that one could hope to access in Uganda, even with this new facility. I was only in Uganda for a week in May 2015, but my fast impression is that my American and Ugandan colleagues do not necessarily share the view through my social scientist goggles of gloom. They may see these inequalities being cemented in mortar and concrete, but for them, that’s beside the point. For Mary Kalinaki, who worked at the UCI since the 1970s, “This is a miracle from God.”501 Three years ago, where this building stands there was a dilapidated former maternity ward that was overflowing with pediatric cancer patients. Now there is a brand new facility,

501 Ibid.
lovingly designed, astonishingly well resourced, and waiting to be filled with patients and research protocols.

**Final Words**

This dissertation has carefully reconstructed the history of research practices and cancer care at the Uganda Cancer Institute since its inception in the 1960s. This story, as I see it, deepens our understandings both of the everyday stakes of seeking care and relief, and the exceptionality of biomedical research in 20th century Africa. Said a different way, the Institute is a hospital—a microcosm of postcolonial everyday life in Uganda—and an experimental infrastructure—a site of ongoing biomedical research on Africans both by African physician-researchers and internationally based scientists. This is a political and social history—the stories of how medical personnel and patients alike survived politics at the Institute during times of war, austerity, and the HIV epidemic allow us to deeply and viscerally engage with the texture of everyday life in Uganda since independence. I have endeavored to show how people cope with *malignant states*, both on the cancer ward and within the broader political and economic landscape where those in power are committed to advancing and maintaining that power through corruption, graft, or the threat of violence. The histories of the biomedical research conducted at the Uganda Cancer Institute deepens our understanding of the waxing and waning of international research interests in cancers in Africa. From “geographical pathology and chemotherapy” in the 1960s and 1970s to a reinvigoration of interest
in infectious diseases and cancers, we have seen how Ugandan physicians use research as a powerful resource for mobilizing and extending care, even if they do so in a highly unequal world.

Historians do not like to make predictions, but I'll venture one here. Social, political, epidemiological, economic, and scientific circumstances well beyond the control of the staff and patients at the Uganda Cancer Institute will, in all likelihood, continue to impact this facility in the fifty years to come. Ugandan citizens will continue to contend with malignancies on the wards and malignant states. Committed Ugandans, these “physician intellectuals,”502 will keep these new investments in cancer services going long after this latest international research partnership with the Fred Hutchinson Cancer Research Center comes to a close. Research is a resource, but it is one fundamentally situated in the temporal shifts of politics, economics, scientific priorities, and personal relationships.

502 Feierman, Peasant Intellectuals.
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Oral Histories and Interviews Conducted by Author
Oral histories were conducted between 2012 and 2015 by the author. Their names
have been redacted to preserve privacy. Those quoted directly in the dissertation
are either public figures or gave permission to be on the record.

MS, audio recording
NX, fieldnotes, audio recording
AK, fieldnotes, audio recording
VM, fieldnotes, audio recording
TT, fieldnotes, audio recording
MK, fieldnotes, audio recording
SS, fieldnotes, audio recording
FO, fieldnotes, audio recording
AO, fieldnotes, audio recording
NN, fieldnotes, audio recording
AC, audio recording
DS, audio recording
KM, audio recording
CO, fieldnotes, audio recording
JZ, fieldnotes, audio recording
CO, audio recording
JO, fieldnotes, audio recording
RM, fieldnotes, audio recording
RC, fieldnotes, audio recording
AB, fieldnotes, audio recording
DS, fieldnotes, audio recording
RO, fieldnotes, audio recording
CC, fieldnotes, audio recording
ES, fieldnotes, audio recording
MU, audio recording
EM, fieldnotes
VW, fieldnotes,
JB, fieldnotes
GG, fieldnotes
EK, fieldnotes,
MA, fieldnotes,
SK, fieldnotes,
SB, fieldnotes,
SB, fieldnotes
KM, fieldnotes
SG, fieldnotes
WP, fieldnotes
JB, fieldnotes
DW, fieldnotes
MP, fieldnotes
PV, fieldnotes
DK, fieldnotes
LK, fieldnotes
SA, fieldnotes
DM, fieldnotes
NM, fieldnotes, audio recording
SJ, audio recording
NH, fieldnotes
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