

**Title:**

Experimental Infrastructures:

Fifty years of creativity, crisis, and cancer in Uganda

Author Contact Information:

Dr. Marissa Mika

Wellcome Trust Research Associate

Institute of Advanced Studies, University College London

m.mika@ucl.ac.uk

Author Bio and Acknowledgements:

Marissa Mika is a Research Associate at the Institute of Advanced Studies at University College London. She is writing a historical ethnography of the Uganda Cancer Institute, which examines the politics and histories of biomedical research as technology transfer in postcolonial Africa.

She is starting a new project on the histories of chronic disease in South Africa as part of a research project on critical histories of the epidemiological transition in Africa, which is funded by the Wellcome Trust. She wishes to thank all who made this research possible, especially the current and past directors of the Uganda Cancer Institute, Dr. Jackson Orem, Dr. Edward Katongole Mbidde, Dr. Charles Olweny, and Dr. John Ziegler, and Dr. Corey Casper at the Fred Hutchinson Cancer Research Center. The Social Science Research Council and the Wenner Gren Foundation financially supported this work. She also thanks the two anonymous reviewers, P. Wenzel Geissler, and Noémi Tousignant for generous feedback on the various iterations of this article.

## **Abstract**

This article tells the story of the Uganda Cancer Institute over the past 50 years. I discuss the fundamental dynamism of research collaborations and the ways in which they bring vital yet partial investments in improving the capacity of medical facilities in sub-Saharan Africa. I explore the ways in which patient populations and the needs of caretakers themselves shape research collaborations. I also show how extreme oscillations in the capacity to conduct oncology research and provide care were (and are) tied not only to shifting international research priorities, but also to broader upheaval and periods of stability in Uganda since independence in 1962. Rather than dwelling on the debris, ruins, or an emptying of capacity in the health sector in Africa, this article highlights how this experimental infrastructure in East Africa not only survived, but also fundamentally shaped a culture of care and oncology practice that lived on.

## **Keywords:**

cancer, Uganda, capacity, survival, infrastructure

## **Introduction**

In 2004, Dr. Corey Casper, an American infectious disease researcher, came to the Uganda Cancer Institute (UCI). The UCI stands at the top of the hill on Mulago National Referral Hospital's campus. Mulago is the major public teaching and tertiary care hospital in Kampala, Uganda's bustling capital city. Dr. Edward Katongole Mbidde, who was the Institute's director, took Casper on a tour of the site. On ward rounds, they saw children with Kaposi's sarcoma, adults with liver cancers, and countless women suffering from cervical cancer. Casper was struck by the sheer abundance and wide variety of patient conditions, especially the breadth of cancers that are common in those living with HIV/AIDS (Wabinga 2014). It was clear this would be an ideal site to study the relationship between cancer and infectious disease. The last stop on the tour was a room in a dilapidated building. The ceiling was caving in and leaked during the rains. It was infested with plump, Kampala sized rats. There was no running water or electricity. In this room sat a cluster of refrigerators and freezers that were long abandoned. It 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 (Engel 2015 a).

A decade later, the Uganda Cancer Institute and the U.S. based Fred Hutchinson Cancer Research Center (FHCRC) officially opened a new three-story research and outpatient treatment facility in Kampala, Uganda. His Excellency, President Yoweri Kaguta Museveni, was the guest

of honor. A troupe performed iconic dances from the north, south, east, and west of the country. Nurses filled their plates high with samosas, eggrolls, and biscuits. International research scientists and representatives from the United States Agency for International Development toured the building, admiring the gleaming laboratory equipment and the inviting chemotherapy administration wards.

The grand opening marked a decade long partnership focusing on malignancies and infectious diseases between the UCI and the FHCRC. Over the past ten years, this partnership made systematic investments in building infrastructural and human capacity for cancer research and care in Uganda. In 2000, there was one oncologist practicing in Uganda. Today, there are over eleven newly trained oncologists, many of whom did a year of study in the United States at the FHCRC in Seattle, Washington. The number of patients seeking care at the Uganda Cancer Institute increased from less than 500 a year in 2008 to more than 40,000 a year in 2015.<sup>1</sup>

At the same time, 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. The combination of more Ministers of Parliament getting cancer and the visibility of the FHCRC partnership created a climate where it was possible to politicize oncology. The crowning achievement of Orem's leadership so far is a newly built, six-story in-patient cancer hospital backed by Ugandan government funds. The East African Development Bank recently granted a \$45 million (USD) loan to the Institute to create a regional center of oncology training and excellence, which began in January 2016. In August 2016, the U.S. based Texas Children's Hospital and Baylor University launched an East African pediatric oncology and hematology training fellowship.<sup>2</sup> In the past ten years, the UCI shifted from a place where

you were “sent to die” to a center of excellence in research and clinical care.<sup>3</sup> It is perhaps no wonder that the Uganda Cancer Institute’s current slogan is “Research is Our Resource.”

In many ways, this story is an increasingly familiar one about the entanglements of global medical research and its impact on the infrastructural, technological, and human capacity of health services in contemporary Africa. The long and pernicious HIV and AIDS epidemic across southern and eastern Africa inadvertently created a “living laboratory” for medical research (Tilley 2011). Over the past ten years a massive yet uneven rollout of highly subsidized antiretroviral therapy restored lives and bodies across the continent. These populations offer new research possibilities on infectious diseases and cancers, the pharmaceutical treatment and prevention of HIV, and co-infections with tuberculosis and sexually transmitted infections. A “scramble” for African research subjects is remaking the built landscape of biomedical care in environments deeply hit by the turn to structural adjustment in the 1980s and 1990s (Petryna 2009, Crane 2013). These experiments bring vital yet partial investments for improving the capacity of medical facilities across sub-Saharan Africa. Newly constructed global health research facilities often stand alongside older, dilapidated African health care infrastructures. In Uganda, for example, the Infectious Disease Institute built with the backing of international research partners in the early 2000s boasts a world-class laboratory facility and flagship HIV clinic. It stands directly across from Makerere Medical School’s department of pathology, which has not been seriously upgraded since the 1960s.

Scholars are increasingly turning their attention to the debris, ruins, residue, and detritus of medical collaborations and experiments as a way to open up important histories of the practices, ethics, and legacies of biomedicine in colonial and postcolonial African contexts (Hunt 1999, Stoler 2008, Geissler and Molyneux 2011, Droney 2014, Graboyes 2015). The Uganda

Cancer Institute's freezer graveyard functions as a time capsule of sorts and vividly shows that experiments travel and bring resources, but they can rot, atrophy, or become trash over time. But as the latest partnership with the FHCRC suggests, new rounds of internationally funded medical research often build on the foundation of preexisting buildings, records from previous patient cohorts, and already established African medical partners. In short, the latest iteration of global health research collaborations in the present relies on the infrastructures and practices of medical research from the past.

For this special issue on health and capacity in Africa, I use the history of the Uganda Cancer Institute over the past 50 years as a way to examine the fundamental dynamism of medical practice and research in Africa. The Uganda Cancer Institute's history is marked by formidable individuals who keep medical research and care infrastructures functioning long after international funding grants expire, maintenance contracts end, or political climates shift in such a way that everyday life becomes fundamentally unstable. I am particularly interested in highlighting the connections between the built environments of medical research and the labor of Africans themselves who conduct medical research and receive care at these sites in times of optimism and duress. 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 Uganda Cancer Institute. This experimental infrastructure was designed in the 1960s to facilitate chemotherapy clinical trials, animating the movement of bodies, information, and materials. Following the lead of science and technology studies scholars who argue that maintenance is at the core of any infrastructure and its longevity, I discuss the labor of maintaining buildings, study cohorts, and data sets at the Institute over time (Starr 1999, Edwards 2010, Larkin 2011). The article traces fifty years of institutional history, highlighting

how an extraordinary group of Ugandan physicians, nurses, caretakers, administrators, and laboratory workers keep things like refrigerators, ward rounds, and data sets going long after research partnerships end. I begin with a short overview of the establishment of the UCI in the 1960s and the ways in which this research site was initially set up to do clinical trials and long term patient follow up research. From there, I focus on the efforts of the UCI's first Ugandan director, Charles Olweny, and the work of his staff to keep the Institute open and able to produce cutting edge chemotherapy survival research in the middle of Idi Amin's Uganda. I then discuss how work at the Institute carried on, despite the twin challenges of the HIV/AIDS epidemic and the gutting of funding for public health services in the 1980s, 1990s, and early 2000s. Lastly, I turn to the present-day situation at the top of Mulago hill, exploring the ways in which this experimental infrastructure is being remade. This experimental infrastructure in East Africa not only survived, but also fundamentally shaped a culture of care and oncology practice that lives on, both in Uganda and in the wider world.

This material draws from historical and ethnographic research at the Uganda Cancer Institute, which began in 2009 and is still ongoing as of 2016. In total, I have spent over two years at the Institute. I spent ten months in Uganda in 2012, and made trips of spanning one week to three months every year between 2009 and 2016. My methods draw from hospital ethnography as well as approaches in African history that value the triangulation of oral sources, archival resources, and ethnographic research. Data for this article draws from participant observation on the wards, oral histories with physicians, nurses, laboratory technicians, administrative staff, interviewing patient caretakers, and extensive photographic documentation of the Institute's spatial transformations. Additionally, I draw from archival research across a variety of sites in the United States, the United Kingdom, and Uganda, which includes patient

records, medical memoirs, institutional correspondence, and historical photographs. I use pseudonyms to protect the identities of participants who wished to remain anonymous and they are marked with an asterisk throughout the text. Individuals and entities referenced in publicly available materials over the course of the Institute's history and present day are not anonymized, reflecting the conventions of historical scholarship.<sup>4</sup>

### **Building an Experimental Infrastructure**

Across the hills of Kampala, hospital and treatment sites established in the late 1800s and early 1900s by medical missionaries and colonial government officials continue to be spaces of medical care and research in the present. Of these sites, Mengo Hospital and Mulago Hospital are particularly important in the history of cancer research and care in eastern Africa. In the first half of the 20<sup>th</sup> century, medical staff at these two institutions documented cancer cases in patient records, which created a robust knowledge base (Iliffe 2002). This concentration of biomedical expertise combined with the sedimentary layers of knowledge about the prevalence, distribution, and different kinds of cancer proved invaluable for Ugandan, American, and British physician-researchers in planning and establishing the UCI in the 1960s.

Cancer epidemiology was one major arena of cancer research in Uganda in the 1950s. Physicians wanted to know whether or not cancer was a new ailment emerging as a consequence of increasing urbanization, changes in diet, and patterns of consumption brought by colonial encounters in eastern Africa. In order to answer this question, physicians needed evidence about the patterns and distribution of cancer in Uganda. Pathologist J.N.P. Davies and colleagues established the Kampala Cancer Registry to systematically document cancer incidence and prevalence in the areas surrounding Kampala in the 1950s. Records from the early 1900s at Mengo Hospital provided a baseline of cancer prevalence and distribution around Kampala in the



early 1900s (Davies 1958).<sup>5</sup> The Kampala Cancer Registry and the Mengo Hospital records suggested that cancer was a longstanding affliction in and around Kampala, but that the types of cancer commonly seen in central Uganda were quite different from those seen in Europe and the United States. Cancers that were highly common in east Africa but rare elsewhere included Kaposi's sarcoma, some kinds of liver cancer, and Burkitt's lymphoma (Davies 1958).

Of these cancers, it was Burkitt's lymphoma (BL) captured the imagination of researchers during the 1950s and 1960s. BL is a fast acting lymphoma that typically presents as a horrendously disfiguring jaw tumor in children between the ages of two and seven years old (Burkitt 1958). It is thought to be the most common pediatric tumor in eastern Africa. This tumor, named after the Irish surgeon and colonial medical officer, Denis Burkitt, caused a sensation across the international cancer research community in the late 1950s and early 1960s. Although the tumor was surgically inoperable, it responded very well to cytotoxic drugs available at the time (Burkitt 1964). In lectures in Kampala and London alike, Burkitt shared unnervingly vivid photographs illustrating jaw tumors evaporating. These melting tumors caused a sensation. Among pediatric leukemia researchers in the United States and Europe and cancer specialists in east Africa, there was tremendous excitement that these long-term remissions indicated that Burkitt's lymphoma was curable, either with cyclophosphamide or combination chemotherapy treatments of cyclophosphamide, methotrexate, and vincristine (Burchenal 1966, Burkitt and Wright 1970, Walusansa et. al. 2012). Additionally, the geographic distribution of Burkitt's lymphoma spread across a wide swath of tropical Africa. Emerging research suggested that Epstein Barr virus, the environment, and endemic malaria all contributed to the pathogenesis of Burkitt's lymphoma (Epstein 1995). But despite the excitement about the treatment and epidemiology of Burkitt's lymphoma, Mulago Hospital's capacity to determine the long-term

survival of patients treated with chemotherapy was quite limited in the early 1960s (Burkitt 1970). Patients would vanish after one round of chemotherapy treatments or not make it to their next treatment appointment. This made it nearly impossible to determine whether or not Burkitt's lymphoma could actually go into permanent remission. Mulago Hospital lacked a robust infrastructure for long-term cancer clinical trials, including tools to follow up with vanishing patients.<sup>6</sup>

The interest in Burkitt's lymphoma and cancer epidemiology blossomed during a time of profound political transition in Uganda (Kasozi 1994). After independence in 1962, British colonial medical contracts started to expire. Expatriate staff remaining at Makerere Medical School saw continuing Africanization of the medical profession and the specialized training of promising east African physicians in Master's of Medicine programs as one of their top priorities (Ilfie 2002). The head of Makerere Medical School's surgery department, Ian McAdam, was particularly interested in the project of Africanizing medical education and research. His colleague, the Muganda surgeon Sebastian Kyalwazi, had a keen interest in chemotherapy research and medical oncology. Both wanted to improve cancer research infrastructure at Mulago. McAdam and Kyalwazi galvanized stakeholders from the American National Cancer Institute, the Makerere Department of Surgery, and the British Empire Cancer Campaign. Working with a team of American oncology and epidemiology colleagues including Paul Carbone, Joe Burchenal, John Ziegler, Richard Morrow, and Gordon Zubrod, they made plans for Uganda Cancer Institute. This site would study the effects of chemotherapy drugs and their efficacy in creating long-term remissions in a variety of cancers, namely Burkitt's lymphoma, liver cancer, and Kaposi's sarcoma (Walusansa et. al. 2012).

The task of setting up the Lymphoma Treatment Center (LTC), the original UCI ward, fell largely on Ziegler and Hilary Martins. Ziegler was a 29 year-old talented chemotherapist from the American National Cancer Institute with a keen interest in Burkitt's lymphoma. Martins worked in hospital administration at Mulago for many, many years. The Ugandan government donated an abandoned former maternity ward at the top of Mulago Hill to be the new LTC. Over the course of about six weeks, Ziegler and his Ugandan colleagues refurbished this rat infested building and turned it into a viable experimental infrastructure. They set up beds, painted walls, and equipped a small laboratory. Ziegler and his NCI contributed boxes of gloves, stockpiles of syringes, vials of cyclophosphamide, and massive amounts of gauze. Martins managed the practical logistics. He worked as a fixer, a go-between, and a translator. He knew what was essential and what was optional in a Kampala hospital setting. As a Ugandan of Goan origin, Martins had longstanding business relationships with Indian traders in Kampala town, which made it easier to stay within the modest equipment budget. The Institute was, in John Ziegler's words, a "hospital built from scratch."<sup>7</sup> Ugandan and American colleagues strategically designed the Institute's laboratory facilities so day-to-day procedures for clinical trials could be done on the site. This included a chemotherapy mixing laboratory, an X-Ray unit, a pharmacy, and a lab for routine blood tests, bone marrow aspirates, and malaria smears at the top of the hill. They did not invest a new infrastructure for surgery, pathology, and medical illustration. These services were already available through Makerere Medical School, which was a short walk down the hill towards new Mulago Hospital.

Physical structures such as wards and laboratories were only one component of the Institute's experimental infrastructure. Oncologists treating cancers usually give doses of chemotherapy over several months and in combinations that are time sensitive. Side effects such

has hair loss and nausea are common, but more importantly, immunosuppression can leave patients vulnerable to infections, sepsis, and death. As a result, residential stays of two or three weeks at a time were (and to some extent still are) common, especially in pediatric treatment settings (Cambrosio and Keating 2012). Research staff had to create reliable systems and procedures for running clinical trials in a context where most cancer patients moved back and forth between their largely rural villages and the hospital in Kampala.

On the wards of the Lymphoma Treatment Center, this mix between the village and the hospital shaped day-to-day clinical practice and oncology research. Ziegler and NCI staff brought a set of practices from their training in medical oncology from US hospitals. They instituted these practices such as ward rounding, the proper way to write up a chart, and protocols for doing complete blood work ups before deeming it safe to administer chemotherapy. Within the first few weeks of opening in August 1967, patients and their caretakers started to reshape the scope of residential requirements for research and care on the wards in unexpected and important ways. Since patients came to the Uganda Cancer Institute from all over the country, often at great distances, they often brought an entourage of caretakers and family members with them. Ziegler and his American colleagues quickly realized that in order to treat cancers, they also had to treat families. Mothers were coming to the wards with babies on backs, and sicknesses from villages. Worms, malaria, colds, and tuberculosis—these were all conditions that needed to be treated in the whole family, or the patient undergoing chemotherapy would surely catch an illness from his brother or sister.<sup>8</sup>

Because chemotherapy treatments entailed residential stays, Ziegler and colleagues realized that patients and families needed additional supportive care. Parents were extremely anxious about keeping their children out of school for medical care. Others were concerned with

returning to the village in time to attend to groundnut crops. The Institute invested in providing schooling, food, and transport support in order to ease the burden on parents and patients. These innovations on the wards intuitively captured something that historians of Africa have long identified as the fundamental logic of caregiving in African societies. Patients tend to move with large “therapy management groups,” and families fundamentally determine the course of care (Janzen 1978). Ziegler and colleagues understood that in order to run clinical trials, they needed to modify their experimental infrastructure to accommodate the care of whole families rather than individual patients. Institute staff conceptualized care broadly and well beyond the narrow scope of biomedical treatments.

As I stated earlier, there were two main reasons for establishing the Uganda Cancer Institute. The first was to create a clinical trials setting where chemotherapy protocols could be administered with proper informed consent procedures, drug administration, and supportive care to manage side effects. The other main purpose of the Institute was to track how long patients lived after they received chemotherapy treatments. The Institute developed an expansive patient follow-up program to track the long-term effects of chemotherapy treatments in creating cancer remissions. On paper this program was concerned with three basic questions: Were patients still alive, and if so were they cancer free? Were patients dead, and if so was it because of the cancer? Or were the patients untraceable and lost to follow up? Answering these questions involved a rigorous patient follow up and outreach program, which Institute staff developed and maintained from 1967 to 1977.

Like the built environment of the Institute itself, both Ugandans and expatriates developed and tinkered with the infrastructure for the patient follow up program at the UCI. The two original architects of the follow up program were Richard Morrow, an epidemiologist from

the World Health Organization researching the geographical distribution of Burkitt's lymphoma and Moses Asimwe\*, a pediatric clinical officer who came to the UCI via Mulago. Asimwe and Morrow started working together in 1966 to resolve the problem of tracking down Burkitt's lymphoma patients who had been treated at Mulago in the 1950s and early 1960s. They had little to work with other than a list of patients from Burkitt and their accompanying patient information records. Mulago admissions officers routinely completed "face sheets" when new patients came to the hospital. These sheets recorded names of patients and his or her relatives, age information, "tribe," diagnosis, and date of admission. These sheets also described where the patient was from, stating the district, saaza, gombola, and finally, the village. Using this data, Asimwe and Morrow were able to develop a map of patients treated for Burkitt's lymphoma across Uganda.

Working with maps and data from face sheets as a guide, Asimwe drove across much of Uganda in a Volkswagen Beetle for follow up interviews. As he recalls:

This patient follow up was more than 7 years. It was made up by experiences. Memory. Long drives. Mud going through the bush. [ . . . ] These long drives were very tiresome. Driving Volkswagen Beetles. They are really helpful. They can go through swamp. [ . . . ] 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.<sup>9</sup>

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 many of these villages were off the tarmac. 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. As Asiimwe recalls:

[. . .] 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 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.<sup>10</sup>

Taking time was part of the “careful approach” to finding patients and conducting patient follow up work. After gaining permissions and access from village chiefs to find and approach patients, Asiimwe 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.<sup>11</sup>

From many years of working as a clinical officer, Asiimwe understood the familial dynamics of everyday caregiving for sick children. He knew caretaking most usually fell on mothers or female kin, and he also understood that fathers or other male heads of household often granted approval for travel and treatment. The technique of “making friendship” by patiently spending time with mothers before approaching fathers with travel requests was

certainly time consuming. But Asiimwe and Morrow saw “making friendship” as a vital part of patient follow-up. Writing about the follow up program, they said:

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 (Morrow 1967).

The methods and practices that Asiimwe and Morrow created for patient follow up in the late 1960s remained a vital part of the Institute’s experimental infrastructure over the next decade.

By the early 1970s, the Uganda Cancer Institute consisted of two wards and an administration building at the top of Mulago Hill. Building on the success of the LTC, a Solid Tumor Center opened in 1969 to investigate the treatment of adults with hepatocellular carcinoma as well as Kaposi’s sarcoma. Forty beds were available for research in these two wards, which were housed in separate donated buildings. In the late 1960s and the early 1970s, the Uganda Cancer Institute occupied a singular space on the top of Mulago Hill. The work on treating Burkitt’s lymphoma, liver cancer, and Kaposi’s sarcoma had national and international visibility. The Institute developed a reputation for high standards. Promising Ugandan medical students applied to the Institute for competitive cancer research internships, which involved participating in clinical trials and living on site to tend to night emergencies. The Institute routinely welcomed international visitors specializing in medical and surgical oncology from Nigeria, Ghana, Kenya, South Africa, the United States, the United Kingdom, France, and Sweden among others. Publications showcasing data on long-term Burkitt’s lymphoma survivors circulated to cancer specialists on the African continent and beyond. The Uganda Cancer Institute’s built infrastructure was nothing fancy. The Lymphoma Treatment Center and Solid



Tumor Center were very modest physical structures. What made the Institute unique was the way staff balanced high standards of clinical research with equally high standards for meeting the everyday needs of patients and their families.

### **Institutional Survival in the Times of Idi Amin**

In 1971, Idi Amin rose to power in a military coup. A year later in 1972, Amin declared an economic war and expelled the Asian community who were largely responsible for trade and commerce (Hansen 2013). American research scientists working in Uganda felt they needed to leave for their safety. A fierce debate ensued at the National Cancer Institute—should they close the unit and halt the research? Or should they keep the Institute open in a political climate where doctors were being put into the trunks of cars, never to be seen again (Kyemba 1976)? They decided to accelerate the Africanization of the Institute’s top leadership. Ugandan staff would oversee the day-to-day functioning of the experiments and infrastructure at the Institute. American partners would continue to supply drugs and provide a budget for salaries and patient follow up.

Colleagues at the Uganda Cancer Institute had already chosen Charles Olweny, an exceptional Ugandan physician, to be trained as the country’s first medical oncologist. Olweny started working at the Uganda Cancer Institute for his Master’s in Medicine thesis, conducting research on the treatment of Hodgkin’s disease in adults with cytotoxic drugs 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.’”<sup>12</sup> Capacity building, in this case, meant training Olweny in medical oncology, research practices, and laboratory techniques overseas at the Karolinska Institute in Sweden and the National Cancer Institute in the USA. Shortly after the Asian expulsions in

1972, however, While Olweny was studying in the United States, he received notice from Kampala with a simple message, “Better come back now, or there will be nothing to return to.”<sup>13</sup> Olweny returned and briefly overlapped with remaining expatriate colleagues. They handed over many obligations—the Burkitt’s lymphoma and Kaposi’s sarcoma patient cohorts, the storage of sera, blood, and tissue samples in several freezers on site, and of course, the ongoing randomized control trials of chemotherapy drug combinations.

The 1970s are often characterized as a period of profound chaos in Ugandan history. Amin’s rule certainly brought mercurial violence and profound economic crisis. At the same time, Olweny and his colleagues maintained the Institute’s international research profile, generating a decade’s worth of knowledge about the relationship between chemotherapy treatments and BL survival. Asiimwe and others continued to follow up with long time Burkitt’s lymphoma patients. In a time where mobility was heavily compromised and travel was potentially perilous, fieldwork staff routinely used their status as medical men and scientific researchers at the Uganda Cancer Institute to pass freely through roadblocks manned by soldiers. Out of a cohort of over 200 pediatric patients, only about 6% were lost to follow up (Ziegler et. al. 1979). As Olweny remembers, “The UCI made its name not only because we were able to treat people well, but we were able to follow up everyone. 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. And we traced every body.”<sup>14</sup>

On the wards, patient care required both chemotherapy drugs and food. Staff at the Institute continued to cast supportive care in broad terms. Bus vouchers, translation on the wards, and ensuring that family members had a place to sleep continued to be 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. The UCI's leadership went to great lengths to ensure that the food-catering program at the Institute continued to operate not only for patients and their families, but also for the staff.<sup>15</sup> Over the course of the decade, it gradually became more and more difficult to conduct fieldwork with patients and their families in remote villages, or to keep the refrigerators humming at the laboratory. Part of these challenges came from the overall deterioration of basic infrastructure such as electricity, water, and transportation in Uganda. Rampant inflation and the soaring costs of petrol made it very difficult to buy basic sundries on the legal market (Hansen 2013). Suppliers sometimes fell flat, leaving periods where it was "extremely difficult to run this Unit without soap, salt, sugar and cooking oil."<sup>16</sup>

In 1977, the National Cancer Institute canceled its financial and administrative support of the UCI. NCI leadership decided that the research coming from the UCI no longer merited the expense and challenges of supporting the Institute in precarious political times in Uganda (Varmus 2014). Many of the founding American staff who invested their time and energy in the Institute and later supported it from afar also left the NCI during this period, leaving the Uganda Cancer Institute particularly vulnerable to budgetary cuts and shifts in priorities at the top levels of leadership. The NCI was the first major international partnership to both invest in the development of the Institute's experimental infrastructure and then withdraw support. Rather than shutter the Institute, however, Olweny and his colleagues actively sought new partners in the international oncology community and engaged with the Ugandan government. In the late 1970s, the Ugandan Ministry of Health agreed to financially support the Institute. The UCI received a budget separate from Mulago Hospital that provided the funds for cancer drugs and staff salaries. Olweny's work to garner support from new international research partners kept the Uganda Cancer Institute after the NCI support came to a close.

## **HIV and Austerity**

In 1979, Amin's regime was overthrown in a war of liberation by Tanzania (Avirgan and Honey 1982). Unfortunately, this was a liberation war that did not bring peace. Violence and instability plagued Kampala and central Uganda in the early 1980s. In the 1980s and 1990s, the Ugandan government went through an aggressive series of structural adjustment policies that promoted financial austerity, the radical underfunding of basic government institutions, and the promotion of public-private partnerships. The government funded health sector went through an aggressive series of user fee schemes, which made the purchase of everyday medications challenging for patients (Dodge and Wiebe 1985). The 1980s marked a new era at the Uganda Cancer Institute. Olweny left the Institute for a position with the World Health Organization in Zambia and did not return. His long-term deputy and colleague, Dr. Edward Katongole Mbidde, took over the Institute as the country's only oncologist. During this time of social upheaval, financial distress, and an emerging HIV and AIDS epidemic, the Institute was folded into Mulago National Referral Hospital. The UCI saw its budget for drugs, equipment, and salaries dramatically decline.

At the same time, an epidemic of Kaposi's sarcoma and other HIV-related cancers emerged on the wards of the Lymphoma Treatment Center and Solid Tumor Center. Much of the data the UCI produced on the treatment, staging, and disease progression of Kaposi's sarcoma in the 1960s and 1970s provided the foundation of knowledge about the cancer in the 1980s for HIV/AIDS researchers, who saw this condition in young, homosexual men in urban centers of the United States and Europe (Olweny et. al. 1981). The young Ugandan women and men suffering from epidemic Kaposi's sarcoma, severe wasting, and opportunistic infections on the wards of the Solid Tumor Center provided an important point of reference for understanding the

vast differences and similarities between the clinical presentation of this illness in Africans and Americans that we would come to call AIDS (Serwadda et. al. 1985). A series of new international partners came to the Uganda Cancer Institute with a variety of small research projects. But the therapeutic optimism and the infrastructural investments that accompanied the establishment of the UCI in the 1960s was nowhere to be found. In a time before antiretroviral therapy development and then ARV access, Institute nurses and medical officers were left to tend to bed sores, dispense morphine, find saline bags if they were in stock, and make patients comfortable with the resources they had (Epstein 2007, Iliffe, 2006, Kaleeba 1991). The Institute became one of the key places on Mulago Hill where patients suffering from HIV/AIDS were “sent to die.”<sup>17</sup>

At the Institute, from the early 1980s to the late 2000s, cancer drugs and other sundries were rarely available to the public at no cost. Some staff recall receiving only one shipment of chemotherapy a year. They remember drugs running out within one month.<sup>18</sup> The pharmacy was rarely stocked with morphine or gloves. Financial austerity stripped UCI staff of their ability to provide resource-intensive care. The chemotherapy for debulking a late stage liver tumor or antibiotic ointment for infection prevention in KS lesions was simply not available unless families purchased it. Staff drew upon the remains of the Institute’s experimental infrastructure from the 1960s and 1970s. They relied on practices that signaled professionalism and excellence. Even if the chemotherapy stocks were empty, you could still perform a meticulous ward round. You could still write the order for a careful diagnostic work up of cancer stage and request a histopathology diagnosis, even if the pathology department itself was out of important reagents and that diagnosis languished for six months. You could spend the afternoon at the typewriter

writing letters to pharmacists to request cutting the price of cyclophosphamide for this one promising case of early stage Burkitt's lymphoma.<sup>19</sup>

But when Dr. Tony Owor\*, who now works at the UCI full time as an oncologist was asked to describe what they were doing at the UCI when he worked there as a medical student and volunteer medical officer in the early 2000s, he said, "I'm not sure what kind of care we were providing. But we weren't doing medicine."<sup>20</sup> Were you doing palliation? I asked. "There was nothing to palliate with. The work went on, but we had serious issues at that point."<sup>21</sup> At the same time, there were moments of reprieve when patients did survive and greatly improve. Owor said, "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."<sup>22</sup> As Owor 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 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. As Owor remembers, "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."<sup>23</sup>

Certain components of the experimental infrastructure developed in the 1960s at the Institute such as rigorous patient follow up and catering to the financial needs of patients, were impossible to maintain in this climate of austerity. At the same time, other aspects of the UCI's original infrastructure endured, such as the buildings themselves and the practicing high

standards. Those who worked with Dr. Mbidde remember him doing a daily “cleanliness round” in which he would walk into the wards and run his finger along the window ledges looking for dirt. He chided nurses if the toilets smelled. Thanks to an arrangement with a patron, patients were given tea and two meals a day. The work continued on.

### **Experiments and Infrastructures in Transition**

The Uganda Cancer Institute was thirty-seven years old, when Dr. Casper visited for the first time to assess the feasibility of doing cancer research in 2004. In one sense, he walked into a freezer graveyard, a decaying clinic where infrastructural and medical capacity had been systematically hollowed out by the violence of dictatorship, structural adjustment, the HIV/AIDS epidemic, and the erosion of research partnerships. But in another sense, he walked into something truly unique. This was a one of a kind African cancer hospital with case records stretching back to the 1960s. There were committed nurses who knew the side effects and dosing schemes of all of the major off-patent cancer drugs. They could administer these drugs through flimsy IV cannulas inserted into people’s hands on the first try. There were specialists like Dr. Mbidde, who arguably knew more about Kaposi’s sarcoma than most other clinicians across the world. This modest research partnership set up by the National Cancer Institute and the Makerere Department of Surgery had lived on thanks to an exceptional group of people. To his credit, this Casper recognized this. Recalling his first visit to the freezer graveyard, he said, “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?’”<sup>24</sup>

In the past ten years the UCI-FHCRC partnership invested over ten million US dollars for infrastructure improvements, oncology training, and research capacity building in an effort to avoid leaving another abandoned freezer in a dilapidated building. These investments in the

capacity to do cancer research have not been seen since in Uganda the original development of the Uganda Cancer Institute in the late 1960s. In May 2015, the UCI-Fred Hutch Cancer Centre opened officially. The FHCRC calls this facility a “strategic investment” to help “the UCI grow from a small facility with limited resources—including one oncologist—to a state-of-the-art UCI–Fred Hutch Cancer Centre, that can treat up to 20,000 patients a year (Engel 2015).” The new UCI-Fred Hutch Cancer Center literally stands on the foundation of the Lymphoma Treatment Center. It was bulldozed in 2013 to make way for a new era of clinical trials. I was not there, but apparently it only took half a day to bulldoze the Lymphoma Treatment Center. It came down easily. The bricks and the plaster 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. They called it, “The heart and soul of the Institute.”<sup>25</sup>

Today, the Uganda Cancer Institute is an experimental infrastructure undergoing profound transformations. The most visible changes are those in mortar and concrete, such as the demolition of the Lymphoma Treatment Center, the new six-story in-patient cancer hospital funded by the Ugandan government, new radiotherapy bunkers, and the UCI-Fred Hutch Cancer Center. These physical infrastructures developed to streamline research are transforming clinical care. Practices of ward rounding, for example, have shifted dramatically in the past five years. For thirty years, ward rounds were structured around a lone oncologist model of going from bed to bed with an entourage of nurses and medical students. Now groups of oncologists, nurses, pharmacists, and others sit down together on a weekly basis at tumor boards for pediatrics, lymphomas, gynecology, and other cancer services. At the same time, knowledge generated



about cancer in the 1960s and 1970s at the Uganda Cancer Institute continues to shape research and care. For example, many of the drug regimens that were studied at the UCI, both to treat Burkitt's lymphoma and to prevent relapse in the central nervous system, are still used as the standard of care on the wards (Orem 2008). The recently established Burkitt's Lymphoma Project also aims to revitalize many of the substantially atrophied structures that made Burkitt's lymphoma survival possible—timely pathology services, close ties with the surgery department, warm referral relationships with up country hospitals, and translators who can communicate with families. Technologies have changed practices of “making friendship.” Calling patients on mobile phones has replaced driving Volkswagen Beetles to villages in an effort to follow up with patients. A new infrastructure for experiments is slowly replacing the old.

## **Conclusion**

While this past decade brought a substantial reinvigoration of oncology capacity in Uganda, the future is not necessarily certain. It is not at all certain if funding for “global oncology” will greatly expand over the decades to come. The director of the American National Cancer Institute, Harold Varmus, recently stepped down from his position. This decision was made in part because of an extremely harsh funding environment for cancer research (Reardon 2015). 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.

Going forward, the Uganda Cancer Institute will face hard decisions about how to prioritize care and for whom. More and more Ugandans, including members of parliament and their loved ones, are receiving diagnoses of cancer that can be attributed to aging, transformations in diet, urbanization, toxic exposures, and infectious disease. One Member of

Parliament, Yefusa Okullo Epak, beloved and respected by many, died of lung cancer after spending many painful 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 in 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 with the roof caving in. It was his dying wish that his colleagues in the Ugandan government take cancer seriously, and that they allocate funds and resources accordingly.<sup>26</sup> Governmental support for public oncology services has greatly improved the UCI's drug supplies, salary allowances, and physical infrastructure. The Institute now operates with a dual mandate. It is both a center for cutting edge cancer research in eastern Africa and the only comprehensive government funded cancer facility for the Ugandan public.

It is an open question as to how this generation of Ugandan oncologists will negotiate the tension between meeting the requirements for clinical trials in cancer research and providing the supportive care necessary for patients and their families. The new UCI-Fred Hutch Cancer Center is a case in point. In contrast to the original Lymphoma Treatment Center and Solid Tumor Center, it is not a residential facility. The new building is designed for blood taking, chemotherapy 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 the questions are inevitable. Who should be granted a soft chair in a room with decent ventilation and privacy? Who should continue to receive their treatments on a hard plastic chair reminiscent of a waiting room at the bus park in the company of twenty other unfortunate passengers? My great concern that 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. It would certainly signal a profound continuity if the focus of the research at the new UCI-Fred Hutch Cancer Center remained solely on those two cancers that captured the imaginations of physician-researchers half a century ago. At the same time, creatively addressing the needs of patients and their families in broad terms made research at the Lymphoma Treatment Center in the 1960s and 1970s. If the past fifty years are any indication, Ugandan clinicians, patients, caretakers, and politicians will harness these collaborations and shape them to meet the needs of patients.

The UCI-Fred Hutch building will in all likelihood be a freezer in the freezer graveyard at some point. Or it will be bulldozed like the Lymphoma Treatment Center. In thinking about capacity and health in a sub-Saharan African context, and indeed across the globe, the Institute and its history offer a salient reminder that experiments create infrastructures. The material, technological, and infrastructural elements of research projects can change and atrophy over time. It is ultimately Ugandans who harness these collaborations, define the research agenda, and shape these periodic investments in experimental infrastructures to meet the needs of patients. For a recent visitor to the top of Mulago Hill, the UCI-Fred Hutch Cancer Centre looks entirely new. But these present day and profound investments in infrastructural and human resource capacity for cancer in Uganda build on more than fifty years of creatively providing cancer care, often in times of great crisis in the country.

#### Archives Consulted

Rhodes House Collection, Oxford University, Oxford, United Kingdom  
Uganda Cancer Institute Archives, Kampala, Uganda

Interviews Conducted by Author

\* denotes pseudonym

Moses Asiiimwe\* February 2012  
Tony Owor\* March 2012  
Charles Olweny May 2012  
John Ziegler June 2012  
Richard Morrow November 2012

## Bibliography

- Anderson, Warwick. 2007. *The Collectors of Lost Souls*. Baltimore: Johns Hopkins University Press.
- Avirgan, Tony and Martha Honey. 1983. *War in Uganda: The Legacy of Idi Amin*. Lawrence Hill and Co.
- Burchenal, Joseph. 1966. "Geographic chemotherapy--Burkitt's Lymphoma as a Stalking Horse for leukemia." *Cancer Research* 26: 2393-2405.
- Burkitt, Denis and Denis Wright. 1970. *Burkitt's Lymphoma*. London: Livingstone.
- Cambrosio, Alberto and Peter Keating. 2012. *Cancer on Trial: Oncology as a New Style of Practice*. Chicago: University of Chicago Press.
- Crane, Johanna. 2013. *Scrambling for Africa: AIDS, Expertise, and the Rise of American Global Health Science*. Ithaca: Cornell University Press.
- Davies, JNP et. al. 1958. "Cancer in Kampala: a survey in an underdeveloped country." *British Medical Journal* 439-443.
- Decker, Alicia. 2014. In *Idi Amin's Shadow*. Columbus: Ohio University Press.
- Dodge, Cole P. and Paul D. Wiebe, editors. 1985. *Crisis in Uganda: The Breakdown of Health Services*. Oxford: Pergamon Press.
- Doyle, Shane. 2013. *Before HIV: Sexuality, Fertility and Mortality in East Africa, 1900-1980*. Oxford: Oxford University Press.
- Droney, Damien. 2014. "Ironies of Laboratory Work in Ghana's Second Age of Optimism." *Cultural Anthropology* 29: 363-384.
- Edwards, Paul. 2010. *A Vast Machine*. Cambridge: MIT Press.
- Engel, Mary. 2015 a. "Building a legacy of hope: A Fred Hutch Doctor Changes Uganda and Uganda changes him." Fred Hutchinson Cancer Center News Service.  
<http://www.fredhutch.org/en/news/center-news/2015/02/hutch-uganda-world-cancer-day.html>  
Accessed August 22, 2015.

Engel, Mary. 2015 b. "An 'audacious and ambitious building' Seattle celebrates the opening of the new Uganda-Fred Hutch cancer center," Fred Hutchinson Cancer Center News Service. <http://www.fredhutch.org/en/news/center-news/2015/06/an-audacious-ambitious-building.html> Accessed June 22, 2015.

Epstein, Anthony and MA Eastwood. 1995. "Denis Parsons Burkitt. 28 February 1911- 23 March 1993." *Biographical Memoirs of Fellows of the Royal Society*. 14:89-102.

Epstein, Helen. 2007. *The Invisible Cure: Why we are losing the fight against AIDS in Africa*. New York: Picador.

Graboyes, Melissa. 2015. *The Experiment Must Continue: Medical Research and Ethics in East Africa, 1940-2014*. Athens: Ohio University Press.

Hansen, Holger and Michael Twaddle, editors. 1988. *Uganda Now: Between Decay and Development*. London: James Currey.

Hansen, Holger and Michael Twaddle, editors. 1991. *Changing Uganda: The Dilemmas of Structural Adjustment and Revolutionary Change*. London: James Currey.

Hansen, Holger. 2013. "Uganda in the 1970s: a decade of paradoxes and ambiguities." *Journal of Eastern African Studies* 7: 83-103.

Hunt, Nancy Rose. 1999. *A Colonial Lexicon*. Durham: Duke University Press.

Ilfie, John. 2002. *East African Doctors: A History of the Modern Profession*. Kampala: Fountain Press.

Ilfie, John. 2006. *The African AIDS Epidemic*. Oxford: James Currey.

Janzen, John. 1978. *The Quest for Therapy in Lower Zaire*. Berkeley: University of California Press.

Kasozi, A.B.K., Nakanyike Musisi, and James Mukooza Sejjengo. 1994. *The Social Origins of Violence in Uganda, 1964-1985*. Montreal: McGill-Queen's University Press.

Kaleeba, Noerine. 1991. *We Miss You All: AIDS in the family*. Kampala: The AIDS Support Organization.

Katabira, Elly et. al. 2000. *HIV Infection: Diagnostic and Treatment Strategies for Healthcare Workers*. Kampala: Uganda Ministry of Health.

Kyemba, Henry. 1977. *A State of Blood: The Inside Story of Idi Amin*. New York: Ace Books.

Lalani, Z. 1997. *Uganda Asian Expulsion: 90 Days and Beyond through the Eyes of the International Press*. Bloomington: Indiana University Press.

- Larkin, Brian. 2013. "The Politics and Poetics of Infrastructure." *Annual Reviews of Anthropology* 42: 327-343.
- Lawrance, Benjamin, Emily Osborn, Richard Roberts, editors. 2015. *Intermediaries, Interpreters, and Clerks. : African Employees in the Making of Colonial Africa*. Madison: Wisconsin University Press.
- Leopold, Mark. 2005. *Inside West Nile*. Oxford: James Currey.
- Livingston, Julie. 2012. *Improvising Medicine: An African Oncology Ward in an Emerging Cancer Epidemic*. Durham: Duke University Press.
- Lock, Margaret and Vinh-Kim Nguyen. 2010. *An Anthropology of Biomedicine*. New York: Blackwell Publishers.
- Mamdani, Mahmood. 1973. *From Citizen to Refugee: Uganda Asians Come to Britain*. London: Frances Pinter.
- Martin, David. 1974. *General Amin*. New York: Faber.
- Morrow, Richard et. al. 1967. "Survival of Burkitt's Lymphoma Patients at Mulago Hospital, Uganda." *British Medical Journal* 323-326.
- Mukherjee, Siddhartha. 2010. *The Emperor of All Maladies*. New York: Knopf.
- Mulemi, Benson. 2012. *Coping with Cancer and Adversity: Hospital ethnography in Kenya*. Leiden: African Studies Centre.
- Olweny, Charles et. al. 1971. "Adult Hodgkin's Disease in Uganda." *Cancer*. 27:
- Olweny, Charles. 1980. "The Uganda Cancer Institute." *Cancer* 37: 367-370.
- Olweny, Charles et. al. 1980. "Long-term experience with Burkitt's lymphoma in Uganda." *International Journal of Cancer* 26: 260-265.
- Olweny, C., M. Hutt, and R. Owor. 1981. "Kaposi's Sarcoma." *Antibiotics and Chemotherapy*. 29.
- Ombongi, Kenneth. 2011. "The Historical Interface between the State and Medical Science in Africa: Kenya's Case." in P. Wenzel Geissler and Catherine Molyneux. *Evidence, Ethos, and Experiment: The Anthropology and History of Medical Research in Africa*. New York: Berghan Books.
- Orem, Jackson et. al. 2007. "Burkitt's lymphoma in Africa, a review of the epidemiology and etiology." *African Health Science* 7: 166-75.

Orem, Jackson and Henry Wabinga. 2009. "The roles of national cancer research institutions in evolving a comprehensive cancer control program in a developing country: experience from Uganda." *Oncology*. 77: 272-80.

Peterson, Derek and Edgar Taylor. 2013. "Rethinking the state in Idi Amin's Uganda: the politics of exhortation." *Journal of Eastern African Studies* 2: 58-82.

Peterson, Kristin. 2014. *Speculative Markets: Drug Circuits and Derivative Life in Nigeria*. Durham: Duke University Press.

Petryna, Adriana. 2009. *When Experiments Travel*. Princeton: Princeton University Press.

Reardon, Sarah. March 4, 2015. "Harold Varmus to resign as head of US Cancer Institute." *Nature*.

Redfield, Peter. 2013. *Life in Crisis: The Ethical Journey of Doctors Without Borders*. Berkeley: University of California Press.

Schumaker, Lynn. 2002. *Africanizing Anthropology*. Durham: Duke University Press.

Serwadda, David et. al. 1985. "Slim disease: a new disease in Uganda and its association with HTLV-III infection." *The Lancet* 326: 849-852.

Southall, Aidan and Peter Gutkind. 1957. *Townsmen in the Making: Kampala and its suburbs*. Kampala: East African Institute of Social Research.

Starr, Susan Leigh. 1999. "The Ethnography of Infrastructure." *American Behavioral Scientist* 43: 377-391.

Stoler, Ann. 2008. "Imperial Debris: Reflections on Ruins and Ruination." *Cultural Anthropology* 23: 191-219.

Street, Alice. 2014. *Biomedicine in an Unstable Place: Infrastructure and Personhood in a Papua New Guinean Hospital*. Durham: Duke University Press.

Tilley, Helen. 2011. *Africa as a Living Laboratory: Empire, Development, and the Problem of Scientific Knowledge, 1870-1950*. Chicago: University of Chicago Press.

Tripp, Aili Mari. 2010. *Museveni's Uganda: Paradoxes of Power in a Hybrid Regime*. New York: Rienner Publishers.

Varmus, Harold. 2014. "Medical Research Centers in Mali and Uganda: Overcoming Obstacles to Building Scientific Capacity and Promoting Global Health." *Science and Diplomacy*. 3.

- Vaughan, Megan. 1992. *Curing Their Ills*. Palo Alto: Stanford University Press.
- Wabinga, Henry et. al. 2014. "Trends in the incidence of cancer in Kampala, Uganda. 1991-2010." *International Journal of Cancer* 135: 432-439.
- Walusansa, Victoria et. al. 2012. "Burkitt lymphoma in Uganda, the legacy of Denis Burkitt and an update on disease status." *British Journal of Haematology* 156: 757-760.
- Wendland, Claire. 2010. *A Heart for the Work: Journeys through an African Medical School*. Chicago: University of Chicago Press.
- White, Luise. 2000. *Speaking with Vampires*. Berkeley: University of California Press.
- Whyte, Susan, editor. 2014. *Second Chances: Surviving AIDS in Uganda*. Durham: Duke University Press.
- Williams, Arthur. 1952. "The History of Mulago Hospital and the Makerere College of Medicine." *East African Medical Journal* 29: 253-263.
- Zeller, Diane. 1971. "The Establishment of Western Medicine in Buganda." PhD. Diss. Columbia University.
- Ziegler, John et. al. 1970. "Clinical features and treatment of childhood malignant lymphoma in Uganda." *International Journal of Cancer*. 15: 415-425.
- Ziegler, John et. al. 1979. "Cure of Burkitt's Lymphoma: Ten-year Follow-up of 157 Ugandan Patients." *The Lancet* 314: 936-938.

## Notes

---

<sup>1</sup> These estimates come from the Uganda Cancer Institute's current director, Dr. Jackson Orem.

<sup>2</sup> This information is current as of August 2016 and verified in informal discussions with UCI staff. See also: Dana Benson, "Baylor and Texas Children's Hospital partner to bring fellowship training in oncology and hematology to East Africa," Baylor College of Medicine Press Release, September 20, 2016, <https://www.bcm.edu/news/pediatrics/training-oncology-hematology-east-africa>. Accessed December 9, 2016.

<sup>3</sup> Interview with Tony Owor,\* March 2012.

<sup>4</sup> Scholars are turning to hospitals as important sites of political, social, technological, and intimate interactions. Path-breaking works include Hunt (1999), Livingston (2012), and Street (2014).

<sup>5</sup> Albert Cook created these records. Cook was a Christian Missionary Society missionary and medical physician, who founded Mengo Hospital in 1897. The hospital's mission was primarily concerned with venereal disease, maternal health, sleeping sickness, and immorality. While the staff saw only a sliver of the general population surrounding the greater region of Kampala, some patients came to receive care for large tumors and cancers. For more on the history of Mengo Hospital and missionary medicine in general, see Vaughan (1992).



---

<sup>6</sup> Denis Parsons Burkitt Papers, Answers to Aide Memoire, Mss. Afr.s. 1872/20, Rhodes House, Oxford, United Kingdom.

<sup>7</sup> Interview with John Ziegler, June 2012.

<sup>8</sup> Ibid.

<sup>9</sup> Interview with Moses Asimwe,\* February 2012.

<sup>10</sup> Ibid.

<sup>11</sup> These case reports are still available in the Uganda Cancer Institute's institutional archives, which are not formally cataloged. I thank Dr. Jackson Orem and Dr. Victoria Walusansa for granting me the permission to review these materials.

<sup>12</sup> Interview with Charles Olweny, May 2012. Olweny did not further elaborate what he meant by "capacity building." It is hard to know if he was applying this gloss retrospectively, or if that was the actual language being used by colleagues in the late 1960s and early 1970s.

<sup>13</sup> Ibid.

<sup>14</sup> Ibid.

<sup>15</sup> Uganda Cancer Institute Annual Report, 1972-1973, Uganda Cancer Institute Archives.

<sup>16</sup> "Letter to the General Manager, Food and Beverages LTD, from Professor Charles Olweny, April 20, 1976," Uganda Cancer Institute Archives.

<sup>17</sup> This account is derived from interviews and fieldnoted conversations with staff who worked at the UCI in the 1980s, 1990s, and 2000s. They are anonymized here to protect their privacy.

<sup>18</sup> 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.

<sup>19</sup> For an account of the resilience of health workers in severely underfunded contexts, also see Wendland (2010) and Livingston (2012).

<sup>20</sup> Interview with Tony Owor,\* March 2012.

<sup>21</sup> Ibid.

<sup>22</sup> Ibid.

<sup>23</sup> Ibid.

<sup>24</sup> This anecdote is drawn from fieldnotes and several conversations with Corey Casper in 2012 and 2013. See also: Mary Engel, "Building a legacy of hope," Fred Hutchinson Cancer Research Center, February 3, 2015, Accessed August 17, 2015 <http://www.fredhutch.org/en/news/center-news/2015/02/hutch-uganda-world-cancer-day.html>

<sup>25</sup> This account is derived from fieldnotes and conversations with UCI staff in 2013.

<sup>26</sup> Joyce Namutebi and John Odkyek, "Oyam South MP Okullo Epak dead," *New Vision*, April 25, 2007 Accessed August 17, 2015 <http://www.newvision.co.ug/D/8/13/561892> Charles Mwanguhya, "Uganda: Faire Thee Well Dr. Okullo Epak," *Daily Monitor* May 2, 2007 Accessed August 17, 2015 <http://allafrica.com/list/aans/post/full/day/20070502.html>. Fieldnoted discussion with Dr. Casper, June 2012, Interview with Tony Owor,\* March 2012.