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The Cancer War(d): Onco-Nationhood in Post-Traumatic Rwanda

A dissertation presented

by

Darja Djordjevic

to

The Department of Anthropology

in partial fulfillment of the requirements
for the degree of
Doctor of Philosophy
in the subject of
Anthropology

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The Cancer War(d): Onco-Nationhood in Post-Traumatic Rwanda

Abstract

In Africa, the effects of the HIV/AIDS pandemic, rapidly expanding industrial and extractive economies, uncontrolled economic growth, environmental and lifestyle changes, and the rising age of populations with better access to medicine have occasioned rising rates of cancer. Rwanda's national cancer program has been hailed as a unique example of how to build clinical oncology into a public healthcare infrastructure. Using ethnographic data, interviews, and historical archives, I address three sets of questions: 1. What historical, economic, social, and political factors have shaped the development of the country's cancer program? 2. How do local clinicians and patients experience cancer as a treatable chronic disease? And how is that experience affected by the development of a national oncology infrastructure and new biomedical technologies? 3. As an instance of the transnational private-public partnerships characteristic of global health interventions in postcolonial Africa, what successes, limitations, and challenges does this cancer program present for envisioning oncology programs elsewhere in the global south? What are the ethical, political, and epistemological stakes involved in different models of cancer care? This project contributes to a new chapter in medical anthropology, one focused on rising rates of cancer in contemporary Africa.

I argue that Rwanda's cancer project is an exercise in the construction of a new sense of sovereignty, rendered through the politics of life as onco-nationhood; that it is an effort to create a postcolonial polity whose citizen body is gifted care of a international caliber provided by a paternal state. In a critical moment of post-traumatic social reconstruction, national biomedicine is becoming the entity through which government seeks to fuse sovereign statehood and nationhood in the cause of a healthy Rwandan future. Theorizing this relationship holds at least one key to developing an anthropology of cancer in contemporary Africa.

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Introduction

I. Background

What does 21st century African nationhood have to do with cancer? What can we learn about sovereignty and techno-modernity from the national oncology program of Rwanda, a poor, largely rural and agrarian, postcolonial and post-genocide nation? How has cancer emerged to shape a new form of biopower in a country whose name has long rolled off tongues in a fluid list of the 20th century's genocides? This chapter grapples with proposed answers to such questions and why they matter.

Rwanda is often described as a poor, landlocked, agrarian country about the size of Maryland, nestled in the borderlands of East and Central Africa—its regional assignation varies by source and discipline. From 1885-1918 it was part of German East Africa, and during World War I, in 1916, came under Belgian administration through a League of Nations mandate as part of the joint Territory of Ruanda-Urundi. Rwanda established itself as an independent republic in January of 1961. It is also a nation that emerged from a catastrophic civil war and genocide only twenty-one years ago—widely cited figures state that between 800,000 and one million Rwandans were killed, in what official histories (in Rwanda and beyond) have since declared a Tutsi genocide.[1] The United Nations, as well as superpowers like the U.S., Britain and France, did not intervene and stop the genocide in time, leading to a widespread sense of guilt and political failure expressed in accounts like that of former UN General Roméo Dallaire, who was the chief of the Rwanda mission at the time.[2] In the months and years immediately following the end of the genocide in July 1994, international

[1] There is a wealth of scholarship on the 1994 Rwandan civil war and genocide, shared amongst the fields of anthropology, history, sociology, political science, human rights law, and legal studies. I refer the reader to the following sources for an in-depth analysis of the genocide and its aftermath: [Scott Strauss, Thomson, Longman, Vansina, Reytnens, Newbury and Newbury, etc., etc.].
[2] Add Dallaire citation.

relief efforts and aid poured into the country. Like all infrastructure in Rwanda, the health care system lay in utter ruin. This devastation was compounded by a sudden rise in HIV prevalence, directly connected to the high rates of rape during the genocide. In this setting, Rwanda became host to a huge number of non-governmental organizations (NGOs) offering basic primary health care, care for orphans, nutrition aid, shelter, and other fundamental services. It was later on that Rwanda would begin to audit the NGOs working in country.

Cancer care in Rwanda has been a transnational assemblage from the start. Some of its origins are located in Boston, Massachusetts, within the teaching hospitals of Harvard Medical School and the NGO Partners In Health (PIH). PIH was founded in 1987 by Paul Farmer, Jim Yong Kim, Ophelia Dahl, and Thomas White. Farmer and Kim are physician-anthropologists by training, each having earned an MD at Harvard Medical School as well as a PhD in social and medical anthropology in the Department of Anthropology within Harvard's Graduate School of Arts and Sciences. They were students in the early days of Harvard's joint program, working closely with Professors Arthur Kleinman, Leon Eisenberg, Byron and Mary-Jo Good, who worked to build a community of scholars at the intersection of medicine and social sciences, along with a supportive intellectual climate that would endure. Dahl had met Farmer in Haiti during a volunteering stint just after high school (?) while he was engaged in his first research endeavor there. The late Thomas White was a wealthy Boston-based philanthropist who contributed seed funding after meeting Farmer, then already rotating through the Harvard-affiliated Brigham and Women's Hospital as a trainee.[3]

[3] The early days of PIH and Paul Farmer's career are recounted by Tracy Kidder's in the biography *Mountains Beyond Mountains: The Quest of Dr. Paul Farmer, a Man Who Would Cure the World* (Random House, 2003).

Partners In Health started its work in rural Haiti, establishing a primary health care center and broad HIV and tuberculosis treatment program. The clinical care of PIH and a system of community health workers who are employees. These *accompagnateurs*, as they are known in the PIH lexicon, were and remain central to the social medicine model of integrated community-based health care that PIH piloted in Haiti, expanded, and later implemented in the many other sites as PIH expanded its work: Peru, Mexico, Russia, Boston, Malawi, Lesotho, and Rwanda.

From the start, Partners In Health was an NGO with an explicit commitment to building enduring health care infrastructure as a public and long-term system rather than delivering emergency medical care and relief in the style of Doctors Without Borders. PIH's mission and approach has been deeply shaped by the currents of thought and ideological commitments that Farmer, Kim and Dahl developed as young student-scholars and activists. These include a rather holistic, socially minded etiology of disease (stretching back even to Rudolph Virchow), human rights theory, liberation theology, and a general insistence that the world's poor deserve access to the same care and technologies as the rich. One part of this approach involves reiterating time and again that civil and political rights like freedom of press or speech, or the right to vote, are evacuated of meaning and value in the absence of social and economic rights like access to health care, education, livelihoods, food and housing. PIH was also adamant in implementing a holistic model of HIV care, and in setting an example for HIV/AIDS care in the global south by not only providing patients with anti-retroviral medications but also ensuring that they have access to clean water and food. Another key aspect of the PIH approach to medical care is that the organization believes that no patient should be turned away, and over the years has actualized a response that involves

doing everything possible for any patient that shows up on a PIH clinic doorstep, regardless of how complicated or unusual the patient's condition may be, particularly in the resource-poor settings of scarcity where PIH works. Thus, the manner in which PIH expands its programs has always emerged out of a grounded philosophy that responds actively to what the community defines as its needs and to the pathologies that surge forth as new epidemics, rising incidences, or simply diseases that become visible as patients gain greater access to health care services and seek them out. In the past seven years PIH has developed a non-communicable disease program in large sites like Haiti, Malawi and Rwanda.

II. A Partners' History of Cancer in Rwanda

Partners In Health arrived in Rwanda in 2005, with Dr. Farmer as a major member of the delegation. As the official story goes, this was at the invitation of the Minister of Health. In tandem with their general approach, PIH asked that the Ministry take them to the most impoverished and devastated region in terms of health care services. They were taken to Rwinkwavu District Hospital, in Eastern Province[4], an area where the majority of the population was comprised of Rwandans displaced by the war and genocide, as well as former exiles. By the end of 2006, PIH had renovated Rwinkwavu District Hospital (this included opening a pediatric ward, an inpatient malnutrition center and an operating suite), improved upon staffing and facilities at other sites Kirehe District (also in Eastern Province), expanded access to anti-retrovirals in these catchment areas, developed full care for pediatric HIV/AIDS

[4] Since the genocide the Rwandan state, led by President Paul Kagame's Rwandan Patriotic Front, has reorganized Rwanda's administrative/political cartography. The country is now divided into 5 provinces: Northern, Southern, Eastern, Western, and Kigali (Central).

patients, nutritional support for HIV and TB patients, and launched the Inshuti Mu Buzima Program on Social and Economic Rights. The latter program focused on building houses, paying secondary school fees, established a carpentry and welding workshop (locals then and now build furnishings for the PIH-supported clinical sites), and issued microcredit loans.[5] These early achievements were reached in collaboration with a variety of donors and transnational institutions providing material resources, logistical support, and expertise: the Clinton Foundation and the Clinton Health Access Initiative, UNICEF, the World Food Program, the Clinton Hunter Development Initiative, Bill and Melinda Gates, and Rwanda's Ministry of Health (a permanent partner), amongst others.

In late 2007, PIH began working with the Rwandan government on rebuilding the health system of Burera District, in Northern Province. Again in collaboration, this time with Rwanda's Ministry of Health, the Clinton Foundation, the MASS Design Group, Brigham and Women's Hospital, and private philanthropists, PIH helped to lead the construction of a new Butaro District Hospital. It was built with the explicit goal of establishing Butaro as a comprehensive, tertiary hospital serving Rwanda but also patients from neighboring eastern Congo and Burundi, and setting an example of what is possible for the East African region. The MASS Design Group, which designed and oversaw construction of the hospital (in the process providing 4000 local jobs), was founded by graduate students at Harvard's Graduate School of Design who had also been educated as critically minded social scientists actively interested in the salience of architecture and design for any social justice project. Burera District had

[5] More precise figures of patients served and the like can be found at [http://www.pih.org/blog/inshuti-mu-buzima-update-january-2007.] Accessed October 8, 2015. In general, a plethora of reports and articles are regularly published on PIH's website at [http://www.pih.org].

been one of the last two districts in Rwanda without a public hospital to serve a local population of 340,000 people.

The land on which the new hospital was built had formerly been home to a military outpost, and the site of much genocidal violence in 1994. Therefore, from the start the Rwandan and American partners in this venture were openly invested in the symbolic and sociopolitical valence of building a high-quality, in certain ways cutting-edge public hospital on land marked materially and morally by the nation's recent, horrifically violent and rupture-replete past. The hospital was inaugurated in January 2011. President Paul Kagame cut a blue ribbon to open the hospital. In July 2012, the Butaro Cancer Center of Excellence was opened. Rwanda's Honorable Minister of Health, Dr. Agnes Binagwaho officiated. Accompanying her for an inaugural tour of the hospital were Dr. Paul Farmer and Ophelia Dahl, Bill and Joyce Cummings of the Cummings Foundation, the Governor of Rwanda's Northern Province, Mr. Aime Bosenibamwe; and the Mayor of Burera District, Mr. Samuel Sembagare. While the involvement of the Clinton Foundation in Rwanda's health sector is laudable in various ways and ongoing, one cannot help but acknowledge a certain irony in the transformed status of former President Clinton. In a Janus-faced kind of gesture, he is now recognized as one of the heroic figures behind global health efforts in Rwanda, despite the fact that his administration was condemned for its failure to intervene in Rwanda in 1994. Many Rwandans refer to Butaro Hospital as one built by "Americans" and "Clinton," and it maintains a good reputation thus far as a place where patients are likely to be well-cared for regardless of their economic means, and with more financial aid than usual. As for the decision to establish the first public cancer referral center at Butaro, in private settings I have heard Rwandan and American clinicians question it

given that Butaro is in the far north of the country, a two and a half-hour drive (half of which is on steep mountain dirt roads) from Kigali, and therefore an eight to ten-hour trek for patients living far south or far east. Many feel that Kigali would have been a more pragmatic and equitable choice, as the capital is in the center of Rwanda and therefore relatively equidistant for citizens living in the far reaches of the country.

While PIH clinicians—locals and Americans—surely encountered cancer amongst their patients and communities within Haiti (and later elsewhere) during the first twenty-five years of their work, it was in the late 2000s that PIH got interested in developing care for cervical and breast cancer in its Haiti and Rwanda sites. I learned of their early efforts with screening and ad-hoc treatment (with chemotherapy drugs donated from the Dana Farber Cancer Institute in Boston), as well as ideas about how to move forward when I attended the conference of a newly created Global Task Force for Cancer Care and Control (GTFCCC) on Harvard Medical School's campus in November 2009. I was a first-year medical (MD-PhD) student on that campus at the time, fresh from recent experiences working with African refugees in France for my Bachelor's and Master's in anthropology, and searching for an African context that I might pursue as my doctoral fieldsite. At the conference PIH clinicians made presentations summarizing a small contingent of cervical and breast cancer patients presenting to PIH-supported clinics in Haiti and Rwanda, and summarized the care they were able to provide. They also gestured towards preliminary efforts in prevention and education for women: plans for rolling out interventions like visual inspection with acetic acid (VIA) and cryotherapy for cervical cancer, and clinical breast exams (CBEs). These efforts piqued my interest and in the summer of 2010, I was fortunate to spend seven weeks at Butaro Hospital as a volunteer also pursuing

some preliminary research. At the time staff was still working in an older, dilapidated one-story structure that served as Butaro Hospital, on a small campus with adjacent small brick buildings that served as a family planning clinic, outpatient clinic, and laboratory. That summer, PIH led a Ministry-supported pilot program in cervical cancer screening and treatment for Burera District which entailed training a cohort of nurses, doctors and midwives from the area in VIA, cryotherapy, and CBEs, and in addition educating community health workers about cervical cancer. As a team we traveled to various health centers for the latter sessions and discussions, and coordinated a two-week training of the cohort using the JHPIEGO curriculum, developed by the experts at the school of public health at John Hopkins University. The 'Master Trainer' was an Anglophone obstetrician-gynecologist from Malawi, and because all the Rwandan clinicians spoke French (having been educated in French) I actually served as the live English-French interpreter during the lectures and didactic sessions throughout the two weeks.

Yet again, the cervical cancer prevention pilot program was a transnational effort with a variety of partners like WeACT, an NGO focused on women's health interventions, Qiagen, a Dutch-German biotechnology firm specializing in molecular sample and assay technologies. It was fascinating to be involved in the JHPIEGO training, which ended with a practicum in the form of a few days of screening local women using the newly learned techniques of VIA and cryotherapy, on site in a couple of the old red brick clinic buildings at Butaro. By the end of the practicum a few hundred women had been screened by the cohort. For many of the women, who ranged in age from their 20s to their 60s, the screening comprised the first-ever clinical pelvic exam of their lives. Naturally such an exam uncovers other gynecological

pathologies, including sexually transmitted infections (other than human papilloma virus which is implicated in the development of cervical cancer), and pathological anatomy such as a prolapsed uterus, or vaginal fistula. Some of the women screened were discovered to have such conditions and were referred to Butaro Hospital for treatment. As I recall there were two cases of potential cervical cancer requiring further investigation. In sum, the results of the pilot program suggested, as various supporters of the district-wide initiative believed, that introducing cervical cancer screening (a "vertical" intervention) would force a greater investment in and expansion of women's health services (a "horizontal" effect) within Rwanda.[6] That summer's cervical cancer screening initiative also introduced a classic, imperative ethical and pragmatic question: screening for any disease leads to greater rates of diagnosis, which then engenders a demand for treatment. During the screening, the few cases of cervical cancer uncovered were referred to Butaro Hospital.

At the time, the Dana-Farber Cancer Institute was donating chemotherapy to the PIH-supported hospitals (Butaro and Rwinkwavu) as needed for individual oncology patients, but there wasn't a steady stock of oncology drugs, nor a public, general oncology program. Let us recall, the inauguration of Butaro Cancer Center of Excellence happened only two years later, in July 2012. This dissertation is based on 12 months of fieldwork and archival research from July 2014 until August 2015, and approximately 7 additional months of research and volunteering from June 2010 until February 2014. During my fieldwork year (2014-15) I was based at the Butaro Cancer Center of Excellence at Butaro Hospital and the Rwanda Biomedical Center in Kigali. I

[6] In the lexicon of public health, a "vertical" health intervention refers to one that is disease-specific, like an HIV/AIDS initiative, as opposed to a "horizontal" health intervention, like building a primary health care system. Public health scholar Dr. Julio Frenk explains this schema in his work on the diagonal approach to building public health systems (Frenk 2006).

pursued cancer program policy events around the country, which mostly occurred at various hospitals in the cancer network, at the Ministry of Health in Kigali, and at national workshops and meetings in Musanze (the capital of Musanze District in Northern Province, this city was previously known as Ruhengeri).

This course of events that I have attempted to summarize above leads us to a burning question: why did oncology make its way onto the national public health agenda of Rwanda so quickly? In private, some leaders within PIH were adamant that they, in association with Harvard's academic clinical centers (Brigham and Women's Hospital and Dana-Farber Cancer Institute) had been pivotal in advancing the cancer agenda while working with the Ministry of Health. They saw their efforts as central to this development and were somewhat dismissive of having an anthropologist interrogate the reasons behind Rwanda's investment in a public oncology program. Other PIH and Harvard clinicians were forthright in their opinion that the term 'partnership' had been evacuated of its authentic meaning in the current Rwandan context: as one American physician put it, "It's not about building partnerships, it's about doing exactly what the government says!" Objectively, PIH and Harvard's medical centers did play a central role in catalyzing the initiation of the national cancer program, and are yet heavily implicated in it as expert trainers, providers, and planners. Yet this does not diminish the salience of asking why cancer and why now, in Rwanda?

Chapter 1 Techno-Modernity and Onco-Nationhood in Rwanda

I. Theoretical Foundations: Sovereignty, Biopower, Techno-Modernity, Onco-Nationhood, the Politics of Life

This brings us to the central preoccupation of Chapter 1, which is to establish an analytical and theoretical framework that will undergird the various sections of this dissertation. The explicit aim is to understand how the national cancer program makes legible that Rwanda is an African nation constructing a certain techno-modernity, and choosing to do so as a nation. This telos of techno-modernity is meant to pull Rwanda onto the Enlightenment side of an old division between those nations that are Enlightened and those that are not. The 'techno-' in techno-modernity is reflected in various iterations of Rwanda's move to become 'the Singapore of East Africa': the effort to ramp up the quality and breadth of internet services, develop young citizens as part of a new knowledge-based economy, and even recent reports in *The Guardian* and on CNN.com on how Rwanda has been selected as the world's first 'drone-port' to deliver medical supplies.[7]

However, the technological contours of oncology are particular, despite their embedment in Rwanda's broader health sector transformation beginning in the early 2000s. Oncology is part of the broader imbrication of nationalism and big science. Rwanda's cancer project is, quite deliberately, an exercise in the construction of a new sense of sovereignty, rendered through the politics of life as onco-nationhood; that it is an effort to create a postcolonial polity whose citizen body is gifted care of an international caliber provided by a paternal state. In a critical moment of post-

[7] See [http://www.theguardian.com/technology/2015/sep/30/rwanda-chosen-for-worlds-first-drone-port-to-deliver-medical-supplies] and [http://www.cnn.com/2015/10/05/architecture/gallery/rwanda-droneport-foster-epfl/]. Accessed October 12, 2015.

traumatic social reconstruction, national biomedicine is becoming the entity through which government seeks to fuse sovereign statehood and nationhood in the cause of a healthy Rwandan future. Thus it is that a politics of life makes nationhood and medicine co-constitutive. Theorizing this relationship, against a background of heavy international involvement, holds at least one key to developing an anthropology of cancer in contemporary Africa.

II. Sovereignty and Onco-Nationhood

The concept of sovereignty has deep roots in Western political philosophy. It is classically traced back to Thomas Hobbes, who in *The Leviathan* (1651), set out a model of the absolute sovereign. He argued that in every human society with a system of law and regardless of its political organization (whether a democracy or an absolute monarchy), there has always been a relationship between subjects who are regularly obedient and a sovereign who is obedient to no one and owes no allegiance of any kind to any superior.

Brenda Chalfin offers a valuable analysis of sovereignty in neoliberal Ghana through her study of customs officials and other bureaucrats working along national borders. In considering how the Customs regime reflects sovereign statehood in Ghana, she reminds us of the imperative to treat sovereignty as a layered reality, asserting how "past and current regimes operate individually and in combination" (Chalfin 2010: 86). This notion of a plurality of regimes is important for understanding the social reality of public oncology in Rwanda, and the connection between national health and sovereignty, despite the constant depiction of Rwanda as a state run and organized solely by President Kagame's RPF (Rwandan Patriotic Front) party with no

room for political plurality. She emphasizes that elements of earlier regimes—such as the colonial and nationalist ones—are difficult to disentangle from one another because certain logics of governance may be shared across time and regimes. One of Chalfin's most critical points is about the always incomplete establishment of sovereignty:

> Thus the case of Aflao suggests that despite the proliferation of state installations and interventions at the frontier, the achievement of sovereignty is always incomplete, both unfinished and unstable. The changeable nature of territorial sovereignty can be attributed only in part to the inherent challenge posed by governing that which is mobile--a problem states have, to some degree, managed for centuries (Ruggie 1993; Torpey 2000)--not least of which, modern African states, from the start cross-cut by highly durable social and material circuits. Rather, in nations like Ghana, these tensions are exacerbated by the country's postcolonial condition. The problem lies not in the intransigence of local political conventions and elites (pace Boone 2003) or the artificiality of the boundaries imposed by colonial regimes--a liability that border residents have turned to their advantage. Instead, it stems from the postcolonial state's very susceptibility to reform, ever invested in 'fixing' the state, in the full sense of the term." (Chalfin 2010: 86-7)

This concept of sovereignty as "unfinished and unstable" might help us think about the particular valence of public oncology and the national health care infrastructure in Rwanda, a state that is not only postcolonial but also operating at a historical juncture that is post-conflict and post-genocide. The stewardship of the Ministry of Health and its strict jurisdiction of health-sector projects may indeed index a particular effort to "fix" the Rwandan state. Finally, Chalfin makes a highly pertinent point about the fragmented sovereignty in a context where a projected image of an omnipotent sovereign state is mediated by the reality of dependence on foreign capital and expertise:

> Both strengthening and undermining the supremacy of the state, even as Tema's maritime frontier remained a site for the expression of the state economic and territorial control, this sovereignty had a different genesis and a different configuration than in the past. Facilitated by and reinforcing the consolidation of state power, the new inspection agreement fostered an image

> of a strong and all-knowing state. Not only could this entity harness the penetrating vision of a cutting-edge technology, this was a state that could make and break rules and interests, a state that could summon international entities to serve its interests, a state that could attract resources away from other states. But given the veiled kinship with foreign capital and expertise on which it depends, such an aura of sovereign renewal--geopolitical, territorial, and technological--comes at the cost of less exclusive control. As a result, the assertion of state authority via the DI system belies a process of contestation, not consensus. We see the fragmentation of sovereign power rather than its constitution from a single source." (Chalfin 2010: 179)

The Rwandan state does configure itself it as one that can "harness the penetrating vision of a cutting-edge technology…make and break rules and interests…summon international entities to serve its interests" and yet, the public oncology program is one initiative that is heavily dependent on foreign capital and expertise. One crucial task is to determine whether Rwanda's sovereignty is fragmented, given my argument that a new sense of sovereignty is rendered through the politics of life as onco-nationhood. In distilling Chalfin's analysis we might conclude that her most important insights are the acknowledgement that the sovereignty of a powerful postcolonial state may integrate various logics and legacies across time and space, North and South, and the idea that even sovereignty that feels consolidated is made and sustained from various sources. In the case of Rwandan oncology, I foreground the transnational collaborations with institutions and expert-clinicians in Boston (as well as the US and Europe more broadly) as projects and actors that contribute in tangible, regular ways to the imagination and achievement of onco-nationhood.

III. Biopower, Biocapital

In the introduction to their first edited volume, *States of Imagination: Ethnographic Explorations of the Postcolonial State*, Thomas Blom Hansen and Finn Stepputat initiate

their discussion with the idea that, "Whether we agree on what the state means or not, "it" is, nonetheless, central to all that is *not* state: civil society, NGOs, the notion of a national economy, the market, and the sense of an international community" (Hansen and Stepputat 2001:2). I wish to think critically about the nexus of the state and non-state in my context: in many ways, the Rwandan state harnesses its non-state resources and expertise, local and foreign, in order to pursue the new project of sovereignty that I'm trying to unpack. Rwanda's public oncology program resembles many other global health initiatives in its transnational configuration, private-public partnerships, and commitments to "task-shifting" and "capacity building." However, the Rwandan case is significant in part because of the strong state that claims itself as the guarantor of rights in the longue durée, such as the right to cancer care. The Minister of Health, Dr. Agnès Binagwaho, is hailed as a global health leader preaching the gospel of accountability, transparency, and the numbers to prove it like striking reductions in all-cause mortality rates, near universal ARV coverage, and universal health insurance. There are also formal rules meant to foster a national science—medicine, public health, epidemiology—such as the requirement to conduct any research with a Rwandan co-PI, co-publish results, and submit data to the national health IRB for periodic review.

These facts are part of the reality that my data describes, and deconstructing them is key to understanding what the delivery of oncology has to do with nationhood, society, and citizenship in post-genocide Rwanda. Hansen and Stepputat further assert that any serious analysis of the state "requires that one study how the state tries to make itself real and tangible through symbols, texts, and iconography, but also that one move beyond the state's own prose, categories, and perspective and study how the

state appears in everyday and localized forms" (Ibid.:5). How does the Rwandan state make itself real and tangible through the symbols, texts, and iconography of oncology, which is gifted to the population as a form of care by a state that sees its citizens as deserving "first world" forms of care? In other words, what state and nation-making efforts can we read in cancer program negotiation meetings (for drugs, radiation, and specialists), policy documents, and the national trainings of the first generation of Rwandan oncology practitioners? Since cancer comprises only a small proportion of the overall disease burden in Rwanda, many of whose sufferers have long gone invisible and undiagnosed, what is special about cancer with respect to biopower and the state?

Hansen and Stepputat define "three practical languages of governance and three symbolic languages of authority as particularly relevant for an ethnography of the state," categorizing them as follows: "The first three are technical languages, the Foucauldian aspect, one may say, of practical governance, discipline, and productive biopolitical governance; the latter three are symbolic languages aiming at reproducing the imagination of the state as that specific authoritative center of a society," including "the institutionalization of law and legal discourse as the authoritative language of the state and the medium through which the state acquires discursive presence and authority to authorize [and] the materialization of the state in series of permanent signs and rituals: buildings, monuments, letterheads, uniforms, road signs, fences" (Ibid.:7-8). Cancer care is a national endeavor that implicates discipline, productive biopolitical governance, and national laws affecting the amount of opiates that can be used at a particular hospital—as such my understanding of the Rwandan state's

implication in oncology and the national imaginaries that accompany it requires an analysis of such languages.

The authors also cite Helmut Wilke as arguing that "the new role of the state is...to supervise governance by semiprivate organizations, local authorities, self-governing bodies of all kinds, NGOs, and so on, rather than to actually govern directly" (Ibid.:15). Through an examination of Rwanda's heavily collaborative cancer program, my aim is to explore forms of direct and indirect governance that the state perpetuates in this program, and to argue that oncology allows for actualization of a certain politics of life. Partha Chatterjee challenges our conceptual apparatus of state vs. civil society with his notion of "political society" (Chatterjee 1998), which is distinct from civil society. It is the field of negotiations and mediations occurring between state and population, in which the main actors are movements, political parties, informal networks, and various other circuits through which the developmental state and the population at large interact. As Hansen and Stepputat insist, "If we are to understand how issues of welfare and questions of rights and democracy are negotiated in the postcolonial world, we need to understand the dynamics, the tacit rules, and the historicity of its many political societies" (2001:27-8). Thus, while a couple years ago I still thought of this project as one posing questions about cancer in an African context, illness experience, suffering, and technology classic for medical anthropology, I have since then also become preoccupied with the relationship between national biomedicine, nation-building, and sovereignty Rwanda. This is an unavoidable and essential point of inquiry given the increasingly cited paradoxes of the Rwandan case: it has been hailed by the development, global health, and humanitarian communities for its progress in the realm of health, and now it is delivering high-tech oncological care; yet,

scholars, analysts, and activists have begun to seriously interrogate its authoritarian state and the denial of civil and political liberties, questioning the relationship between authoritarianism and health, but also the long-term viability of Rwanda's yet stable polity and social/health sector achievements.

In their other edited volume, Hansen and Stepputat tackle the question of sovereignty in the postcolonial world, questioning "the obviousness of the state-territory-sovereignty link and seeking to "conceptualize the territorial state and sovereignty as social constructions" (Hansen and Stepputat 2005:2). Moreover, they contend that "sovereign power and the violence (or the threat thereof) that always mark it, should be studied as practices dispersed throughout, and across, societies... Although the meanings and forms of such performances of sovereignty always are historically specific, they are, however, always constructing their public authority through a capacity for visiting violence on human bodies." (Ibid.:3). This point bolsters the importance of studying sovereignty as it is expressed in health initiatives and national medicine, although the aim of the latter is to ensure the body politic by caring for the body. Cancer is a unique disease through which to think this problem, because it causes profound disfigurement, and oncology introduces technologies (chemotherapy, radiation) that change and mark the body in particular ways. However, I take the cancer program as an instantiation of sovereign power expressed through care and the delivery of a type of medicine associated with middle-income countries and advanced health infrastructures.

The work of political theorist Carl Schmitt on sovereignty inspired the work of Giorgio Agambem, whose figure of *homo sacer* has been heavily deployed in medical anthropology literature. Schmitt defined "the political" as the antagonistic relationship

between friend and enemy, concluding that law does not encompass the norms of a society, but rather the authority, will, and force of those with the power to define the law (Schmitt 2007). Of the sovereign he said, "For a legal order to make sense, a normal situation must exist, and he is sovereign who definitely decides whether this normal situation actually exists" (Schmitt 1985:13). This sovereign also defines the exception, through which, according to Schmitt, "the power of real life breaks through the crust of a mechanism that has become torpid by repetition" (Ibid.:15). Here, the sovereign enables the authority of the law, and his work can be read as equating sovereignty and state power (see Hansen and Stepputat 2005:16). Agamben dismisses Foucault's conception of sovereignty as an archaic form of power replaced by modern biopolitics, arguing that "the production of a biopolitical body is the original activity of sovereign power. In this sense biopolitics is at least as old as the sovereign exception" (Agamben 1998:6). Drawing on Schmitt amongst others, Agamben goes on to assert that "bare life," or plain biological life forms the political and ontological category whose definition and subsequent exclusion are foundational for the polity in the Western tradition. While bare life is excluded from the political community, it is constitutive of and essential for both society and economy. Agamben takes Western antiquity as his starting point, wherein free men and citizens comprised political community, while the vast majority of the population (women, slaves, pariahs, etc.) was excluded. The ability to define and/or expel *homo sacer* (an originally Roman idea: the sacred man who is cast out of the community and may be killed by its members, but is unworthy of being sacrificed before the divine) is, for Agamben, the most rudimentary exercise of sovereign power, and has remained determinative of political community. Given that bare life and biopolitics comprise enduring preoccupations within medical

anthropology, Jean Comaroff's recognition of the limits of bare life as a political and conceptual category, often devoid of an essential local historical analysis and producing oversimplication, are particularly relevant (Comaroff 2007). She urges us to consider how the figures, politics and signs that AIDS lays bare are "caught up in an ongoing dialectic, at once positive and negative, of history and power, capital and geopolitics," and calls us to "something we have all but forsaken: an unalienated sense of politics as a positive calling" (Ibid.:215). Indeed, I am not interested in producing a study of how sovereign power in Rwanda can be further read into cancer care as one that decides who lives and dies—given the imbrication of transnational actors, materials, and values the cancer program involves, the very constitution of sovereignty, its multiple negotiations and instability, and its spatial reach, must be deconstructed. My aim is to develop an argument around how oncology is part of the politics of life that a post-genocide Rwanda enacts.

In his work on AIDS in Burkina Faso and Côte-d'Ivoire, Vinh-Kim Nguyen takes a cue from Schmitt and argues that the international agencies and transnational programs deciding who gets HIV/AIDS treatment in a system of triage exemplify a new form of political power in deciding who lives and who dies: he terms this "therapeutic sovereignty" (Nguyen 2010). He also identifies "therapeutic citizenship" as something that emerged as West Africans living with HIV "developed a powerful sense of rights and responsibilities inherent to their medical predicament" (Ibid.). What kinds of rationing decisions and triage effects are playing out in Rwanda's yet new cancer program? How will they impact our understanding of the imbrication of sovereignty and national medicine/health? Given the similarly transnational and foreign presence making on the ground decisions about cancer care alongside

Rwandan clinicians and policy makers, how does therapeutic sovereignty look different in Rwanda than in Nguyen's West African case? James Ferguson's older work on development in Lesotho has also inspired my deeper thinking about the entanglement of global health, development, and states, all being political actors with discursive and material political effects. Ferguson famously argued that "the 'development' apparatus in Lesotho is not a machine for eliminating poverty that is incidentally involved with the state bureaucracy; it is a machine for reinforcing and expanding the exercise of bureaucratic state power, which incidentally takes "poverty" as its point of entry—launching an intervention that may have no effect on the poverty but does in fact have other concrete effects. Such a result may be no part of the planners' intentions—indeed, it almost never is—but resultant systems have an intelligibility of their own" (Ferguson 1994:255-6). Rwanda's program has already made a positive impact on Rwandan lives through the expansion of access to chemotherapy, the gradual development of palliative care, and the opportunity to save the lives of women with cervical cancer or children with tumors treated on time. In this dissertation, I intend to examine other effects of the cancer program, in the realms of public health as well as global health relations and debates, and also with respect to questions of technology and development, professionalization processes, and understandings of the body from both the citizen and clinician perspectives. Further, as Rajan notes in his analysis of systems of exchange implicating the life sciences and capital, we must be attuned to the multiple subjectivities that such systems produce: in the US he finds sovereign consumers, and in India experimental subjects, both of personalized medicine (Rajan 2005). Given the nascent battle over access to oncological drugs in Rwanda and Africa more broadly, as well as the Western

development of technologies for "resource-poor settings" such as an HPV assay test that Rwanda began using in 2011, I want to investigate the varying forms of subjectivity, value, and exchange that the development of oncology in Rwanda implicates.

IV. Oncology's Technological Landscape and Techno-Modernity

Scholars in STS have written about the centrality of technology for any serious social analysis. Sheila Jasanoff has foregrounded the concept of "co-production," which is the idea that social and natural orders are always produced together (Jasanoff 2004). She has argued that "The dominant discourses of economics, sociology and political science lack vocabularies to make sense of the untidy, uneven processes through which the production of science and technology becomes entangled with social norms and hierarchies" (2004: 2). In the Rwandan context at hand, the science and technology is that of medical oncology, surgical oncology, radiation oncology, and cancer genomics. The technologies applied are those of chemotherapy, radiation oncology, genotyping, vaccines, and the like. Jasanoff's conclusion makes the case study of oncology in Rwanda all the more compelling because it offers an opportunity to examine how the *introduction* and production of science and technology (within oncology) are mediated by existing social norms and hierarchies, as well as those in-the-making, and those in flux owing to the conjunction of American and Rwandan biomedicine. Further, science and technology studies (STS) can also be critiqued—one regular comment is that the discipline does not offer deep accounts of power and how it operates. Another should be that STS has long displayed a strong Euro-American bias, having focused largely on and taken inspiration from research in the global north. Rwandan oncology offers an opportunity to construct an anthropology of science that

is derived from the global south, casting it as a site from which we might build knowledge about biomedicine and its economy of signs and practices (Comaroff and Comaroff 2012). Jasanoff does make a strong case for co-production:

> The texture of any historical period, and perhaps modernity most of all, as well as of particular cultural and political formations, can be properly appreciated only if we take this co-production into account. Briefly stated, co-production is shorthand for the proposition that the ways in which we know and represent the world (both nature and society) are inseparable from the ways in which we choose to live in it. Knowledge and its material embodiments are at once products of social work and constitutive of forms of social life; society cannot function without knowledge any more than knowledge can exist without appropriate social supports. Scientific knowledge, in particular, is not a transcendent mirror of reality. It both embeds and is embedded in social practices, identities, norms, conventions, discourses, instruments and institutions--in short, in all the building blocks of what we term the *social*. The same can be said even more forcefully of technology." (Jasanoff 2004: 2-3)

The emphasis on co-production for any understanding of modernity is salient here, and for a concept of techno-modernity with which I am experimenting. Techno-modernity is, in a way, a version of modernity that Rwanda aims to project as its worldly image. Jasanoff's insistence (or reminder?) that scientific knowledge takes effect in and is shaped by practices, identities, institutions is extremely relevant in the Rwandan context, and illuminates the attention to these areas that a theory of onco-nationhood demands. Jasanoff also offers a potent reminder that rapid technoscientific change does not necessarily engender rapid social change: "At the same time, when we tune into rhythms of everyday life, even at times of exceptionally rapid technoscientific change (as arguably in the late twentieth century), we experience more often the steady hum of continuity than the sense of disequilibrium" (ibid.: 16). We will think further about this contention when we examine practices on the oncology ward at Butaro Hospital, opened in July 2012 and where, and consider what effects the new availability and centrality of chemotherapy has had on the patients and

clinicians involved. In doing so we shall consider the four themes which Jasanoff sets forth as recurring ones for the co-productionist idiom: "The *emergence and stabilization* of new technoscientific objects and framings, the staple concern of constitutive co-production; and, on the interactional side, the resolution of scientific and technical *controversies*; the processes by which the products of technoscience are made *intelligible and portable* across boundaries; and the adjustment of science's *cultural practices* in response to the contexts in which science is done" (ibid.: 38). In medical anthropology, a variety of ethnographies (Livingston 2012; Crane 2013; Keshavjee 2014) have paid particular attention to how "the products of technoscience are made *intelligible and portable* across boundaries" and to how global health partnerships have led to "adjustment(s) of science's *cultural practices*"—these processes also emerge as central for comprehending how the effects of and endurance (thus far) of Rwanda's public oncology intitiative. What the Rwandan case offers is a special opportunity to study "new technoscientific objects and framings" with an eye to the salience of oncology for a broader national project, and also to understand the recent emergence of a global oncology movement, and the prioritization of oncology initiatives.

In her more recent work, Jasanoff emphasizes that little has been done in STS and other social sciences to link imaginaries, "securely established in interpretive social theory as a term of art referring to collective beliefs about how a society functions" to "modernity's grand aspirations and adventures with science and technology" (Jasanoff and Kim 2015: 5). The techno-modernity that onco-nationhood constructs and perpetuates serves up a rich opportunity to build the connective tissue that Jasanoff names as greatly lacking. She goes further, arguing that "society's self-reproduction--the enactment and reenactment of its imaginaries--so heavily depend

on experiment and demonstration, practices that intimately linked to science and technology" (ibid.). This point serves as a potent directive to think about how oncology in Rwanda implicates a series of experiments and demonstrations. Sometimes these experiments involve the introduction of advanced technologies prior to acquiring all the standard prerequisites (material and infrastructural) for them, and at certain points the demonstrations are self-consciously referring to a new kind of postcolonial modernity. In writing about Rwanda's ICT (information and communications technology) sector investments, Warigia Bowman suggests that "an imaginary rooted in concerns for sustainability might also have placed greater emphasis on grassroots participation" (Bowman 2015: 97). She concludes this following her observations of Rwanda's insistence on implementing advanced technologies without the "necessary infrastructure in place" (ibid.) and in a top-down authoritarian manner rather than in genuine collaboration with local citizens.

In addition to Bowman's contribution, which analyzes the development of Rwanda's ICT sector from an STS perspective, I must also acknowledge other scholars who have advanced an anthropology of science derived from the global south. One such is Johanna Crane. In her ethnography of American global health science AIDS-focused research in Uganda, she interrogates how to put medical anthropology and STS into conversation: "What might a field primarily concerned with the politics of suffering and inequality and a field focused on the production of expert knowledge have to say to one another?" (Crane 2013: 15). Her answer is essentially that the fields are necessarily in conversation and already entangled if one engages a full analysis of global health science. This is so because over the past three decades, AIDS in Africa has been a site of extreme production of "two phenomena [that] are deeply

interdependent" (ibid.): human suffering and scientific knowledge. Crane explains that "it is the presence of untreated illness on a massive scale that has drawn an unprecedented level of international scientific attention to Africa; and it is the desire to produce new knowledge, as well as mitigate suffering, that drives studies of HIV and other global health endeavors on the continent" (ibid.). Indeed, Crane's insight holds true for American-Rwandan oncology research in Rwanda, and this will be made clear in Chapter 2 where I examine the research apparatus in detail. Her most useful assertion is that for global health science, "the scientific imperative to produce data is indivisible from both the humanitarian commitment to saving lives and, increasingly, the development imperative to "build capacity" by fostering economic and educational opportunities" (ibid.: 16). However, the Rwandan context differs quite substantially from the Ugandan one that Crane describes, in that the insistence on "build[ing] capacity" is very much a nationally enforced project.

Indeed, beyond the clinic and the spaces of oncology program policy work, how was onco-nationhood as a project made manifest? Here we do well to remind ourselves of Jasanoff's insistence that the way in which nature and society are represented within a culture are inseparable from the way its social actors inhabit that culture. In a June 2011 speech to open the 42nd Commonwealth Parliamentary Association Conference in Kigali, President Paul Kagame stated the following:

> Citizens must be empowered to participate actively in the process that determines their livelihood and well-being. Accountability is key and this refers to the responsibility of leaders towards citizens. Corruption cannot, and should not, be tolerated because it has proven to be a malignant cancer on our continent and beyond.[8]

[8] See [http://www.paulkagame.com/index.php/news/365-president-kagame-opens-42nd-commonwealth-parliamentary-association-conference]. Accessed January 13, 2016.

Kagame's invocation of a "malignant cancer" as a metaphor for corruption in Rwanda demonstrates one of the ways in which cancer is deployed in official discourse. Because the African continent has been plagued by corruption and its malignancy has been verified, it follows that Rwanda aims to rid itself of this malignancy and set an example. This can also lead us to think about the other meanings that treating cancer in Rwanda embeds—malignancy in Rwanda may further index the trauma and potential for hate or violence experienced during the 1994 genocide and civil war. Ridding Rwanda of cancer might be akin to ridding it of its violent and scarred past, of its discord and difference, which by some accounts lurk just beneath the surface of social relations.

In general, Kagame was very clear about framing cancer care as a privileged enterprise that signaled the general developmental ascent of Rwandan society. Speaking at the Rwanda Youth Forum in May 2015, Kagame reminded his audience that the country had recently achieved a massive reduction in mortality from "malaria and other preventable diseases," naming it "the fastest rate of reduction of these mortalities in the whole history."[9] While the validity of this claim to the greatest reduction of mortalities in history—whether human or Rwandan, which Kagame did not specifiy—should be examined critically given the interests of the Rwandan state and the complexities of health statistics, it is important to note that it was put forth to prove Rwanda's incredible capacity for momentous development. Kagame went on to refer to the Butaro Cancer Center of Excellence: "Now we have a specialist cancer hospital near Musanze. Cancer is a problem, that we did not have the luxury to even

[9] See <http://www.paulkagame.com/index.php/speeches/summits-meetings-conferences/1534-remarks-by-president-kagame-at-the-rwanda-youth-forum>. Accessed January 13, 2016.

acknowledge before."[10] This particular framing of oncology as a "luxury" is a representation that speaks to how the Rwandan government considers oncology programs to be the purview of middle-income countries.

The pronounced aspiration for Rwanda to become aid-independent in the coming years is not simply one that President Kagame puts forth in isolation. He and former US President Bill Clinton (the reader will recall the major involvement of the Clinton Foundation in Rwanda) visited Eastern Province together in July 2012, just one day after jointly inaugurating the Butaro Cancer Center of Excellence. During a visit to the Rwamagana School of Nursing and Midwifery President Clinton made a speech to students:

> Since 94, life expectancy in Rwanda has doubled; 90% children are immunized, maternal mortality has dropped by 60%. Over 90% HPV vaccinated compared to 26% in USA and per capita income has increased 5 times. Rwanda did not get here by accident, you had a vision of a country where everyone counts and every child has equal opportunity. Your country has a strategy and owes its progress to the leadership: I believe under this leadership people will be coming from all over the world to receive health care. The government of Rwanda asked for assistance to build quality health system that can be run without a single cent from foreign aid: A large percentage of most foreign aid goes to organizations from donor countries and very little is spent to benefit people. I believe that in seven years, Rwanda will be running a quality health system without foreign aid.[11]

In addition to the ambitious and optimistic forecast that by 2019 Rwanda would be aid-independent, this speech is significant for other reasons. Clinton singled out Rwanda as a country that is exemplary for the global community—he envisions a Rwanda that will become a hub for high quality health care. He wanted to highlight the extent to which Rwanda's public health sector is technologically advanced and did so through a

[10] Ibid.
[11] See [http://www.paulkagame.com/index.php/news/725-president-kagame-and-president-clinton-visit-eastern-province]. Accessed January 13, 2016.

disparaging comparison of its national HPV vaccination rate to that of the USA, its rich, first-world donor and partner. Further, the depiction of Rwanda's health care system as one of immense and rapid progress establishes it as one with the sophistication and capacity to take on a disease as complex as cancer.

V. Radiation Oncology and the IAEA visit in Rwanda

Rwanda's aspiration towards techno-modernity can be understood at various levels, from that of cancer policy in the making and the transnational private-public partnerships embedded in such work, to Butaro's oncology ward, to that of the individual Rwandan patient and family. In this chapter I focus on the instantiations of this techno-modernity as seen in the spaces where the infrastructure, policy and long-term plan of the national cancer program are negotiated, with the state (the Ministry of Health and other such actors) assuming a major role as the owner and steward of such processes.

One of the forms of technology implicated in cancer treatment is radiation therapy, which utilizes high-energy radiation to diminish the size of tumors and kill malignant cells. X-rays, gamma rays and charged particles are all types of radiation used for treatment, which may be administered by a machine external to a patient's body (external-beam radiation therapy) or may emanate from radioactive material placed in a patient's body near cancer cells (internal radiation therapy, or brachytherapy). Rwanda does not yet have a radiation therapy facility anywhere within its borders. At Butaro over the past few years, PIH has been paying in full for 20 patients per month, accompanied by one of the Butaro oncology ward nurses, to go to

Mulago Hospital in Uganda, where they receive radiation therapy.[12] However, Rwanda is already a member state of the International Atomic Energy Agency (IAEA), this being a prerequisite for any country to begin the process of building infrastructure for radiation therapy (or for other uses of nuclear power, or radioactive waste management, etc.). Radiation therapy itself involves many technical experts and various pieces of complex machinery: in order to plan the treatment clinicians need high-quality radiological imaging of the body in order to carefully map the anatomical contours (in 3D) of the area(s) that will receive the radiation. This imaging include the various standard types, like tomography (CT) scans, magnetic resonance imaging (MRI), positron emission tomography (PET), and ultrasound (US) scans. Therefore one needs the machines that produce these scans as well as technicians to handle them as patients undergoing imaging. Radiation oncologists (as opposed to medical oncologists managing chemotherapy) rely on collaborative work with medical physicists and dosimetrists (as well as other staff), who use sophisticated computers to design the precise radiation plan for a patient. Finally, of course, one needs the actual machines that deliver radiation. Today in the global north, one of the major standard machines for external-beam radiation therapy is known as a linear accelerator, or LINAC. The LINAC utilizes electricity to create a stream of fast-moving subatomic particles, which results in high-energy radiation that can target cancer cells. The LINAC has replaced

[12] There is a process each month involving deadlines for clinicians at Butaro to propose which cancer patients should be sent to Mulago for radiation. The ultimate decisions are based on the disease stage, clinical prognosis, urgency, age, and other factors, with the aim of sending those patients who will derive the greatest possible benefit from radiation therapy. Beyond Butaro and the PIH-funded access, I did encounter cancer survivors who had gone to South Africa, Kenya, Uganda, or India for chemotherapy and radiation therapy, but they were rich compared to the average Rwandan citizen, and representative of a very small sector of Rwandan society. I also met a member of civil society who had been working for the government at the time of her breast cancer diagnosis, whose treatment costs were partially covered by her insurance plan, RAMA (la Rwandaise d'Assurance Maladie), managed for employees of the private and public sectors.

the older cobalt-based machines which used cobalt particles to achieve high-energy radiation. The machine(s) at Mulago Hospital in Uganda deliver cobalt-60 therapy[13], and in general one is much more likely to see cobalt machines in the global south as they have mostly been replaced by the LINAC and other modalities able to deliver higher energy radiation than that generated by cobalt technology[14]. Furthermore, cobalt-based radiation carries side effects, like severe burns and skin necrosis at the site of radiation (or often cervical stricture in patients treated for cervical cancer), which are virtually absent with LINAC-based radiation.

In November 2014, with the aim of forwarding its agenda of developing in-country radiation therapy, Rwanda hosted an IAEA-led assessment. The IAEA (based in Vienna, Austria) will visit member states to pursue what is known as an integrated mission of a Programme of Action for Cancer Therapy, or imPACT. The purpose of an "imPACT Review Mission" was explained to me as follows by a member of the visiting delegation:

> "This service assesses a member state's readiness to develop and implement a long-term radiation medicine infrastrutcure and capacity building plan, including the relevant safety, regulatory and quality assurance requirements within the framework of a National Cancer Control Plan (NCCP). The imPACT Review is carried out, upon request from the Ministry of Health of a Member State, in consultation and close collaboration with WHO [the World Health Organization], IARC [the International Agency for Research on Cancer], and other partners. The imPACT Review team visits the Member State to assess its comprehensive cancer control capacity and needs. During the mission, the team examines the status of existing strategies, plans, safety practices, regulations, capacities and infrastructure related to cancer services (from prevention to palliative care including radiation medicine and human resource development) and advises on actions to be taken on the issues reviewed."[15]

[13] Cobalt-60 therapy utilizes gamma rays from cobalt-60 radioisotopes as the source of radiation.
[14] Investigate this to explain accurately and succinctly. I.e. have to review since cobalt is still used in gamma knife radiation used to treat brain tumors, etc.
[15] Interview with author, 10 November 2014.

The imPACT delegation's visit to Rwanda spanned five days, and indeed the delegation was comprised of representatives of the IAEA's Department of Technical Cooperation, the IARC, and the WHO, who met with a team from the Ministry of Health and one Ministry of Foreign Affairs employee who served as an envoy from Rwanda's National Liaison Office. The Ministry of Health team featured three major representatives: the Director General of Clinical Services; a lawyer who had studied in Washington, D.C. but later returned to Rwanda and was now the Ministry's Legal Advisor; and the Head of the Noncommunicable Disease Division of Rwanda Biomedical Center. Rwanda Biomedical Center (RBC) is an agency of approximately 600-700 employees, formed in 2011 through a merger of about 13 of Rwanda's health-related institutions, including its National Reference Laboratory. RBC is a public entity and Rwanda's Parliament (with involvement of the Ministry of Finance) approves its budget each year: about 10% of the its funding comes from the government, while much of the remaining 90% comes from the U.S. U.*S.* President's Emergency Plan for AIDS Relief *(*PEPFAR), and the Global Fund to Fight AIDS, Tuberculosis and Malaria.

While RBC's budget is separate from that of the Ministry of Health (MoH), and the Director General (DG) of RBC reports to the Board of RBC and not to MoH, the DG at the time of my fieldwork acknowledged that in practice RBC did most of its reporting and was accountable to the MoH. He also called the current Minister of Health "very hands on," and said that he had spent a lot of time coordinating RBC's efforts with those of the MoH, and getting help from the latter. RBC unites various disease areas through an Institute for HIV Disease Prevention and Control[16], and the

[16] A number of non-HIV departments and divisions at RBC fall under the umbrella of the Institute for HIV Disease Prevention and Control (IHDPC). These include departments and divisions focused on HIV, malaria and TB, maternal/child and community health, vaccines, mental health, epidemic

Noncommunicable Disease Division, in which there are four units (cancer; cardiovascular disease; other diseases; injuries and disabilities). While RBC was a major actor within the national cancer program and major site within my fieldwork, it was indeed clear that they were constantly submitting their agendas, proposals, results, and reports to the Ministry for review and eventual approval.

On the first day of the visit, all of these principle imPACT Review Mission participants were assembled on the premises of the Ministry of Health in Kigali to hear presentations about the current standing of various areas of cancer care in Rwanda: 'control planning,' registries, prevention, early detection, diagnosis, treatment, palliative care, and civil societies. They were assembled around a long table with a projector screen at one end and the Minister of Health, Dr. Agnes Binagwaho[17], seated at the other end, there to lead the meeting in her usual demeanor of self-assured authority and determination. The rest of us—PIH staff members, Rwandan physicians, some civil society members, and myself were seated in rows of chairs facing one side of the table and occupying much of the rest of the room. Here what is key is that she was leading and moderating the discussions pursued on the first day of the imPACT Review Mission. The delegation's ultimate goal was to generate an "imPACT Review Mission Report" for submission to the Minister of Health, presenting detailed findings

surveillance and response, and noncommunicable diseases. When explaining the organization of RBC to me, the Director General stated that IHDPC was a "signal for the world that we care about HIV, but encompasses all national disease programs." (Interview with author, March 2015)

[17] Dr. Agnes Binagwaho, MD, M(Ped), PhD was born in Rwanda, but received her training in medicine and pediatrics in France, specializing in emergency pediatrics, neonatology, and the treatment of HIV/AIDS in children and adults. She returned to Rwanda in 1996 and first worked as a physician in the public sector, later becoming the head of the National Commission for the Fight Against HIV/AIDS. In 2011 she became Minister of Health, and has since then has often been in the global health spotlight as an effective and pioneering leader of health development in Rwanda. She also holds lectureships at the medical schools of both Harvard University and Dartmouth College. In 2014 she earned her PhD from the University of Rwanda. As an important social actor in the landscape of Rwanda's national health projects, she will reappear throughout the narrative of this dissertation, and I will present a longer discussion of her role in Rwanda's landscape of clinical and public health research.

and expert recommendations. In return it was expected that the Ministry of Health would develop a " 'Short- to Medium-Term Action Plan' that may endeavor to improve services while ensuring the most efficient use of resources in the control of cancer."

The Head of RBC's Noncommunicable Disease Division gave the first presentation, which was an overview of the current landscape of cancer care in Rwanda. She reviewed important facts about currently available material and human resources for cancer care within Rwanda as the number of radiological imaging machines in the country (a list which included 3 CT scanners in public institutions, 2 CT scanners "in the pipeline," and a greater number of X-ray and ultrasound machines), the supply of opioids for pain, the number of pathologists, hospital-based registries, and vaccination campaigns targeting human papilloma virus (HPV) and hepatitis B virus (HBV) (implicated in the etiologies of cervical and liver cancer, respectively). She also mentioned the passage of national legislation to regulate tobacco in Rwanda, and the launching of various related awareness campaigns. After the presentation and a round of introductions, Dr. Agnes was quick to state that Rwanda would be procuring a LINAC machine soon "through a public-private partnership," and had chosen a LINAC to avoid the disadvantages of cobalt therapy. However she was aware that a LINAC requires constant electricity, and this would be a challenge. Further, she wanted the mission members to think about how Rwanda might procure a backup machine—"We cannot start a national program with one machine!" One soft-spoken epidemiologist from the IARC wanted to know about the vaccination coverage rates, and the Minister was quick to reply that the coverage rate for HBV vaccination was 90%. As for the HPV vaccination rate, the Minister replied, "Oh Madame, we have been doing it for three years! We have a 98% coverage rate for

girls aged 12-16. And HPV was a campaign but is now becoming part of routine vaccination. Now we have a deal with GAVI[18] and a huge copay from the government." As the exchange proceeded to the issue of cervical cancer screening, the Head of the NCD Division at RBC explained the current status of the screening program and explained that there had been problems with the first-ever use of the rapid HPV test (developed and donated by Qiagen[19]), and that it was not yet clear whether the errors had resulted from a problem with the machines or the individuals operating them. To this, the Minister said, "Let's analyze what we have. We can still catch up with the rest. Follow-up is an issue. If we do an announcement via radio people will come. But we did not since we want to analyze first and see what we have. Also the report on the first cohort should be ready at this point." Here we have two salient comments from the Minister to consider: one about the choice of a LINAC machine and the immediate imperative for a second, "backup" machine; the other concerns a decision to delay cervical cancer screening involving the new HPV tests for a second cohort until the benefit and correct usage of the test have been confirmed through careful examination.

Both of these choices index the Rwandan state's overall commitment to gifting care of an international caliber to its citizenry as it builds a national oncology program. If the world's best cancer centers featured LINAC machines, then it was necessary that

[18] Here the Honorable Minister was referring to Gavi, the Vaccine Alliance, formerly known as the Global Alliance for Vaccines and Immunisation (GAVI). Gavi is a massive private-public partnership that unites recipient and donor governments, the World Health Organization, UNICEF, the World Bank, the global vaccine industry, research agencies, civil society, and private philanthropic foundations. Of note, Gavi announced on September 21, 2015, that the "internationally renowned development economist and former Nigerian Finance Minister Ngozi Okonjo-Iweala has been appointed Chair-elect of the Board of Gavi, the Vaccine Alliance." For the press release and for Gavi's full donor list, see [http://www.gavi.org/Library/News/Press-releases/2015/Ngozi-Okonjo-Iweala-appointed-Chair-elect-of-Gavi-Board/]. Accessed October 15, 2015.

[19] Qiagen is a biotechnology firm based in the Netherlands and Germany, specializing in molecular sample and assay technologies.

Rwanda procure the same technology; a new test should be thoroughly evaluated for its overall benefits before continuing with a screening program, and especially in light of challenges already present with its use. Indeed, the Minister was forthright with her new interlocutors that what she was ultimately seeking from them was expertise and aid that would enable the Ministry, and therefore the Rwandan state, to develop a national, sustainable cancer program. In this vein, she spoke to the delegation once again:

> "So what you can do for us is support formal education for doctors, nurses, and techs to maintain the equipment. Also we have KIST [Kigali Institute of Science and Technology] who educates engineers, if we can bring them and train them—the capacity for radiotherapy, and also doctors and nurses in oncology. If we can train Rwandan and East African people we can create capacity. If you go and train just two it's just survival, and hope no one will get into an accident or intoxicated. But if you train in country, this is building capacity."

The idea of building capacity by training "in country" and training "Rwandan people" demonstrates the degree to which building up a national cancer program goes hand in hand with building up the nation. Investing in Rwanda's engineers and, doctors, and nurses is a viable long-term method as opposed to stopgap measures that only allow for minimum "survival." Later on the Minister went on to discuss cancer treatment protocols. She confirmed that Rwanda had protocols in use for certain cancers, mentioning an international meeting to review them alongside South African and French colleagues. Dr. Agnes reported, "We were really inspired by South Africa [which has] the same protocol setting as ours so we are sure it's internationally sound." Yet the protocols themselves—which I will examine in a later chapter, based on experiences in both a policy setting and on Butaro's oncology ward—remain aspirational in their high international standard, because often a number of the drugs (whether hormonal, chemo- or biologic therapies) and other crucial modalities

(radiation therapy, surgery) are not available in Rwanda or accessing them takes extra time in the face of high demand.

Further, while South Africa certainly has many more fully trained specialists in oncology as well as a much broader array of cancer drugs in the national formulary compared to Rwanda, there is a serious shortage of specialists and overall, public sector oncology in South Africa is extremely limited[20]. Later in the meeting, another IARC representative asked for clarification on the status of cancer registries in Rwanda, and the Minister was adamant that a centralized national registry was in the making, and was undergoing technical updates to meet "international standards." A physician from Kigali's major private hospital (part of the national cancer care system) present at the table wanted to clarify the registry issue further and explained to everyone, "Each hospital is entitled to have a list but what we are referring to now is a population-based registry, all units…The initial one was NIH-funded [National Institutes of Health, USA]. That's why the ministry had to bring it here. Now it's becoming a Ministry of Health product, not an NGO product. That is the transition too." This comment fits into a general discourse about national ownership of all oncological and biomedical programs in Rwanda.

The registry is just one instantiation of how Rwanda constructs cancer care around the nation—in this case one that will be unified in a national cancer registry

[20] In July 2014 while in South Africa, I spent a few days following an oncologist who saw patients at both the Donald Gordon Medical Center (a private institution affiliated with Wits University) and at the Charlotte Maxeke Johannesburg Academic Hospital (public sector). I also visited the wards at Baragwanath Hospital. This oncologist related to me that there are only 120 oncologists in South Africa, for a population of approximately 50 million people. Furthermore, she estimated that 10% of South Africans have private medical insurance. Within South Africa's oncology landscape, the public sector relies heavily on international pharmaceutical companies for drugs attainable by way of participation in clinical trials, and for funding to support education and even public hospital renovations.

managed by the state, and physically located in the Ministry. In fact, two thirds of the way through the meeting the Minister defended Rwanda as a place with the "political space" necessary to allow for civil society's presence in the health sector. She spoke as follows:

> "I've been working in the health sector in Rwanda for nineteen years. And people outside are always saying that there is no political space—well ask her [she gestures to a civil society representative, a leader of one of the breast cancer advocacy groups]. And we have done that for every disease. We have ten [civil society groups] and we always invite them. And it's in our constitution. And we love our constitution and we follow our constitution! But the world doesn't want to see it. So spread the word!"

This speech evokes the fact that national biomedicine is becoming the entity through which government seeks to fuse sovereign statehood and nationhood in the cause of a healthy Rwandan future. I say national biomedicine because this project extends beyond cancer to many other diseases—here the Minister proclaims that civil society has been involved "for every disease." Naturally for this claim to work one has to understand civil society as part of the nation. Oddly enough, near the very end of the meeting the Minister made an offhand comment about how Rwanda needed to "find a way to survive the IMF [International Monetary Fund]. If we don't have civil servants involved the IMF will cut funding." Naturally, the state's projects are also shaped by external pressures, but this does not change the way in which biomedicine, and oncology, are vehicles for a national project in post-genocide Rwanda.

The question of how specifically oncology attaches to a certain form of nationhood brings us back to the question of technology. The power of the cancer agenda is that it catalyzes the development of various forms of technical expertise and science. As the Minister communicated that day, Rwanda had also received a grant from the African Development Bank to start a Master's in engineering at the Kigali

Institute of Science and Technology, and the Ministry's vision was that this program would produce the engineers needed for the maintenance of radiation therapy machines. As she reminded everyone, Rwanda's referral hospitals already had fully trained engineers, and this fact was meant to reiterate Rwanda's capacity for building up this kind of technological capacity.

Participants in various roles and at numerous levels within Rwanda's national cancer program highlighted the importance of various technologies as well as properly trained technicians and specialists for the future of the program—in no way did these priorities seem to be solely or mostly the purview of the state (through the Ministry of Health, or Rwanda Biomedical Center). One Rwandan doctor who had completed full specialty training abroad and worked in both private and public hospitals went so far as to say that he thought the oncology program should be "owned by oncologists," that they should own it, plan it out, and oversee it, because oncology is "very clinical, very scientific." He felt that "ownership" of the program by anyone other than oncologists would be detrimental, and that achieving this was actually more important than any public education campaign. To this end, he was also dissatisfied with any suggestion (or reality, like the provision of oncology by general medicine doctors at Butaro with relatively brief oncology training) of training oncologists for "two or three years," seeing this as insufficient. He emphasized that Rwanda needed oncologists and pathologists, but that they should undergo training of the same length and structure as that he had received abroad.

This foregrounding of the long/term goal of having oncologists run Rwanda's cancer program naturally belies how this physician had a certain anxiety about his status as a specialist (practicing in both the state-funded military hospital and a private

hospital) in a country lacking specialists, but aspiring to build medical specialties into its relatively new public health infrastructure. In reality, he was one of the only two formally trained oncologists in the country (both trained in South Africa). In general, this doctor was convinced that establishing oncology at a standard at all inferior to its forms in the developed world was a futile enterprise—the program should be built slowly with conventionally trained oncologists and a steady building up of the national armamentarium of cancer drugs. Yet he also spoke from the vantage point of the private hospital serving the extreme minority of Rwandans with the means to pay for expensive treatments. Indeed, the dualistic situation in Rwanda figured a dichotomous situation in which the drive and insistence on northern oncology and similar training schedules stood alongside the grounded reality of a very different version of oncology.

This physician also explained that the pathology lab of one of the hospitals at which he worked had the infrastructure to perform immunohistochemistry—a diagnostic and research technique using a process of identifying antigens (certain types of proteins) in cells of a tissue because they will bind to specific antibodies that are introduced. Immunohistochemical staining is utilized for the diagnosis of abnormal cells like those characteristic of malignant tumors, and for basic research investigating biomarkers and differentially expressed proteins in varying parts of a biological tissue. Indeed, one of the endeavors at Butaro Cancer Center of Excellence over the past few years has involved training pathology lab technicians to use immunohistochemistry techniques to prepare tissue slides (the tissue coming from patient biopsies) which can then be sent to Harvard hospitals for analysis. This same physician offered an additional instantiation of the way in which Rwanda's oncology project foregrounds certain technologies that are new even in the global north, in this

case the HPV test, and of how this reality simultaneously transforms Rwanda into an appealing laboratory for such recent innovations. Specifically, he told me that the department at one of his hospitals had collaborated with a US academic medical center (this time not Harvard) on a proposal for an HPV testing study to be carried out across Rwanda, and that they had just been awarded a National Institutes of Health (NIH) five-year grant for the study.

There were other arenas in which the imbrication of oncology's technologies with a certain project of nationhood and state-making crystallized. One such area was that of the creation of national cancer protocols. A treatment protocol is a document that precisely outlines in step-wise fashion what interventions should be employed (whether medical or surgical) and differentiates decisions according to particular attributes of the patient's diagnosis and prognosis. Protocols are established to standarize and unify treatment at the level of an institution—be it a hospital or health clinic—and also at the international level to standardize that which is deemed the "standard of care" or "best practice" at a given time. For instance, the World Health Organization (WHO) develops and publishes treatment protocols, as well as various guidelines which are aimed to help ministries of health develop appropriate protocols. Academic medical centers may also generate protocols. In September of 2014, I attended a two-day 'Cancer Cluster Retreat' hosted by Rwanda Biomedical Center (RBC), at which participants worked on revising Rwanda's national cancer protocols. RBC was hosting the event with the approval and support of the Ministry of Health, and the latter would have to approve and essentially 'ratify' the protocols generated by the workshop. This particular workshop was focused on a variety of adult cancers—

breast, gynecological and urological ones (including cervical and prostate), gastrointestinal ones, lymphomas, chronic leukemia, and acute leukemia.

At present, the major institutions comprising Rwanda's national cancer network are comprised of public, state-funded hospitals: two university-affiliated hospitals, Centre Hospitalier Universitaire de Kigali (CHUK), Centre Hospitalier Universitaire de Butare (CHUB), Rwanda Military Hospital (Kanombe), Butaro Hospital, and the private (though government-owned) King Faisal Hospital in Kigali. While these hospitals can be differentiated in terms of their private vs. public status, their direct affiliation with a university (although all serve as training hospitals for Rwanda residents), and the specific international private-public clinical and research-based collaborations that each is home to, they share one major entity in common: cancer patients. Essentially all Rwandan cancer patients (excluding members of the wealthy elite who often travel abroad for treatment) pass through a few of these hospitals as they seek care (and once they have progressed from the community health center level to that of referral hospitals).

Chemotherapy, surgery, and pathology services are differentially available at these institutions; in fact it is more accurate to state that the availability and quality of these different components of cancer treatment has varied at different times over the past few years, often owing to the shortage of pathologists, surgeons, and various specialists in Rwanda, and the shorter work contracts that physicians from abroad fulfill. As such, it was logical that when Rwanda Biomedical Center (RBC) hosted a national cancer protocol workshop in September of 2014, representatives of all these hospitals, approximately fifteen physicians, were present. This group included both Rwandans, and foreign (American, Nigerian-American, Canadian) physicians working

at the aforementioned hospitals through Partners In Health or Rwanda's Human Resources for Health program. The goals expressed at the protocol meeting reflected the desire of Rwandan physicians to deliver care of an international caliber to their population, although this caliber was largely an aspirational given the yet total absence or shortage of various oncology drugs, imaging modalities (such as MRI and CT), and specialists. In one way the protocol was an opportunity for the involved physicians to clearly communicate what they deemed the most urgent needs for advancing cancer care in Rwanda, like radiation therapy, additional HER2 receptor testing for breast tumors and a related drug (Herceptin), better access to imaging and surgery, and the like. As one Rwandan oncologist put it, "We've been first for many things in Africa! So let us be 1st for HER2-targeted therapy [drugs like Herceptin]. I would be happy to see that!" Such a statement substantiates the idea that oncology is part of a broader project of building a post-genocide Rwanda that can be in the vanguard of technological and health development. Yet this same physician was concerned that such aspirations be carefully weighed against the impossibility of certain standards for the near future and the resulting need to avoid establishing a protocol that would paralyze an already stressed system. For instance, he felt that making ultrasound and mammogram mandatory diagnostic steps for any breast mass would be problematic.

A radiologist from one hospital chimed in about the need to expand access to mammograms, as they can reveal masses not visible on ultrasound images. Then one of the American doctors suggested that perhaps the protocol should prescribe biopsy first, without any imaging, given that so often Rwandan women presented with "huge masses" for which treatment decisions could be made without imaging. A visiting Canadian oncologist supported this notion. The Rwandan oncologist reacted

vehemently—how could they be discussing the incorpotation of HER2 receptor testing but then questioning the place of ultrasound in the protocol? Ultrasound was unequivocally a simpler, far cheaper technology, and the priorities of the protocol must ultimately remain logical, he argued. Yet his immediate response against any suggestion by a foreign colleague that the protocol be simplified technologically in the face of material and human resource challenges, because of the ongoing reality of patients presenting with late-stage cancers, also embodied the intense commitment to proposing and pursuing the international standard of care for cancer patients. It was also one of the many moments I observed during my fieldwork in which national ownership of a national product crystallized during a decision-making process, even if this process was subsumed by a transnational collaborative environment characteristic of any initiative within the national cancer agenda.

On the second day of the protocol revision meeting, I witnessed a discussion about the prostate-specific antigen (PSA) test, used both in screening for and monitoring prostate cancer in the US and throughout the developed world. The Federal Drug Administration (FDA) first approved the PSA test in 1986 to monitor the progression of prostate cancer in already diagnosed men, and its 1994 approved its use in conjunction with a digital rectal exam to test asymptomatic men for prostate cancer. However, in recent years the use of the PSA test has been hotly debated in the US, because of concerns that its widespread use for screening may lead to false positive results, unnecessary biopsies and therefore avoidable costs and anxieties. One Rwandan physician joked, "Ever since Mitterand and Mobutu's involvement in this country everyone wants a PSA!" The participants in the room erupted into laughter. The joke referred to the fact that both former President of France François Mitterand

and Mobutu Sese Seko, military dictator and President of the former Zaire (now the Democratic Republic of the Congo), had passed away from prostate cancer. This witty remark also indexed an association between cancer and powerful political figures, or perhaps cancer and power, predating Rwanda's post-genocide construction of a national cancer program. A Rwandan oncologist pointed out that it was "good news that we're not the only ones dealing with this issue—Americans also are not sure about PSA. And if you read recommendations and debates it never says a total rejection of PSA; it says 'Well, PSA can be considered.'" He coupled this with a remark on how Rwandan physicians were seeing increasing numbers of advanced cases of prostate cancer. This move to align Rwanda's public health and oncology fields with those of the US was one of many moments in which Rwandan clinicians expressed their intense desire to consider their cancer program as one of the highest international caliber. Their aspirational stance was focused not only on acquiring the same technologies and infrastructure as an oncology program in the US, but also to engaging the same types of debates, interrogations, and revisions with respect to the implementation of various clinical tools.

This kind of ambitious national public health endeavor also requires an extensive engagement with private biotechnologial entities and donors, and a number of the world's largest, for-profit pharmaceutical companies who manufacture oncology drugs and have fought to extend patents on many such drugs. A Canadian oncologist volunteering at one of the hospitals for three months related, "During the year I spent preparing to come here I asked Roche Canada and Roche USA—spoke to the Canadian director directly—for compassionate donation of Herceptin and they said no!" The Rwandan oncologist chimed in, stating that just a week before the protocol

workshop he had met with East Africa region representatives for Roche Pharmaceuticals in an attempt to negotiate the price of Herceptin. He stated in a tone of resignation, "they won't negotiate, and told me if we pay for twelve Rwandan patients [to take Herceptin] they will give treatment for six patients for free." His Canadian colleague reacted unequivocally, saying, "Tragic! A multi-billion dollar company and this is curative treatment. I'll try again when I go home." The realities of oncological drug procurement, a series of efforts that must necessarily be transnational and which will take time, are amongst those constraints that relegate certain elements of the national cancer protocols to the status of aspirations.

The revision of national cancer protocols also highlighted the tension between public oncology initiatives indivisible from a certain form of state-making, and the smaller private sector, where ideas about an actionable standard of care differ from those promoted at the public Butaro Cancer Center of Excellence. A Rwandan physician who practiced at both King Faisal Hospital (private, but government-owned) and Kanombe Military Hospital was one of the major participants in the review of lymphoma and leukemia protocols. He wanted to drive home the point that anything less than the international standard of care was unacceptable for Rwandan patients, and that the national protocols must formalize this standard regardless of actual resource constraints or the current availability of material and human resources. He insisted, "We should be aiming for the highest. If we keep saying that the standard is lower then we will never attain the standard of care we need. I will not treat patients with that which is not the optimal treatment."A foreign doctor working on the oncology ward at Butaro responded, "Well, often the international best standard of care is not available and we can only offer what we have. So that makes it very difficult

to ensure or offer the standard, so it may be better to do what we can." Before he could continue, the Rwandan doctor interjected: "This is completely unacceptable. Either the best care available in terms of treatments and technologies—nothing less...Those who cannot pay cannot pay and that is not our responsibility." The members of the oncology team at Butaro were clearly dismayed by this comment. In a certain way, the Rwandan oncologist's vehement comment clearly undermined the project of a public national oncology program. Yet in another vein it was perhaps a strategic statement from a physician convinced that high-quality oncology care could only come to fruition soon within the limited private sector with its smaller patient reach but greater financial endowment. After all, this was the same physician who had been adamant about the importance of having Rwandan oncology be "owned" by Rwandan oncologists, and about expanding the latter's cadre through formal training programs abroad. It was also a symbolic reaction to the public oncology approaches of Butaro Hospital, and to any suggestion by a foreign physician that the protocol be revised to reflect the realities of resource constraints. Also of note was that this physician had previously completed his specialty training in South Africa, a country where the distinction between the health sector's private and public institutions remains stark in terms of access to drugs and specialty care.

VI. Conclusion

What I wish to develop (and there is a huge amount of work yet to be done—theoretical and empirical/ethnographic) in this chapter is an argument about how the technological contours of oncology are particular, fitting into Rwanda's wider health sector transformation beginning in the early 2000s. I'm mining my data and relevant

literature to define how oncology is part of the broader imbrication of nationalism and big science. Rwanda's cancer project is, quite deliberately, an exercise in the construction of a new sense of sovereignty, rendered through the politics of life as onco-nationhood; that it is an effort to create a postcolonial polity whose citizen body is gifted care of an international caliber provided by a paternal state. In a critical moment of post-traumatic social reconstruction, national biomedicine is becoming the entity through which government seeks to fuse sovereign statehood and nationhood in the cause of a healthy Rwandan future. Thus it is that a politics of life makes nationhood and medicine co-constitutive. Theorizing this relationship, against a background of heavy international involvement, holds at least one key to developing an anthropology of cancer in contemporary Africa.

Chapter 2 The Transnational Private-Public Partnership

I. Introduction

In this chapter I offer an ethnography and critical analysis of the transnational private-public partnership, a critical entity within Rwanda's national cancer program. My goal is to provide an engaged sociological portrait of that transnational private-public partnership as it figures in Rwanda's national cancer program. In anthropology and sociology, there is a relatively small literature treating the private-public partnership (PPP), despite its omnipresence in global health and a reality of the neoliberal moment. How is the PPP configured and understood by actors embedded within its projects? How are knowledge production and parameters of 'global' leadership negotiated among private and public constituents? How does the private sector within health—both domestic and international—exert its effects and delineate its power in a context where Rwanda's post-genocide state is so adamant about national ownership and supervision of health sector interventions? What is the balance of multilateral interests within the transnational partnerships of the cancer program and how do they impact the social and moral work that such a program does?

Adriana Petryna has written about PPPs in her work on the globalization of clinical trials (especially the recruitment of human subjects) for the multinationally-run pharmaceutical industry, noting that "Public-private partnerships come in various forms, have multiple interests, and create new norms for institutional action. They have stepped in to fill public health voids in places where national systems and markets have failed or been absent altogether (Petryna 2009). Of course, in Rwanda the government wields major power and the work of PPPs is always framed around

building a strong and eventually sustainable "national system." Petryna further cites the work of anthropologist and legal scholar Annelise Riles in addition to outlining a possible agenda for social scientists studying global health:

> [She] has argued that novel transnational formations (such as those she studied promoting women's rights) often operate beyond formal contracts and organizations (2000). Networks and partnerships deploy a universal lexicon and are diffused and sometimes chaotic in form. They are both fragile and powerful means to mobilize information, allies, and resources. In this mode of global 'postpolitics,' much is sidestepped. We need new analytic frameworks and institutional capacities that can address the fragmentation of efforts in global health, as well as broaden social impact and keep national governments and donors accountable in the long run. Moreover, new public-private initiatives should not divert the attention of activists and policy-makers away from the need for comprehensive reforms in drug pricing, patent law and intellectual property regimes, and health-care infrastructure." (ibid.: 193-4)

It remains to be seen to what extent the existing and proposed transnational formations of Rwanda's oncology landscape exceed "formal contracts and organizations," particularly given a context in which adherence to national protocols, agreements, and etiquette is constantly emphasized. While we shall pay careful attention to the ways in which partnerships in Rwanda "deploy a universal lexicon," they also incorporate a local discourse that sheds light on the particular postcolonial politics that shape a state's investment in a self-consciously public oncology program at a crucial moment of social reconstruction, and the building of sovereign authority and legitimacy.

Petryna's argument about the imperative reforms is salient in the context of global oncology and Rwanda's public health/oncology system. The ongoing batttle for access to ARVs is a form of struggle that needs to be pursued for oncology drugs on a broad scale. Finally, she notes that "Private-sector research thrives on the public sector, and the public sector is altered in the process..." (ibid.: 197-8). She describes

Brazilian clinical research scientists as "engag[ing] the withdrawal and acquiescence of the state, particularly in the field of medical research and drug marketing, as they are crafting a new public out of the public/private matrix that facilitates global experimentality" (ibid.: 199). In the case of Rwanda we must ask what kind of public is being crafted out of the public/private matrix that emerges from the partnerships I describe later in this chapter.

In an edited volume, Petryna and João Biehl highlight a case study that "shows how the current configuration of global health, with its emphasis on Public-Private Partnerships (PPPs), arose not simply from firmly held ideological convictions at the WHO, but as a response to a number of external pressures, chief among them a shrinking budget and an antagonistic political arena" (Biehl and Petryna 2013).

Another scholar who has analyzed PPPs is Rene Gerrets. In his work on Tanzania, he notes that "while (public-private) partnerships are well-established neoliberal tools for shrinking the public sector (especially in wealthy countries), in low-income countries (LICs) these entities are assuming core functions that public sector agencies either are unable or unwilling to conduct" (Gerrets 2015: 180). Gerrets makes a distinction that liberates PPPs in LICs from the neoliberal critique. Rwanda is one such LIC where PPPs function in concert with public sector agencies and engender the production of transnationally conceived agendas. He also marks PPPs as a newer configuration that has gradually replaced older forms such as multilateral agencies: "partnerships have also assumed enormous responsibilities on the transnational plane and nowadays often feature prominently in activities that used to be dominated by multilateral agencies (e.g., the Global Alliance for Vaccines and

Immunization, which emerged out of and eclipsed the floundering WHO-led Childhood Vaccine Initiative [Muraskin 2002]" (ibid.).

Ultimately, Gerrets offers a case study of a transnational malaria research and control partnership in Tanzania and argues that "several Tanzanian partners…bolstered state influence in health governance at the district and the national level. These effects were mostly unplanned and arose through complex and often markedly indeterminate and idiosyncratic processes" (ibid.). He contends that "Tanzanian state institutions…could thrive in the para-statal space that, at first glance, appeared more conducive to the interests and priorities of non-state actors" (ibid.: 181). While he doesn't define the "para-statal space" in any great depth, he makes it clear that it was one in which Tanzanian actors could advance "local agendas, issues, and priorities," (ibid.: 199), whether these were defined at the national or regional level of the public sector. In defining the political character of this space, Gerrets coins the term "makeability" to index how partnerships are conceived in terms of "goals, inputs, outputs, and desired impacts" (ibid.), but the translation of such plans into a functioning reality is wrought with challenges and complex negotiations which can be utilized (or manipulated?) by social actors to further shape agendas at hand. In his Tanzanian case study, Gerrets wants us to understand that there is major flexibliity and ambiguity built into the PPP, rendered visible by the loosely drafted protocols and project plans, and the ways in which participants tacitly agree when to step back rather than act at a moment of mishap.

Researchers in public health and health economics have also investigated the balance between the private and public sectors in healthcare reform and delivery in

China, paying specific attention to the effects of rapid privatization. However, rather than examine the imbrication of public and private sectors within PPPs, they have been mostly interested in the effects of rapid privatization on health care efficiency and "consumer satisfaction," some concluding that the private sector actually disproportionately serves low-middle income groups and that satisfaction may be higher for certain aspects of care compared to the public sector (Liu et al. 2006: 219). Others have cautioned that China's recent reform history lays bare the massive risks for citizen health and government stability posed by the fairly rapid and extreme privatization of the healthcare sector (Blumenthal and Hsiao 2005: 1170), but more recently have highlighted China's reform decisions as constituting "major health care experiments" (Blumenthal and Hsiao 2015: 1285). Among the lessons they cite from these "experiments" are that community health workers (such as China's barefoot doctors in the Maoist period and subsequently) can significantly ameliorate the health status of citizens, especially in low-income countries with enduring large, rural populations. Further, a shared culture of physician professionalism may be crucial for securing the trust of political leaders and the general public (ibid.). Further analyses by health economists have warned that China must tackle rapid cost inflation, the result of an "irrational and wasteful health care delivery system" (Yip and Hsiao 2008:460). None of these studies has commented specifically on the unique private-public formations in China's health economy nor made especially focused arguments for this conjunction, though it has been suggested that private hospitals should have to compete against public hospitals serving as benchmarks, and in general quality should be the parameter by which performance is judged (Yip and Hsiao 2014).

In Rwanda, there are various actors that figure into PPPs: the public sector (Rwanda's Ministry of Health and so forth); the private sector (multinational or international biotech and pharmaceutical companies); the American university actor (i.e. Harvard in this case) which is nonprofit and operates with both federal research grants and a private endowment; and the Harvard-affiliated hospitals. Brigham and Women's Hospital and Massachusetts General Hospital are part of Partners HealthCare, a private, not-for-profit health care system in Boston. As such, their budget is technically also derived from both the public and private sectors—federal research grants, public (Medicaid and Medicare) and private insurance reimbursements, and philanthropic contributions. Dana-Farber Cancer Institute is also a private, not-for-profit hospital and as a world-renowned cancer center receives funding from the National Cancer Institute, the National Institute of Allergy and Infectious Diseases, private foundations and donors, and so forth. It seems important to specify the multilayered private and public composition of all these actors before engaging any analysis of the PPP.

It would be hard to deny that BWH and DFCI, as private-academic entities pursuing global oncology and global health science 'experiments', need public, local subjects. Their engagements interpellate these subjects in particular ways. Johanna Crane is among those to remind us that in general, much of the funding for universities to pursue global health science research comes from federal and therefore public sources, which makes the PPP of global health different from the one Petryna describes as led by contract research organizations (CROs) working for multinational pharmaceutical corporations. However, private sector funding represents a major

proportion of the funds utilized by Harvard-affiliated hospitals[21] and Partners In Health (PIH). In fact, at the end of 2015 the Senior Director of Development at PIH informed me that 62-66% of the organization's annual revenue comes from individual donor contributions.[22] The mission of Partners In Health is explicitly focused on delivering high-quality health care (with all its accompanying technologies) to the world's poorest communities, and to undermining the hegemonic discourse of "cost-effectiveness" that has for so long plagued the fields of international development and aid, as well as its younger cousin, global health (see Farmer 2006, 2013; Crane 2013). Beyond this fact, as discussed in the Introduction, PIH is a staunch advocate of building sustainable public systems in collaboration with local governments. As such, the context for oncology in Rwanda complicates series of contentions that PPPs are simply a neoliberal tool allowing private market logics and agendas to dominate in many settings where the state has retracted, owing to a lack of both resources and consolidated power.

II. Private-Public Partnerships for Rwandan Oncology

At this point it may be prudent to first describe the private-public partnerships at hand. How did private-public partnerships actually operate on the ground within the cancer program, sustaining transnational collaborations why also serving to invigorate a predominant form of nationhood, tied to technology and developmental progress? Contained within Rwanda Biomedical Center (RBC), described in Chapter 1, there were other institutional entities that emphasized national health infrastructure as a key project for a nation seeking to extirpate itself of the deep fissures borne of

[21] Need more specific stats on this. Speak to Paul et al.
[22] Personal communication to the author, December 2015.

horrific violence and disintegration. One such institution was the National Reference Laboratory, which had begun as an HIV-focused laboratory in 2004 but since then expanded its areas of work and been incorporated into the Biomedical Services Division of RBC. In November 2014 I attended an NRL workshop (managed and paid for by RBC) the agenda of which was to determine how it could expand its capacities to serve better as a reference laboratory. This meant improving the extent to which the NRL performed the most sophisticated and demanding tests in terms of technology and expertise to serve patient care needs nationwide, while having laboratories at the health center, district, and reference hospital levels perform more straightforward and basic clinically relevant laboratory tests. One of the products that resulted from this workshop was a list of desired tests and techniques for the next upgrade of the NRL, including electron microscopy and many surface protein expression tests[23] for tumors of various organs.

At the start of the workshop, the deputy director general of the NRL, Dr. Deo, announced that the group of professionals (including pathologists and technicians)—"all these brains"—from Rwanda's referral hospitals had been assembled to determine how the NRL could "make the 'R' in 'NRL' real!" Dr. Deo, also an ordained priest who completed his theological studies as well as a PhD in tumor biology in the US, is a gracious and sunny presence—he exuded his usual warmth and enthusiasm before the serious participants assembled, wearing a lilac shirt and a shiny purple tie. He cited the "need to do this for future generations to build upon." The division manager for the NRL within RBC gave a presentation summarizing the current state of the NRL. He outlined its core functions of diagnosis, disease control and surveillance, specialized

[23] Various tumors—of the breast, kidney, thyroid, lung, gastrointestinal tract, etc.—may be tested for the expression of particular proteins, which guide both diagnostic and prognostic conclusions.

testing, laboratory improvement, and mentorship. Dr. Deo also explained the NRL's progress toward lab accreditation, a process launched in 2009 to develop the quality and performance of the NRL's satellite labs, and assign a star rating to each of them. At this point in the workshop, this manager made much of the need to decentralize lab services. Yet later on the group discussion would turn towards ideas about centralizing lab services to increase the turn-around time for results and thus overall efficiency.

One participating physician pointed out that the accreditation system, which was based on a World Health Organization checklist used to assign star ratings (2-star, 3-star lab, etc.) after an assessment via "proficiency testing," should be managed in-country rather than paying experts from Australia and South Africa. Another doctor affirmed that Rwanda had sufficient experts among the pool of doctors and scientists to carry out the testing on its own. Dr. Deo agreed and affirmed that he wanted the NRL "to live up to the expectations of Rwanda." A number of the physicians present were concerned that Rwanda solidify its self-sufficient capacity to perform various laboratory tests as another way to reduce costs and work towards "sustainability." The division manager also highlighted this need particularly during a moment in which external global health grants were declining but the government's base and tax-based budget was expanding—he named 2014-2020 "challenging years." In that regard, a recent event was recalled. In August 2014, a German medical student, recently arrived in Rwanda from West Africa, was suspected of having Ebola: his blood sample was sent to Entebbe, Uganda because the NRL was still not a WHO accredited lab. In addition to the cost incurred by the Ministry of Health, it took 48 hours to receive the result. Dr. Deo assured everyone that the NRL was not in competition with district and referral hospitals and that its goal was rather to define "what is done where in the best

interests of each institution and the country." He invoked the "country" at other moments: after one pathologist present remarked that there were referral centers with no connection to the NRL, he offered up a parable about a man who had lost many kin during the genocide. Afterwards this man made many friends who attended his wedding and later visited when he was sick, but he kept exclaiming upon how alone he was. Dr. Deo pointed out that this man had been living in the past instead of being grateful for the present; he linked this story to the issues at hand by pointing out that there had been communication problems in the past yet everyone should be focused on moving forward. Thus, the necessity of developing the NRL was framed in patriotic, financial, and pragmatic terms.

Such moments made legible the indelible links between Rwanda's past, the active production of a new nationhood, and aspirations for sustainability and self-sufficiency within clinical medicine and science. Various of the final recommendations emerging from the workshop were focused on the benefits that would derive from better communication between various laboratories, and centralization of many services at the NRL in order to reduce processing time, remove the pattern of redundant biopsy testing pursued at various labs, and "increase efficiency." Thus, pragmatic concerns about the access to and quality of health services further drove the desire to centralize more complicated and high-tech clinical laboratory tests, a decision that could ultimately result in the NRL having greater power and serving greater needs as a stronger central and state-based institution. This was an instantiation of the project to have medicine serve as a form of social cohesion and solidarity.

The production of the Rwandan nation in terms of onco-nationhood depends on a number of private-public partnerships. Yet, definitions of private and public were

malleable, even in the face of rigorous state mediation and ownership within both sectors. I argue that in present-day Rwanda, we see the categories of public and private being defined anew and reciprocally. The presence of a national private sector is quite new in a nation that continues to rely so heavily on international aid but which has bold aspirations to free itself of this dependency in the coming years.[24] At the same time, defining the accountability of the public sector in certain ways is a major component of the project to define a new nationhood, renouncing a past of genocide, violence, and fragmentation. One fact emphasized at the NRL workshop was the new reality that RBC had been "allowed to become an income-generating entity and so will be operating as if it were semi-private." There was talk of the need to come up with a plan to make this semi-private endeavor successful, to generate adequate profit for a self-sustaining national enterprise.

Indeed, the private-public partnership (PPP) was something that I came to better understand after talking with one of the leading directors of RBC, Dr. Schiller, a foreigner who spent two years devoted to its institutional improvement. During an interview I asked him to speak to the valence of the PPP for RBC. He was quick to identify what he saw as two factors driving development of PPPs in Rwanda—first, the lack of national resources to carry out large investments, and second, a higher level "push from President Kagame to inject more private sector behavior in Rwanda." However, he was cautious about the eventual success of any PPP in Rwanda:

> The flip side of the coin is that Rwanda is a very administrative culture; there's a couple of reasons for that. If you compare Rwanda to its East African neighbors, they were colonized by financial adventurers, whereas Rwanda was colonized by small-time administrators from Belgium. And Rwanda was politically unified and hierarchical before colonization. Hierarchy and process

[24] Quote Kagame on going aid-free by a certain date.

> run the show, which can be great, since [this] can push [the] government, but there is also not a lot of flexibility.[25]

Here the RBC leader wanted to contrast administrative culture with the entrepreneurial culture necessary to build up a private sector. To his mind, "hierarchy and process" were essential for the effectiveness of a strong central government, but not conducive to the creativity that any PPP would require. Dr. Schiller further noted that within RBC, "we're very stuck on rules, and if there's no rule on PPPs, they'll sit and not do anything." This leader within RBC was very clear that should the state succeed in establishing a public national cancer program (which he considered minimal in its current instantiation), it could derive considerable public revenue from such "investment." In fact, he drew attention to the way in which the private sector did exist for cancer care, believing that effective cancer care at present was either PIH-based and "bypassing RBC," or was offered in private hospitals and clinics. Nonetheless, his overall goals as a foreigner with a powerful position among the leadership of RBC suggested that having a stake in the 'public' or government controlled aspects of a national cancer program remained difficult and the state's set of resources for cancer care were still meager.

Thus, attracting investment and invigorating the business climate of Rwanda by nurturing it as a place hospitable to private investments became central to solidifying the public in a post-genocide Rwanda. A precise example was the fact that this interlocutor was keen on having Rwanda become a destination for clinical trials. However, he already saw the public sector as one that had been "pretty effective, if you compare it to the other countries in the region, who don't have this public sector

[25] Interview, March 2015.

tradition, their governments are much weaker in making these things happen." As for the private sector, he characterized Rwanda's commercial culture as weak compared to that of some of it regional neighbors, arguing that of Kenya as "1000 times more sophisticated." Yet he was certain that President Kagame was acutely aware of this and for this very reason was constantly engaged in a campaign to promote what my interlocutor called "Rwanda, Inc." Further, he was convinced that the genocide had catalyzed a sense of urgency about national development and pursuing it in innovative ways, and that this sense of a ticking clock did not exist in other countries. As for the particular role of the private, profit-driven global pharmaceutical industry with respect to cancer care in Africa, he admitted that "in the case of ARVs [antiretrovirals for AIDS] you had a funder, like PEPFAR [The United States President's Emergency Plan for AIDS Relief] but with cancer it's going to be a combination of a little corporate responsibility with wanting to expand the growing African middle class." While this comment was one about Africa in general, it was pertinent for Rwanda insofar as a national stockpile of oncology drugs is yet in process and being negotiated, and at Butaro, for one, all chemotherapy is paid for by Partners In Health.

Indeed, the PPP remains a crucially relevant object of analysis not only because this configuration is constantly cited as the key to effective development in this neoliberal moment (cite cite), but also because it is central to the agenda of Rwanda, which like other African nations of late seeks to free itself of a serious dependence on foreign aid. As the state works on its own sustainability and legitimacy, it needs private capital—economic, social, cultural—to realize the public sector as one that offers world-class care to its citizens. At one point I interviewed a young economist working in RBC, Oliver, and asked him how might Rwanda establish independence from

foreign aid. He confirmed that the transformation of RBC into an income-generating institution was yet in process, and that it was part of a larger initiative to generate revenue in the face of decreasing donor aid. When I asked him to quantify the decrease in donor aid, he estimated that by 2020 donor aid would decrease overall by 40%. As an economist who had completed his Master's in the US, Oliver stated that one major idea for Rwanda's development was to leverage its consulting capacity given its experience in technology and systems-building, and thus to eventually serve as respected consultants in the region. He briefly pointed out that in Rwanda there was as yet no capital market for foreign investment, that raising taxes on foreign businesses would be counterproductive because "they will stop doing business here," and finally that there was no product Rwanda could create and export in the health sector. He gave greatest weight to the idea that Rwanda's health sector institutions might obtain research funding as do institutions in the US, and generate revenue from it as profit for the invested grantors. This profit might derive from health innovations, services, and data with the potential to benefit the whole region in terms of its health systems rather than just Rwanda. When I asked Oliver to explain his distinction between research grants and aid, he affirmed that a research grantor expects a return on his investment in some form, whereas this is generally not an expectation of a donor.

At this juncture it is evident that research—both biomedical and clinical—was a field in which many aspirations, competing interests, and imaginaries converged. On the one hand, civil servants[26] like Dr. Schiller and Oliver (both at RBC) saw large research initiatives and clinical research trials as a potential site for the generation of

[26] As RBC was considered a public institution with strong ties to the Ministry of Health and a major role in the public health infrastructure of Rwanda, its employees are seen as civil servants. Perhaps (elsewhere) I should explicate this based on definitions of civil service in Africanist literature.

national revenue that would enable onco-nationhood as one of the keys to a viable, independent Rwandan nation-state. This was imagined in a context of waning international aid—a vision that endured despite the risks of having foreign pharmaceutical or biotechnological companies rely on Rwanda as another poor nation suited to provide experimental subjects (see Petryna 2009). On the other hand, leaders of the Rwandan public health field were unequivocally committed to building a field of clinical and biomedical research in oncology and more generally, a field to be owned and managed by a first generation of Rwandans trained in research. The project of national research capacity was greatly supported and aided along by Partners In Health and other partners figuring in the cancer program. It was an endeavor that was evident at many levels, from that of the state, to the transnational partnerships figuring in the cancer program such as those between Boston and Butaro, to specific national institutions like the College of Medicine and Health Sciences at the University of Rwanda. The Minister of Health, Dr. Agnes, has in fact been vocal on a number of occasions as to how Rwanda will not stand to be exploited as a site for American researchers (or any foreign researchers for that matter) building their careers, knowledge, and fame, but offering nothing in return [include speech excerpts].

This approach is made evident in the national IRB process required of any researcher pursuing research that will involve clinical medicine institutions or patient contact, a process that engaged me over the course of twelve months as I prepared for my fieldwork year (2014-15) in Rwanda. Like any foreign researcher, I was required to have a designated Rwandan co-Principal Investigator in my research protocol. This policy was announced as one that was meant to engender collaborative research, and ensure that all scientific publications based on research in Rwanda featured both

locals and foreigners as authors. To those leading the development of the Rwandan oncology program, and the health sector more generally, the crucial connection between research and publishing was evident. They had realized that to be part of the global realm of clinical and biomedical research one needed to publish constantly, and join conversations and circulations of knowledge, heavily dominated by academic medical centers in the global north, found in globally prestigious journals of clinical and biomedical research.

Building research capacity was also an undertaking that was supported by various partners, and one in which a public in-the-making and national agenda were pursued in partnership with private and foreign partners. During a week-long visit by the collaborative team from the Dana-Farber Cancer Institute (DFCI, a major partner of Butaro Cancer Center of Excellence; see above) to Rwanda in September 2014 there was a meeting with the Principal of the University of Rwanda's College of Medicine and Health Sciences to discuss medical education and training. At that meeting, the Principal, an academic primary care physician from Scotland who had taken leave of his regular appointment for a few years to hold this leadership position in Kigali, was quite vocal. He explained that the College was part of the University of Rwanda, a new institution inaugurated in September 2013 from a merger of seven previously existing schools, with five nursing schools under the jurisdiction of the College. He enthusiastically explained the mission of the College:

> "His Excellency [President Kagame] has given us the task of carrying the University of Rwanda forward in the same direction as that in which the country is headed. Which means that our goal is to have people say in 10 years, 'Ah, you got your Master's from the University of Rwanda? Eh eh eh! [Everyone present laughs.] So I don't know if DFCI grants degrees and how that works, but to have a joint PhD between DFCI and the University of Rwanda, for example. We want to teach the value of getting a PhD or MA. So just as Dr. Bosco [Director of Butaro Hospital] is going to get his PhD next now

> that he has finished his Master's, we want other Rwandans to see the value of research and degrees."

This agenda, as the Principal put forth, indexed the pervasive sense that indeed biomedical higher education and research were part of the knowledge economy that would establish Rwanda as a leader among its regional leaders and on the African continent. Not only is the University offered as a site for the actualization of a broader national agenda as proposed by the President; what is more, getting Rwandans to "see the value of research and degrees" is part of establishing a new north-south dynamic. This is one in which Rwanda produces first-rate scientists leading research projects within their nation rather than remaining a developing postcolonial country overrun with American and European (the majority) researchers who mine Rwanda's complex culture and history but offer little to Rwanda in return. Even so, the project of making the University of Rwanda a world-class institution was envisioned as one that could be accomplished with the help of institutions like Harvard University and DFCI. Thus, such national projects were always mediated by the transnational, in terms of the institutions, imaginaries, and partnerships that were involved.

As to the private-public dynamic, once again, while the University of Rwanda was a public institution with an agenda to educate and empower a new public, it engaged private expertise and investment from abroad to do so. This was always evident in discussions I observed that pertained to the most ambitious ideas pursued within Rwanda's cancer program—for instance, the NRL and DFCI met to brainstorm the potential future of genomics research (clinical and epidemiological) in Rwanda, given that genomics represents one of the new frontiers in cancer treatment in the global north. At that meeting I heard about ambitions to have Rwanda become a

regional leader in the field of genomics, pursuing new collaborations with DFCI scientists and clinicians to train Rwandan counterparts and develop critical laboratory infrastructure. Dr. Deo shared with the group assembled that the NRL actually had certain machines used in genomics, but lacked the trained staff to operate them. Further, he asserted Rwanda's desire to have sovereign control over a national genomics initiative, and also framed such a project as part of the path to becoming a regional leader:

> We have genomics ambitions for Rwanda but we can break down the ambition into smaller ambitions to achieve them together...We can help each other to make our enterprise the very best one in the heart of Africa...We have infrastructure; we already do some sequencing...[Gesturing to one of the NRL employees] That guy can give me the genotype/phenotype of the tumor...perhaps Rwandan tumors are not American tumors; they may be different.

The idea of building a genomics enterprise that might be "the very best one in the heart of Africa" indexes the desire to be the sovereign leader of a technologically sophisticated area of scientific and clinical relevance with little precedent in the region. He highlighted the human capacity that was already available in the laboratory, as a kind of positive comment on the viability of this ambitious project. The last idea that the profile of cancers in Rwanda might be different from that in the US may have been to bolster the legitimacy of such a pursuit before an audience of collaborative experts from the Dana-Farber Cancer Institute and Partners In Health.

One question that emerges from these comments is who is the "We" that Deo invokes? Does this "We" index his Rwandan colleagues or the Rwandan-American collaborative crowd that was present for his comments? I argue that it indexed Rwandan onco-citizens, as a certain kind of biocitizen (see Petryna 2002). The summary of present capacity in terms of "infrastructure" and "sequencing" suggest a

national Rwandan enterprise. Nonetheless, Deo's statement "to achieve [ambitions] together" and "help each other to make our enterprise the very best one in the heart of Africa" both speak to the transnational collaborations that allow for a genomics program to be on the national agenda in the first place.

Rwanda's sovereign health ambitions are often co-conceived with Partners In Health and Dana-Farber Cancer Institute, and therefore the sovereign ambition is usually a transnational one. One of the major leaders of the Dana-Farber team was an American oncologist and powerful administrator, Dr. Hoch. Years before Rwanda's Ministry of Health had begun to include public oncology on its agenda, he had helped Partners In Health treat cancer patients on a more ad hoc and individual basis in a few of the countries in which PIH works. At the genomics meeting he related that in collaboration with colleagues at Butaro Hospital, his team had applied for genomics-related development grants. He explained to the group that "We need to tell the rest of the world what we're doing, and figure out how [to do that]. Also it's good for you and Rwanda to be seen as a leader in this area...and you're already a leader in so many areas like HPV vaccination." Here Dr. Hoch reminded everyone that Rwanda had recently adopted a new technology, the HPV vaccine, which is now part of the standard vaccination schedule, and therefore already proved the national capacity to be at the vanguard of biomedical technology within the region. Dr. Hoch pitched this all as a collaboration—he suggested that perhaps Rwandan scientists and clinicians might visit Boston and Dana-Farber to "learn some technologies and come back [to Rwanda]" and shared that the team was working on procuring necessary machines for the NRL to gradually build a genomics repertoire.

Dr. Hoch was clearly invested in seeing the partnership between Dana-Farber, the Rwandan Ministry of Health and Partners In Health further expand and thrive through a new genomics initiative to be pursued with the NRL. He was also very forthright about the unique challenge of keeping up with the biomedical and clinical cutting edge represented by genomics, even for a world renown cancer center like the Dana-Farber. He explained that in cancer medicine treatments were increasingly based on genetic analysis, and that this was difficult because every few years, with rapid technological advances/advancements, "what we do changes." He phrased Rwanda's challenge as follows:

> So how can we work together on a 5-10 year plan here in Rwanda that moves quickly with the science? Every 12-18 months we change the technology we use to do genetic analysis…That's the challenge here—the train is moving fast…How do we leave the station?

Dr. Hoch's particular proposal that Rwanda develop a long-term plan to enable its genomics program to "move quickly with the science" demonstrates one of the many instances in which the national ambition to have the most cutting-edge and/or most advanced possible technology for cancer (and healthcare more broadly) was generated by a key partnership. As such, ownership of such an ambition could be complicated, precisely because it was not simply a national ambition owned by national experts. Naturally, his plan was also framed in terms of the collaborative "We," as a shared journey to "leave the station." He later used local epidemiological observations to make a case about the relevance of genomics research in Rwanda given its specific *national* disease patterns, asking how Rwanda might build teams to investigate the high prevalence of Wilms' (or Wilms) tumor, a pediatric kidney cancer that he deemed "very rare in the US."

In response to Dr. Deo's admission that there was likely already "underused equipment" and "sophisticated equipment" at the NRL that would be relevant to genomics, Dr. Hoch extended an invitation to NRL technicians to spend time at Dana-Farber learning to use pertinent machinery. He noted that in the recent past while developing the clinical pathology laboratory at Butaro Hospital technicians from Butaro had visited labs at the Dana-Farber in order "to get some training and learn from experts," resulting in "a positive experience for those in Butaro who've done it...they now have colleagues in Boston they can consult." As if to encourage everyone in the face of a logistically, technically and financially challenging endeavor, Dr. Hoch focused his gaze on Dr. Deo and those flanking him at the head of the table. He offered one of his closing thoughts: "For this to work in the end much of it is developing relationships and partnerships." It was very common for American clinicians and staff members from the Boston hospitals and Partners In Health—whether working on research, IT, education or fundraising efforts—to invoke the "relationship" and the "partnership" as not only central to their work in Rwanda, but also as a prerequisite for achieving any goals shared with the Rwandan hosts and counterparts.

There were moments in my fieldwork when it seemed that the terms "partnership" and "partners" were used with such frequency by Americans and Rwandans[27] in the cancer program that they seemed fetishized, or as if they lost some of their force through sheer use. Or perhaps it was crucial to reiterate the partnership regularly in a context where American partners were quite aware of a central state that was vehement about national ownership and direction of the cancer program and other health sector projects. By constantly mentioning partnership, American

[27] Maybe I should quantify this—it seems that the 'partnership' was maybe invoked slightly more often by American actors. Probably should review notes to see about invocation of partnership by Rwandans.

collaborators could index their commitment to Rwanda's oncology program as a national project, precisely because, as they often pointed out, such partnerships were impossible with "weak governments."

Naturally there are immense daily challenges in the delivery of cancer care in Rwanda's private sector, regardless of the partnerships with buttress it. This reality will be illuminated in a deeper experiential fashion in Chapter 3, which examines experiences on Butaro's oncology ward and in the outpatient clinic, but it came through regularly in the declared struggles that surfaced during meetings at which PPP partners assembled to work on clinical care. One such example was an intensive, one-day meeting to revise the national pediatric cancer protocols. Participants included members of the Ministry of Health, RBC, PIH, and DFCI and the meeting was scheduled during another week-long visit of DFCI contingent members in March 2015. The day's program featured presentations by physicians mostly from Butaro Hospital, CHUK, and DFCI, small group revision sessions focused on specific cancer protocols, and group discussion of the proposed revisions. Also present was a young Rwandan doctor who was in the midst of specialty training in South Africa but visiting home and planning to return once trained to work in pediatric oncology. One enduring challenge that was mentioned by various Rwandan pediatricians at the protocol meeting was the time lag in diagnosing patients because of the ongoing major dependence of Butaro Hospital and CHUK on BWH and DFCI to process biopsy specimens and provide definitive pathology reports, critical to establishing each patient's diagnosis and thereby proceeding with treatment.[28] One CHUK doctor, Dr. Placida, explained that

[28] In 2010 when I began my research and involvement in Rwanda's cancer program it was already the case that Butaro Hospital and CHUK would send gross (as in not yet prepared into a slide) tissue biopsies to BWH's Department of Pathology, through an agreement negotiated and mediated by PIH.

the ultimate turnaround from the day of a patient's admission to his final diagnosis was often six weeks—because of pathology material shortages, the sample was often sent to Butaro and from there onto Boston where the processing would take a few weeks.

In this and other pragmatic ways, public sector cancer care is heavily reliant on the private-sector resources, both human and material, of BWH and DFCI. The power of PIH to have catalyzed and continued to support such a PPP indicates its probable status as a Para-state institution (see Geissler 2015). The question about how such a partnership serves the interests of BWH and DFCI remains an obvious one given the fixation on "partnership," and certainly coalesces at least partially around the power of becoming a leader in global health science (Crane 2013; Brada 2011).

Naturally, it is important to consider the various ways in which participants in Rwanda's cancer program conceptualized the meaning and function of "public." At the same protocol meeting, Dr. Placida, emphasized that "public awareness" was still a major barrier in her mind because "most patients come at a late or [in the] last stages of the cancer…But if society has been sensitized about the signs they won't consult witchcraft and will come earlier." The phrase "public awareness" is certainly one that has been learned from the constant American presence in Rwanda. Thus, this is an apt juncture at which to consider how both the Rwandan and American contingents of

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On a number of occasions I delivered biopsies and the pertinent paperwork to BWH upon my return to Boston, as did many PIH physicians and team members. There were only two trained pathologists in country. Since that time the Ministry of Health has invested in the training of a cadre of Rwandan pathologists, paying for a cohort of young medical graduates to pursue pathology residency programs abroad (Kenya, Uganda, and South Africa). Within the next few years, members of this cohort will complete their training and return to Rwanda, yielding about 12 new pathologists. Another recent development at Butaro has been a PIH and DFCI-led training of pathology technicians to prepare biopsy samples into slides that can be photographed once under the microscope and sent as cellular-level images to BWH via email, thus speeding up processing time. Furthermore, two Butaro laboratory technicians were sent to Boston to complete an intensive training in immunohistochemistry (IHC), a staining technique also used in the identification of abnormal cells.

PPPs in cancer care worked on "the public." There were a certain number of RBC and Ministry of Health-sponsored public campaigns to teach citizens about breast and cervical cancer by way of radio programs and national "awareness" days.

Also visible were the efforts of members of Rwanda's few civil society groups founded as breast and more recently pediatric cancer associations. Simultaneously, in Butaro and at the level of Burera District, since 2010, physicians from Butaro, PIH, DFCI, and BWH have collaborated around cancer education initiatives aimed at community health workers and patients. Within the latter efforts, the purported emphasis was usually on getting the word out on cancer care so that rural Rwandans would know something about the signs of cancer, the existence of Butaro Hospital and the overall necessity of consulting health care providers in Rwanda's national, decentralized system. This approach was also born of the deeper tradition guiding PIH, derived from Paul Farmer's early and militant scholarly argument that "indigenous culture" (such as voodoo practices in Haiti) was often used by hegemonic first-world institutions to explain why local people did not consult biomedical practitioners and thus could not actually benefit from biomedical treatment on par with international standards of care (Farmer 1999, 2005, 2006). Farmer's contention was (and remains) that, if you bring high-quality, technologically up-to-date and dignified treatment to the world's poorest in any society and they see it work, they will quickly learn to seek it out and local understandings of disease and pathology will change apace. Judging from the pediatrician's comment about witchcraft it does seem that this kind of logic may well be shared by Rwanda's public sector physicians—in fact it is known that the government has been vocal about the need to educate the populace away from traditional healers and witchcraft.

At one high-stakes meeting the Minister of Health mentioned that under her leadership there had been a large gathering of all the traditional healers in the country, asking them to organize themselves into an association that could more easily collaborate with the biomedical field. They had failed to do so—the Minister reported this in a dismissive tone. For Rwandan clinicians, politicians, and civil servants involved in the cancer program, the social work that had to be done on "the public" to bring it up to date, to enable the gradual appearance of cancer patients presenting in early stages of their disease, was part of a deeper set of preoccupations concerning the nation. At the same pediatric cancer protocol meeting, Dr. Béata lamented that there was yet no national cancer registry in place—she and her colleagues had established a small one at CHUK, but this could not yield any "real statistics." She insisted, "We need a registry that functions in every hospital." This concern can be read in a pragmatic light—there can be no national statistics on cancer until there is a national registry, and thus there can be no Rwandan oncology that is based on a legitimate knowledge of national disease burden.

Another grounded challenge that emerged during this meeting (as at others) was the difficulty of coordination within the public sector of the cancer network, despite Rwanda being a very small country. Dr. Béata was the one to voice the problems derivative of having chemotherapy services consolidated at Butaro Hospital, an almost two and a half hour drive from Kigali, half of the journey on unpaved uphill road with an altitude ascent explaining Butaro's cooler climate. She explained the difficulty and effort involved in stabilizing patients and organizing transfers from CHUK to Butaro (usually in an ambulance), and called for an urgent plan of how to establish chemotherapy in all referral hospitals including CHUK. Owing to a general

dearth of ambulances, CHUK could not designate one for the sole purpose of transferring patients to Butaro. Thus, often at issue was also collaboration among the various public hospitals of the cancer network, and their coordination and sharing of resources given a system in which different components of cancer care were siloed within individual network hospitals.

There were other ways in which Rwanda's public health sector received attention in the broader global realm of public health governance, and within larger PPP assemblages. However, sometimes the ambitions for Rwanda were externally conceived and did not necessarily come to fruition. During the September 2014 DFCI visit to Rwanda there was a dinner meeting to discuss cancer-specific revisions and updates for the 18th WHO Model List of Essential Medicines (MLEM), begun by the World Health Organization (WHO) in 1977. As Dr. Hoch explained, the WHO accepted petitions to add specific drugs to this list every two years, but the (cancer?) list had remained unaltered without formal review for a couple decades. Recently, the WHO had asked a group of cancer experts from around the globe including Dr. Hoch, as well as members of the Union for International Cancer Control (UICC) to revise and update the set of oncology drugs included on the list. The group, he said, had decided to focus on 29 cancers that are curable or for which treatment to extend a patient's lifespan made a significant difference (in overall survival?).

The WHO invitation had actually come just a few weeks after a contingent within the expert group had petitioned the WHO to add trastuzumab (Herceptin), used in the treatment of breast cancer, and imatinib (Gleevac), used in the treatment of chronic myelogenous leukemia (CML) and gastrointestinal stromal tumors (GIST), to the list. Dr. Hoch stated that since both drugs are still on patent, the idea had been that

getting them added to the list would be one step in concerted advocacy aimed at reducing their cost. He was adamant that Rwanda had been a major partner in the latter application process, and had "stood by" his group. As for the current project of submitting revisions to the MLEM, Dr. Hoch was convinced that the entire process mimicked the process generally used in Rwanda to determine essential public health interventions and resource goals. He put it as follows:

> In so many other areas of health care, Rwanda has been a leader in the world, in HPV vaccination, in HIV treatment. And we feel that this is a place also where Rwanda can take the lead and set an example for the rest of the world on how to develop essential medicines for cancer in a very practical and doable way. So we think this is a great opportunity[...]

In short, Dr. Hoch was requesting that his Rwandan collaborators take an active role in the list's revision. The composition of the group assembled was certainly promising—present were clinicians and leaders within the cancer program from the NRL, RBC, PIH, Butaro Hospital, CHUK, and KFH; the current Principal of the College of Medicine and Health Sciences at the University of Rwanda. Further, the meeting was co-hosted by the Minister of State in the Ministry of Health in charge of Public Health and Primary Health Care, Dr. Patrick Ndimubanzi, who gave the opening remarks.

There were American and Rwandan surgical and medical oncologists present with varying agendas given the particularities of multidisciplinary cancer care—the surgeons were adamant that certain basic drugs crucial for the operating room were missing, like halothane (an anesthetic that is inhaled in gas form). A young Canadian-American radiation oncologist argued that radiation therapy should be on the list, even if the modality of radiation didn't constitute a "drug," because it was an essential part of standard treatment regimens. One physician from KFH returned the discussion to the subject of oncology drug pricing—"It is not a technical problem but a problem

of funding." Despite his nomenclature, referring to patients as "customers," he was convinced that the same advocacy battle engaged for HIV/AIDS must be pursued for cancer; what was needed was more drugs in the Rwanda's armamentarium and therefore more sources of funding beyond medical insurance.

Nevertheless, the overall discussion was fairly circuitous, with various parties voicing their concerns, a spattering of debates, and few disagreements as to what was at stake. On a few separate occasions, certain individuals interjected to remind everyone that the goal of the evening was to generate a new list of essential cancer drugs, and not to get distracted by too many issues. Yet in the end the major agenda—revising the list—was not engaged. There were whispered rumors that the medical oncologists had a monopoly on the list. In any case, when WHO published the new list, with Dr. Hoch at the helm of the expert group, there was zero mention of any Rwandan participants.[29] Why include this event in my ethnography? To show that at certain moments, very powerful foreign partners within the PPPs figuring in Rwanda's national cancer program proposed ambitions for its involvement in major initiatives that were not feasible or could not succeed given differing agendas and challenges. This event also indexed the power dynamics of the international public health field and its multilateral institutions such as the WHO: its assemblages of expertise are still derived from the global north. Part of this certainly derives from the fact that Rwanda (like other nations of the global south) still suffers from a dearth of medical specialists

[29] For an announcement of the new list and access to it see the following: [http://www.uicc.org/who-publishes-new-edition-its-model-list-essential-medicines]; [www.who.int/medicines/publications/essentialmedicines/EML2015_8-May-15.pdf]; and [www.who.int/medicines/publications/essentialmedicines/Executive-Summary_EML-2015_7-May-15.pdf]. Accessed January 25, 2016.

including oncologists, so that having major input for a document like the MLEM, or leading its drafting in any way still occurs through partners who are traditionally trained specialists in the north.

On a number of occasions, Rwandan leaders in the cancer program also made reference to PPPs as being important for national cancer program aspirations. At a Kigali collaborative meeting of RBC and DFCI also held in fall 2014, participants engaged in a discussion about the future of radiation therapy in the country. This meeting preceded the visit by the IAEA in November. One American assistant from DFCI asked Dr. Sylvia, the head of RBC's noncommunicable disease division, about the Minister of Health's comment that Rwanda would pursue a private-public partnership for its first radiation therapy facility. She replied that the Rwanda Development Board (RDB) had shared the idea of a PPP around radiation oncology with interested (private sector) investors so that they might "support the IAEA" (read political will) and also offer major financial support. The RDB site summarizes its mission: "Fast tracking economic development in Rwanda by enabling private sector growth. The scope of our work includes all aspects related to the development of the private sector."[30] The RDB has been a major political and economic force behind newer institutions like RBC. RDB also claims to be "independent and influential. It reports directly to the President and is guided by a Board that includes all the key Ministers (e.g., finance, commerce, infrastructure, agriculture)."[31]

Thus, yet again, the PPP was politically, practically and discursively mobilized in a setting where any entrenched division between or full autonomy of the private and public sectors was a fiction. Another Rwandan physician invoking the PPP, with

[30] See [http://www.rdb.rw/about-rdb/vision-and-mission.html]. Accessed January 25, 2016.
[31] See [http://www.rdb.rw/about-rdb/history.html]. Accessed January 25, 2016.

distinct private and public sectors despite strong surveillance of all private sector activity by the state was Dr. Blaise Uhagaze, President of Rwanda Palliative Care and Hospice Organization (RPCHO), a civil society group founded in September 2013. He explained to me that the organization's funding came primarily from membership fees paid by its 14 members, many of whom were doctors. However, there was a plan to expand the funding base through private sector contributions, towards the end of their presently twofold agenda: to be involved in community health and to do institutional capacity building. The precise vision was to have a doctor trained in palliative care and thus able to direct this area within each hospital in the country—they had already been training such a cadre in Kigali.

When I asked Dr. Blaise about the role of the PPP, he related that he had led a study of them in 2011 concluding that 40% of all medical consultations in Rwanda were taking place in the private sector. Of course, he said, PPPs were essential and there were already many marking the health care landscape in Rwanda—he cited the private medical insurance companies CORAR and SORAS, pointing out that those whom they insured regularly received care at public institutions like CHUK. Conversely, he said, many insurees of RAMA—the largest insurance program, and public, for civil servants—sought treatment in private clinics. The military insurance program, MMI, was also public, he reminded me. How did he define the private sector? It was represented by "businesses across all sectors." He depicted Rwanda's private sector as an already vibrant one, stating that the state-run Rwandan Social Security Board (RSSB, the equivalent of the French *caisse sociale*) was primarily comprised of private Rwandan investors, although he could not specify the predominant industries of these investors. Indeed, he exclaimed, "Starting next year the RSSB is going to

manage *la mutuelle* [national health insurance system] rather than the Ministry of Health. It has gotten too large for the Ministry in any case." Dr. Blaise was also among a number of interlocutors who insisted that Rwandans were generally quite attuned to quality—whether good or bad—and thus aware that the best quality health care, but also in other areas, was to be found in the private sector. As such, he said, the challenge was to improve quality across the board.

Private-public partnerships also affected the order of development in the cancer program. There were moments when the private sector's contribution drove the pursuit of projects within the developing cancer infrastructure that were not entirely logical at a pragmatic level because the material resources needed to sustain the results were not reliably available in the implicated hospital settings. One example of this was a national training led by RBC, PIH, DFCI in 2014 with a targeted one-year grant from the British pharmaceutical company GlaxoSmithKline to train Rwandan doctors (from various district hospitals) to perform core needle biopsies (CNBs)[32]. At the end of October 2014, I attended a workshop assembling representatives of RBC and PIH with physicians from Butaro Hospital and many other district hospitals had participated in the training, beyond the core set of hospitals in the current cancer network that are described elsewhere. The goal of this workshop was to review the results and way forward for the CNB training program, and also for a series of baseline national cancer trainings geared at doctors and nurses. As regards the CNBs, while the implicated trainee group had performed well in mastering the basic technique, a steady national supply of core needles to supply district hospitals was still unavailable

[32] The core needle biopsy is a common procedure, often used to remove tissue from a tumor that can be felt through the skin, such as a breast mass or enlarged lymph node.

(RBC and the Ministry of Health were engaged in establishing such a stockpile in the near future).

As such, when the trainees returned to their respective hospitals, they had no core needles with which to perform the biopsies as needed on their patients (which also constituted their practice of the technique from the start). There was a discussion of this issue, and in fact the Rwandan physicians were more concerned about it than their American collaborators. Richard, a leading Rwandan doctor within the cancer program who had been a key participant said, "My concern is you send someone for a training, but when he comes back you do nothing to help him practice. This is a serious question because we are giving training to all district hospitals." An American surgeon who had been one of the trainers in CNB responded to him:

> I think exposing people to things before we have them is fine because things are moving rapidly here in Rwanda. It's reasonable to say that in a year we will have core needles in many or most hospitals...In terms of follow-up and supporting people after training, I agree that this is a systems problem. It comes at many levels including RBC and MoH [Ministry of Health]. Every country has their own systems problem. *Pole pole* we are adjusting systems and your point is a very good one Richard, we need to support people after training them.

Here again, as with the WHO MLEM, we see an American collaborator articulate an ambitious vision for Rwanda, a place where health development is known to "[move] rapidly." The surgeon in question was quick to identify the challenge at hand as a "systems problem" implicating RBC and the Ministry; thus an ostensibly public sector problem, while the core needles were inevitably going to come from the private sector, whether through a corporate (pharmaceutical) philanthropic donation or eventual bargaining to procure a national supply at a reduced price per unit.

A number of the Rwandan physicians present were more troubled about the introduction of skills requiring materials not yet steadily available. One local breast

surgeon implied the futility of such interventions when stepwise, concerted planning had not been engaged:

> It's not a problem of biopsy, it's a problem of surgery in general. When you train people to do biopsy; suppose these guys take a biopsy—who is going to transport it, take it to the hospital, package it etc.? This is not planned before we train people. We go back into our daily activities without addressing all of this. [We must] Otherwise we'll be training and training without an improvement.

This kind of widespread opinion indexed a shared understanding (not often voiced) of the pitfalls of accepting a targeted private sector contribution without a strong process in place in the public infrastructure for the field at large—in this case, surgical oncology. It was generally evident that the private-public partnership inherent in the coalition of PIH and the Ministry of Health was eager for any private investment into the cancer program, such that it would accept contributions like that of GlaxoSmithKline, without necessarily engaging the question of the readiness, logic, or sustainability of a specific intervention. The surgeon pointed out the hazard of constant trainings too—there was the risk of fetishizing the training endeavor itself and imparting skills that could not yet be deployed in the context at hand.

Despite the constant bleeding of private into public in the Rwandan context, and therefore the difficulty of disentangling them in social life, there were always scattered attempts to decisively differentiate these sectors. For example, I observed one such attempt when physician compensation was in question. During my fieldwork year, a program of one-day long national cancer symposia was inaugurated, to be hosted on a monthly and rotating basis by each of major hospitals in the cancer network. Cancer care providers from the hosting hospital would give presentations about the state of cancer care delivery at their institution and then engage an extended discussion with clinicians and administrators from the other sites about major

challenges, better ways to share resources and manage patients (many of whom were shared), and clinical protocols. Essentially the focus was the better coordination of care and projects across these sites in the context of an explicitly national cancer infrastructure.

The November 2014 symposium took place at King Faisal Hospital (KFH), a crucial institution to consider if we are to understand the entanglement of the private and public in Rwanda's cancer program. KFH is a private, but government-owned hospital in Kigali, built in 1991 with support from the Saudi Fund for Development. Official sources state that during the genocide KFH served as a refugee camp and medical center for thousands of displaced persons, but established specialist services in 1998 following efforts on the part of the private entity Netcare South Africa, and the Government of Rwanda.

While KFH maintains its status as a private hospital and caters to the small world of wealthy Rwandans for its overall profit base, it also accepts more typical patients with *la mutuelle*. In particular, many of the cancer patients I came to know at Butaro had been referred to KFH's pathology, radiology, and surgery departments, given their comparative strength of material resources and specialists in these areas. As such, both out-of-pocket and nationally insured patients seek care at KFH, so that its position as a "private" hospital is also not clearly distinguished within the national public cancer care infrastructure that is in the making.

During the discussion, one KFH physician proposed to the Butaro team that they consult with their clinical administration to see how to bring KFH's head and neck surgeon there twice a month to operate on patients. "We need to think outside the box," he insisted. Yet he was quick to add, "But of course he would need to be

compensated since KFH is a private hospital; this has to be arranged." The immediate mention of compensation for the KFH surgeon evoked the desire to differentiate KFH physicians as belonging to the private sector and protect their economic interests and status in the context of a cancer network in which private and public institutions must constantly share resources and manage shared patients. This kind of deliberate marking of the private domain exposed the reality that even as the functional domains of the private and public were imbricated, their individual status was constantly being produced and perhaps defended.

And yet, clinicians from KFH were not at all antagonistic towards the project of public oncology—at the same symposium the CEO of KFH remarked that it would be crucial for RBC to engage in advocacy for new laboratory-based diagnostic tests (involving immunohistochemistry) so that *la mutuelle* might begin to reimburse KFH (and other hospitals) for the use of such tests. This, after all, was the only way to make these new diagnostic technologies accessible to the average Rwandan patient. At the same time, KFH physicians wanted to see the private sector grow and thrive. At another inter-institutional cancer symposium, one of their specialist physicians wondered, given the rapid growth of Kigali's population and the fact that KFH teams worked through the night in the event of an emergency, why no one had yet opened a private histopathology lab in the capital. He was concerned that the ongoing dearth of pathologists put too much pressure on KFH: "Can our pathologists work through the night?!" he asked in a tone of mild indignation.

Chapter 3 Malignant Modernity: Unsettling Etiology and the Making of Onco-Citizens

"*Through the square of skin that had been left clear on his stomach, through the layers of flesh and organs whose names their owner himself did not know, through the mass of the toadlike tumor, through the stomach and entrails, through the blood that flowed along his arteries and veins, through lymph and cells, through the spine and lesser bones and again through more layers of flesh, vessels and skin on his back, then through the hard wooden board of the couch, through the four-centimeter-thick floorboards, through the props, through the filling beneath the boards, down, down, until they disappeared into the very stone foundations of the building or into the earth, poured the harsh X rays, the trembling vectors of electric and magnetic fields, unimaginable to the human mind, or else the more comprehensible quanta that like shells out of guns pounded and riddled everything in their path.*

And this barbarous bombardment of heavy quanta, soundless and unnoticed by the assaulted tissues, had after twelve sessions given Kostoglotov back his desire and taste for life, his appetite, even his good spirits. After the second and third bombardments he was free of the pain that had made his existence intolerable, and eager to understand how these penetrating little shells could bomb a tumor without touching the rest of his body. Kostoglotov could not give himself unreservedly to the treatment until he had grasped for himself the theory behind it and so was able to believe in it."

--from Aleksandr Solzhenitsyn's *The Cancer Ward* (p. 68)

I. Introduction

In this chapter I delineate *kanseri* (cancer) as a category that has recently crystallized in Rwandan society; it encompasses a disease group and illness experience with which citizens are constantly experimenting as they work through their ideas about etiology (both instrumental and capacious causes of cancer), prognosis, contagion or transmissibility, treatment, and death. The argument of this chapter encompasses three conclusions. The first is that the manner in which Rwandans contemplate and delineate the socio-biology of malignancy unsettles and ruptures a rigid distinction between infectious and non-infectious disease that has long characterized how we think about disease in the global north and in the global south, and how global health interventions in Rwanda, and Africa more broadly, are framed. Second, ideas around contagion and transmission that have emerged in the Rwandan encounter with tumors are quite culturally specific and relate to the first element of my argument on infectious and non-infectious disease categories. Articulations of the contagious nature of cancer must also be considered within the broader literature that

has described African vernacular ideas about porous boundaries between the body, spirits, and the broader physical environment (Masquelier 2001; Monfouga-Nicolas 1972; Schmoll 1993). The Rwandan case exemplifies a notion of cancer as contagious, but not infectious, meaning that the idea of contagion is at play in the absence of a microbe or virus. It suggests that if malignancy is deemed a contagion, it is as much a metaphysical one as an etiological one. Further, I also bore witness to a rich use of metaphor to talk about cancer—a reminder that illness as metaphor is not simply a Western semiotic practice (Sontag 1978). Third, I will emphasize how the Rwandan state interpellates onco-citizens of the onco-nation through public education campaigns focused on cancer, the HPV vaccination initiative, and radio programs. I want to reiterate that Rwandans are experimenting with ideas about malignancy in the face of new encounters with oncology—these ideas draw on various symbolic repertoires as well as deeper histories and entanglements with disease, suffering, and violence.

It is also important, as an epistemological and political gesture, to foreground a processual account of Rwandan reckonings with cancer, and to insist that responses to cancer are constantly changing according to accrued new experiences, and so my generalizations may be very much embedded in the present moment of the material I collected. At its core, the discipline of social anthropology, and other interpretive social sciences, regard claims about social, political, material, and spatial change with a heavy dose of suspicion, often because claims to significant social change often mask entrenched processes of social reproduction and the perpetuation of structures of domination, exploitation, and inequality. Yet, the fact remains that Rwanda's national oncology infrastructure and agenda has been developing at a strikingly rapid pace:

when I first went to Rwanda in June 2010, there was yet no project of a nationwide cancer program, yet today the country boasts one of the most notable efforts within the global south to build public oncology from scratch, and one of the only such initiatives on the African continent. Again, I must emphasize that while Rwandans certainly had encountered malignancy long before the arrival of programmatic oncology,[33] and cancer has always been there, their association of *kanseri* (derivative of the French word *cancer*) with a pattern of physical symptoms and signs, and biomedical treatments like chemotherapy and surgery, is quite recent. In essence, cancer was always already there in Rwandan experience, but it wasn't known as the disease *kanseri*, and there was likely much less circulating discussion about it than in the present. Indeed, many times (including before 2014 during my shorter field periods in Rwanda) I heard more elderly cancer sufferers and their family members mention how, with their new knowledge of *kanseri*, they could retrospectively identify individuals in their communities who had been suffering from *kanseri*, in some cases many years earlier. A sense of semiotic experimentation and discovery infuses the ways in which Rwandans conceptualize malignancy, but they also speak in very decisive terms about the impoverishment and familial suffering that tumors catalyze.

In this chapter I draw extensively on 45 in-depth patient interviews conducted with cancer patients at Butaro Hospital between August 2014 and March 2015—most

[33] The Belgian archives I consulted reveal record keeping of cancer deaths as early as the 1920s. Furthermore, state-sponsored Euro-American cancer research efforts and academic research projects around cancer in Rwanda, Burundi, and Eastern Congo were numerous in the late 1940s, 1950s and 1960s. I my ongoing research and writing, I look at the fascinating broader history of malignancy and transnational research it spurred in the region from the early 20th century onwards.

on the inpatient ward and some in the outpatient clinic.[34] However, my conclusions also derive from ample time spent on patient rounds and in outpatient consultations during my shorter periods of research and volunteering at Butaro between (June) 2010 and (February) 2014, which also afforded me a great deal of observational time, individual patient interviews, and informal conversations. Further, the analyses are also inflected with the time I spent in people's homes and at various community health centers in Burera District and in Kayonza District (Eastern Province) through the privilege of joining Rwandan-American teams involved in cancer education, prevention, and care. This was largely owing to my initial position as a Partners In Health volunteer and early-stage student researcher. While many of the interviews I use are from 2014-2015, I also make an effort to think back to what Rwandans were saying about cancer in 2010 and 2011. I argue that today, Rwandans talk about cancer using a lexicon of infection and transmission. In particular, they imagine tumors as "abscesses," implicating an infectious process that has taken over an enduring wound. As such, the vernacular view is that cancer is actually a higher order process that builds on processes of infection and transmission. It comes forth when an abscess or wound is not properly cared for and healed. This reality complicates the strict division between infectious and noncommunicable diseases that the national public health system, in collaboration with transnational partners, generally maintains, leaving aside public education efforts around one of the virus-associated malignancies, cervical cancer. My data speak to the manner in which the experience of infectious, acute disease is imbricated with an experience of the chronic, non-infectious character of

[34] The 2014-15 interviews were structured, but I maintained no strict rules about how much time could be spent on each theme or question, which allowed each patient to emphasize the issues he or she felt were crucial to his or her story and trajectory.

cancer, but also to the ways in which Rwandan citizens have a sophisticated and deep engagement with the historical presence and embodiment of both kinds of disease.

As to the circulation of public discourses around cancer, national education campaigns have been present since 2010, and their rhetoric is heard with increasing regularity in daily life. As mentioned in Chapter 1, in 2010 there was the first public campaign for cervical and breast cancer prevention and awareness, aimed at all of Burera District (where Butaro is) in which I participated throughout the summer. It entailed presentations to and discussions with community health workers, as well as the introduction of visual inspection with acetic acid (VIA) and cryotherapy through the first training of midwives, nurses and physicians. The latter immediately applied their new skills over the course of a few days of screening (and referring within the system, as necessary) a few hundred women within Burera District. Reproductions of that initial training have been reproduced by the Ministry of Health and Rwanda Biomedical Center in other districts, and over the years I attended such trainings elsewhere, including as recently as November 2014. Recent years have also seen the occasional billboard or poster displaying messages about screening for breast cancer and doing breast self-exams. Another major instantiation of public discourse about cancer has come through the development of a civil society community focused on breast cancer especially (and pediatric cancer now gradually), which in the past few years has organized an annual breast cancer awareness and fundraiser walk featuring women survivors (in particular the founders of the two major organizations who were treated in South Africa, Kenya, India, and the US), and has initiated other education outreach efforts as well a distribution of wigs and prosthetic bras (at a small cost) in Kigali. A major tool of the state to interpellate onco-citizens has been the radio. The

radio is ubiquitous in Rwanda and serves as the common denominator channel for news, and public communications. Indeed, there has been scholarship on the extensive use of radio during the 1994 genocide and civil war, by the Hutu Power coalition. Beginning just a couple years ago, the Ministry of Health and Rwanda Biomedical Center have sponsored radio programs that address the signs (which can be objectively observed by others) and symptoms (disease manifestations apparent to the patient) of cancer. Such Radio broadcasts have also been used to explain the HPV vaccination campaign, and inform citizens about the importance of seeking care at health centers (as the first point in the referral system) to rule out possible malignancy. Even if not every Rwandan family owns a radio, there is always one in a neighbor's home or a nearby shop or pub, and within villages residents regularly gather around the radio. Many patients mentioned what they had heard about cancer on the radio, as well as discussions within their villages and broader communities, making it clear that cancer has rapidly become a topic in everyday life, largely as a result of a state-sponsored set of public interventions and discourses that continue to proliferate.

II. A Postcolonial Lexicon for the Cancer War(d)

Before delving into the three parts of my argument, I want to present the Rwandan lexicon for talking about tumors and cancer. Very early on in my interviews, one patient used the word *ikibyimba* to denote a breast mass. It translates literally as an abscess or a boil. I was to hear this term used by many different patients to refer to tumors all over the body—those of the breast, brain, colon, rectum, cervix, and eye. 'Abscess' is therefore a better translation, as a boil is specifically defined as a pus-filled

collection on the skin while an abscess can be in any body tissue.[35] The majority of these 45 Rwandans—men and women of varying ages, patients themselves or parents of children with cancer—described having a clinician discover an abscess as the critical event leading to a cancer diagnosis. Some individuals described how they had been told that they had an *ikibyimba cya kanseri*, or abscess with cancer [in it]. An imagery of the abscess as a container for cancer was furthered by the regular comment that one's abscess had been "tested for cancer," part of many narrative moments evoking the experience of having undergone a biopsy. Overall, the notion that cancer develops out of an initial abscess was a strongly held conviction even as patients sought further explanations for malignancies—one 25-year-old woman asked me whether it was possible for people without an abscess to develop a tumor as she had "no idea" about cancerous growths in the absence of an abscess. The widely shared cancer lexicon included other terms derivative of the abscess, *ikibyimba/ibibyimba* (singular/plural)[36]: the diminutive noun *akabyimba/utubyimba* (a small abscess); the verb *kubyimba* (to swell); and the verb *kubyimbuka* (to shrink).

One older man, Philippe, suffering from skin cancer explained to me how he believed that historically, cancer had probably existed but was "unknown." He shared the vocabulary he claimed had long been used to denote masses before they were being re-learned as malignant cancers: *inkabya*, to mean a very large abscess; *umufunzo*, to denote a large wound with a cavity; and *umwingo*, a swelling in the neck. Personally, in the past Philippe had thought cancer was a disease "of rich people," because for a

[35] The Merriam-Webster Dictionary (2015) defines a boil (noun) as "a localized swelling and inflammation of the skin resulting from infection of a hair follicle and adjacent tissue, having a hard central core, and forming pus." An abscess is "a localized collection of pus surrounded by inflamed tissue."

[36] When I refer to Kinyarwanda nouns, I will generally provide the singular and plural forms in this format (singular/plural).

long time he had only known of one person suffering from it, the Director of a branch of what was then the Banque Commerciale du Rwanda, in Butare (a city in Southern Province). He had learned about the man's struggle from conversations in his community, in Southern Province. "Now," Philippe concluded, "I have learnt that cancer is an illness that can affect anyone, starting with children.

III. A Lack of Barrier Protection: Tumors Both Infectious and Non-Infectious

My first contention is that the manner in which Rwandans contemplate and delineate the socio-biology of malignancy unsettles and ruptures a rigid distinction between infectious and non-infectious disease that has long characterized how we think about disease in the global north and in the global south, and how global health interventions in Rwanda, and Africa more broadly, are framed.

Although the Director of Butaro Hospital once warned me in 2014, knowing my set of research interests, that Rwandan patients still knew "nothing about cancer" (in spite of his sustained moral and logistical support of my presence at Butaro), my conversations on the wards revealed patients had assimilated substantial facts about the clinical particularities of tumors. One 34-year-old man told me that as soon as the swelling of his abscess diminished, he had faith that he would recover, thus demonstrating his understanding that a growing tumor was a negative prognostic indicator. Another young man aged twenty-two mentioned that doctors at King Faisal Hospital had discovered by way of a computerized tomography (CT) scan that he had an "abscess" so large it might block his intestines and "prevent anything from moving through," articulating the general concept of intestinal obstruction (whether or not

secondary to a malignant mass) quite adeptly. He was among those to explain that his biopsy had revealed that there was cancer *in* his abscess.

Various patients referred to receiving treatments aimed at preventing their cancer from "getting advanced" or "growing," often using the verb *gukura* (to grow). One 37-year-old mother with a four-year-old daughter undergoing treatment for Wilms' Tumor (nephroblastoma, a kidney cancer primarily affecting children) explained how her child's right kidney had been spared: "Luckily, the right kidney was not affected by the abscess [*ikibyimba*]. The abscess was on a tissue next to the kidney, but not touching it." Thus this mother was also calling the tumor an abscess, and was aware of the prognostic advantage of a smaller abscess that had not grown into both kidneys. It was clear that patients retained a lot of the information clinicians shared with them in explaining cancer diagnosis and prognosis, and treatment courses. Abscesses (*ibibyimba*) could appear quite sinister.

One 60-year-old woman described how she had suffered from a breast abscess with "two heads," which grew until one head burst. At that point she worried that her breast might be harboring an *inyamaswa*, a wild animal or beast. She sought a traditional treatment in the form of grasses (*utwatsi*) and applied it to her breast but to no avail, and later visited a local health center where her trajectory of biomedical care began. She showed me her affected breast, explaining that since the "bursting of one head" she'd had acute pain in the other head, extending to her upper back. In the remaining bulging portion of her tumor, she believed there were "two blisters [*uduheri tubiri*] caus[ing] pain." Interestingly then, there seemed to be a pervasive cancer vernacular drawing heavily on processes of infection and inflammation, as embodied in abscesses, blisters, and wounds, as shall be evident with later examples in my

discussion. “Abscesses” in other places could also burst: Eve, the 37-year-old mother of a five-and-a-half-year-old boy, Jean, described how the first signs of his cancer were a bloated stomach, “a big stone” around his left ribs, and a nosebleed. Her neighbors were quick to tell her that Jean had “*gapfura,*” essentially tonsilitis, which Eve described as a set of small abscesses (*utubyimba duto*) that appear in the throat, which, if not scraped off, burst. It was not only an abscess that was described as “bursting”; a entire breast could also burst.

Another patient, an elderly woman and engaging storyteller, recounted how shortly after her referral to Butaro from another hospital (CHUB) she received a breast cancer diagnosis. The team wanted to biopsy her left breast but then they noticed “that it had burst” (*guturika* = to burst or explode), and they decided “to cut it off” (*gukuraho* = to remove). Months after her mastectomy, in July 2014, she developed a new, small abscess (*akabyimba*) in her “right armpit,” for which the Butaro team gave her pills to take at home, yet the abscess grew and became painful, so she was now receiving treatment weekly. Recalling her left mastectomy as a cure (*gukira* = to cure), she asked me and my research assistant to advocate on her behalf, hoping that we could convince the clinical team to operate on her right-sided abscess, and thus avoid further abscess growth, “bursting,” and pain.

We might wonder if the abscess vocabulary was used by any patients with Kaposi’s sarcoma (KS), one of the cancers that actually has an infectious etiology as it derives from infection with human herpesvirus 8 (HHV-8), and is thus most widely known as a cancer afflicting HIV+ patients, though certain regions of Africa (including that of Rwanda) have endemic HHV-8 which can cause KS in patients without HIV. Indeed, one 28-year-old man was receiving both chemotherapy for KS and ARVs

(antiretrovirals) at Butaro; he described the first manifestations of KS as "small abscesses (*utubyimba*) on my skin, which have left these scars (*inkovo*)," and gestured to the scattered, irregular oval scars on his forearms. The young man didn't talk about the relationship between HIV and KS, but his experience of KS from the very beginning implicated infectious signs, and he explained how these had influenced his care at his local health care center:

> In July 2008 my legs and arms swelled [*kubyimba*, to swell] and I had a very high fever. So I went to N** health center, where they did blood tests and gave me pills for fever. They tested me for *Sida* and I tested positive, have been taking ARVs nonstop since then. They also did tests for malaria and worms but they were negative. They kept changing treatments but nothing helped. After two months they referred me to Nemba Hospital.

His story serves as an excellent reminder of the fact that on the body writ large, cancer can engender signs and symptoms that mimic those of various infections. Further, local knowledge about the biomedical particularities of cancer is burgeoning in Rwanda, but AIDS (*le Sida* in French) is a disease with a longer durée of treatment. In addition to the fact that clinicians are often not primed to recognize early signs of a possible cancer, in many health centers (if not most) and district hospitals there is still a minimal armamentarium of diagnostic tests (blood tests, pathology, etc.) for cancer available.

As mentioned, the pervasive cancer vernacular drawing heavily on processes of infection and inflammation also implicated wounds as a particularly susceptible form of pathology. When asked about his conception of cancer the same young man said, "I knew nothing about cancer before but I had heard people say that it comes when one has an accident and is injured, and when the injury [*igisebe*] doesn't heal cancer [*kanseri*] can develop in it. I heard this from people back home when I was 12 years old." This relationship between an untreated or non-healing wound and cancer was

articulated by other patients as well, and suggests a local belief about a strong connection between cancer and inflammation or chronic infection. A breach of the skin or body in the form of a wound can fester, grow and expand, making room for a malignant growth in the process. We might also venture that this is a local conception of chronicity and cancer as a chronic disease—it develops in a persistent wound which lasts beyond the normal, more acute time frame. Its temporal expanse is longer, a healing process gone wrong morphs into cancer, a long-term and often, in the Rwandan context, intractable pathology.

Another example of how knowledge about infectious diseases mediated conceptualization of cancer emerged in an interview with a 40-year-old woman, Florence, treated for breast cancer at Butaro. She described receiving her diagnosis as a patient at the public teaching hospital CHUK (Centre Hospitalier Universitaire de Kigali) in November 2014: "When I brought the [blood work and radiological] results to the CHUK doctor he said I had caught cancer [*nanduye kanseri*]." Here she used the verb '*kwandura,*' which is always used in the passive form to mean "to catch or receive an illness"; in this case, through a familial (genetic) inheritance. It was not clear whether the physician himself used this verb to talk about cancer. However, Florence further intimated that he had suspected that she had either developed cancer from "improperly treated abscesses" [*ibibyimba*] which had "left wrinkled scars," or it might have "come on its own." Having heard this, Florence concluded, "life would end, there was no treatment, no vaccine for this illness [*uburwayi*]."

Ultimately, Florence expressed the idea, whether articulated exactly as such by her CHUK physician or not, that she had been contaminated with cancer. For her it was a tragedy that there wasn't a vaccine to prevent all cancer—thus, all of her

language suggested that the infectious vs. non-infectious or communicable vs. noncommunicable disease categorical bifurcation was not so stark for all Rwandan patients. Florence did not seem familiar with the HPV vaccine (relevant for preventing cervical as well as head and neck cancers), and she emphasized that her neighbors and various members of her community were the ones to insist to her that there was "no vaccine for this illness [cancer]."

The tumor as "abscess" nomenclature persisted through various stages of cancer treatment, as described by patients. One soft-spoken young (36-year-old) HIV+ woman suffering from lymphoma, Karine, explained that she had heard about the radiation therapy available at Mulago Hospital across the border in Uganda (where a contingent of Butaro patients were sent every month for radiation, with PIH paying the bill): "I heard that at Mulago they burn down abscesses [*gushiririza ibibyimba*]."[37] Given the conceptual link between infection and cancer that many patients articulated to me, and because she was one of the few HIV+ patients with cancer whom I interviewed, I was curious as to whether Karine thought there was any connection between cancer and HIV. She recounted how she had been saved by neighbors and army soldiers during the 1994 genocide and civil war. After the war she began trading goods, but in 1998 she developed chest pain and "a problem with my lungs" (likely pneumonia), and sought care at a local hospital. Soon thereafter she learned of her HIV diagnosis. Karine was certain that there was "no connection" between her HIV and cancer, stating that "because my HIV issue came much earlier, and cancer came much later." For her there was an unbridgeable temporal disjuncture between the onset of her HIV and the onset of her cancer.

[37] The verb she used was *gushiririza* [to burn down]; *gutwika* (to burn); *gushirira* (to be burned down—passive form; *gushya* (to be burned—also passive form).

As we have seen, many patients spoke to me about cancer developing in an abscess [*ikibyimba*] or untreated wound [*igisebe*], therefore suggesting a vernacular understanding of cancer as at least partially the product of a chronic infectious and/or inflammatory process. By this account, considerable time had to pass before a wound or abscess could harbor cancer. Indeed, the other examples I've offered so far didn't involve HIV+ patients speaking specifically about HIV and cancer, but conceptually we can make a link because most Rwandans know that HIV is a virus, or at least that it involves an infection. As such, Karine was one of my outliers. She disavowed any relationship between HIV injection and cancer, on the basis of temporal parameters.

Dancille, another woman of the same age, whose four-year-old daughter Antoinette was being treated for Wilms' tumor, used the same verb [*gushiririza* = to burn down] to describe how they had gone to Mulago for Antoinette's radiation therapy, so that "any remaining cancer would be burnt." She added, "The radiotherapy also was intended to ward off any abscess from developing in the future." Indeed, the rays of radiation therapy do literally burn cancer, so these comments showed a fairly accurate understanding of how this type of cancer treatment worked.

The widespread belief that cancer may emerge from or grow out of an abscess suggests that 'abscess' is not an exact conceptual translation of 'tumor.' Patients regularly dissociated an abscess from active cancer—in short, one could have an abscess persist even after chemotherapy and surgery, or one might simply have an abscess that did not in the end harbor cancer. For instance, 62-year-old Ignace, undergoing treatment for colorectal cancer, explained that doctors at CHUK had located an abscess "in my large intestine, 20 cm from the anus." Thereafter the following transpired:

> Dr. S., who was caring for me at CHUK, said that the abscess [*ikibyimba*} was extraordinary and needed to be operated on. The other doctors at CHUK refused this but Dr. S. insisted, and in the end did a scan [CT]. The scan showed that in the abscess there was cancer [*kanseri*].

Ignace's narrative clearly suggests that one can have an abscess in which there is no cancer. As he understood it (and in clinical terms his story makes sense), the CT scan was used to deduce that the abscess was cancerous. Thus, we can preliminarily conclude that while "abscess" (*ikibyimba*) is the word that Rwandan patients currently use to denote a malignant tumor, it is also used to describe a growth or mass whose status (benign vs. malignant) is yet undetermined. An abscess could also house a wound, *igisebe.* One older woman with breast cancer explained, "Even if my breast is no longer swollen there is still the abscess and the wound, and in the wound I have acute pains [*imisonga*]." Thus, even with an overall clinical improvement (here, the eventual disappearance of swelling) the abscess and its inflamed wound could persist—perhaps no longer a malignant tumor but certainly a mass. Thus the "*ikibyimba*" denotes both the starting point of cancer as a potentially malignant mass, and the physical sign that may endure even if one's cancer has been effectively treated.

At one point my research assistant helped me as a Kiswahili translator, which enabled me to have a lengthy exchange with Josiane, a middle-aged woman from the Democratic Republic of the Congo (DRC). She was fighting breast cancer, which she had first noticed as a "small abscess" [*kivimbe kidogo*] on her right breast. She told us how she had first gone to Bukavu Hospital, where she underwent an operation to remove the "abscess." Afterwards, she explained, "They did tests on the abscess and told me after two weeks that it was cancer [*cancer* (French)]. Then I went home and after two months my breast swelled again and it caused lots of pain. I called the doctor and asked why, given that they had removed the abscess. He said to return to see him."

Evidently, Josiane understood that removing the tumor ("abscess") was one of the first steps in treating cancer, and went on to recount how her further encounters with the Congolese surgeon had unfolded.

> He cut my breast and then after that gave me pills [used the French word *comprimés*] and then after two months the breast swelled instead of getting better. [*Josiane showed me her right breast, marked by a large lumpectomy scar*.] Then he decided to cut off the whole breast to solve the problem, but the higher part of the breast swelled up and was very painful. The doctor said you have to go to Uganda or Europe, if you have money. And then I asked myself what to do because I had no money, and then I went home.

Josiane thus made a distinction between surgical removal of her abscess and surgical removal of her breast. Many patients like her had extensive experience with aggressive cancers that did not respond optimally to surgery (also because of the advanced stage of most tumors upon first presentation to a medical center). Her narrative and others revealed an understanding of the challenge of having a recalcitrant breast tumor even after, or with access to a mastectomy.

As another breast cancer patient, Geneviève, an openly talkative 54-year-old illiterate woman, related that, in September 2014, she had decided to do something about a small abscess [*akabyimba*] in her left breast, which she had noticed two years previously. She explained, "I said to myself this abscess could become serious if it grows." Here then, was yet another patient who understood that the size of an 'abscess', and its growth over time were relevant to determining the overall pathological risk it posed and its potential to engender grave suffering. Geneviève went on to say that both her breast abscess and a small abscess [*akabyimba*] in her left armpit had been biopsied, and that the biopsy results had established her cancer diagnosis. While her care team had not told her what type of cancer she had, they did reassure her that it had not spread to elsewhere in her body. Finally, in Geneviève's mind the

distinction between an abscess and cancer was also a stark one. When I asked her to tell me more about her understanding of cancer, she said, "I knew nothing about cancer; I had only heard people say that a person could have an abscess [*ikibyimba*], or in the cervix [*inkondo y'umura*]. No one in my family has had cancer." Again, an abscess and cancer were two different entities on the body: an abscess could develop cancer in it, or it could remain a cancer-free abscess.

For many of the Rwandan cancer patients I came to know, an abscess was still understood as an infectious entity as it is in global biomedicine—as a swelling with a given body tissue, containing pus. I was struck, for example, by the articulateness of a 64-year-old father of seven and farmer, Anatole, speaking about the cancer of his 5-year-old son, Evariste. He said that when doctors had operated on the abscess, "there was no pus but they removed something like a small stone." This mention of pus suggested that Anatole understood an abscess to have the same feature that characterizes its definition in clinical biomedicine. Interestingly, when he further shared his ideas about the etiology of cancer, it was clear that cancer and infection, or contamination of a certain kind, were entangled:

> They operated on him and instead of recovering the area swelled up a lot [*kubyimba* = to swell]. I think that when the cancer is in the abscess it is microbes [*mikorobe*] that enter the wound and cause cancer. [I asked: If there is no wound where does cancer come from?] We ask ourselves this too, but it comes on its own [in that case], and it's hard to diagnose.
> I think that microbes entered Emmanuel's wound [*igisebe*] and that's how he got cancer. After the surgery they told me I had to go to CHUK quickly otherwise the cancer could enter the wound.

Again, here we see the imbrication of infection and cancer in popular Rwandan beliefs about cancer—microbes add insult to injury, literally a wound (*igisebe*), and cancer can then grow and wreak havoc. Anatole was convinced that no one had been able to prevent microbes from entering Evariste's wound, and thus quite literally, prevent him

from contracting a cancer. However, Anatole was still openly thinking about how cancer could emerge in the absence of a wound. He held, simultaneously, the view that cancer could develop on its own, without any wound to host it. Notably, Anatole was one of the many people who told me that he had heard about cancer described in his village as a bad illness ("*indwara mbi*") and an incurable one ("*indwara idakira*").

The mother of a pediatric cancer patient also explained how she had heard from other people in her community that cancer could develop "in an injury (such as a wound) [*igikomere*] or fracture [*imvune*]," and this seemed plausible to her. But she also pondered the case of a woman in her village who had suffered from diabetes and then developed cancer. She wondered if there was a connection between the two although she did not know which type of cancer had afflicted the woman. Clearly, in Rwanda there are individuals who contemplate the relationship between multiple non-acute diseases (in this case, diabetes and cancer), suggesting that in addition to the imbrication of infectious and non-infectious processes in common explanations for cancer, Rwandans are experimenting with their understandings of chronic disease. Or at least, there is perhaps a connection being made between diseases that have become more visible in recent years owing to the advent of treatment services for them, and which have been taught to community health workers as falling under the rubric of "noncommunicable diseases." Ignace, the colorectal cancer patient I introduced earlier in this chapter, also thought there was a connection between microbes and cancer. He said the following on this matter:

> Because this is the first time I'm hearing about cancer I think it is caused by a microbe [*mikorobe*]. It's as if you have intestinal worms which are caused my microbes, but you can also get cancer from microbes. I hope that I will recover [*gukira*] because they cured my amoebas [*amibe*] which were caused by microbes, so I hope these same microbes which caused my cancer will be treated successfully.

Again, Ignace's take on cancer brought home the extent to which Rwandans' long and deep experience with infectious diseases informs their conceptions of cancer in general, not simply those of virus-associated cancers like cervical cancer. However, Ignace was also uncertain about the precise infectious etiology of cancer. When I asked him about his specific worries around cancer, he volunteered,

> Diabetes is a neighbor, that's all.[38] I find medications against it without a problem. As for cancer, I don't have enough information about it yet—I wonder if it can be cured, if it is transmitted, etc. I accepted my condition but the difficulty is the consequences—my kids who have quit school...Here they told me that cancer is not transmissible/contagious. Currently I don't have enough information about cancer. We know that illnesses are caused by microbes [mikorobe] or viruses [virusi]. I don't know which, microbe or virus, would cause cancer.

Revealing here is the fact that Ignace sees diabetes as a chronic disease, using the metaphor of a neighbor to express the idea that one lives with diabetes for life. But he felt yet uncertain and uninformed about cancer—and what he learned at Butaro had not yet convinced him, it would appear. There they had told him that "cancer is not transmissible," but he still wondered which kind of infectious agent lay behind cancer. Naturally one immediate question might be whether Ignace understood that saying all illnesses were caused by microbes or viruses implied that all illnesses were transmissible? What we can conclude with certainty is that an infectious disease framework heavily informed his reading of and engagement with cancer.

Ignace's first epistemological move was to connect cancer to infectious pathogens, the cause of so much experience of disease and suffering in Rwanda and in Africa more broadly. However, we cannot take this case as proof that cancer is new to

[38] pt 38: [He meant in the sense that it's for life: "*Diyabete ni umuturanyi, byararangiye*."]
Umuturanyi = neighbor; *Byararangiye* from *kurangira* = to finish

Rwanda—Ignace organized his comment around the issue of access to treatment and information—diabetes was a manageable "neighbor" in his everyday life because he could easily obtain insulin and other relevant medications, and its consequences had been less disruptive. Further to this point, diabetes is a condition for which reliable treatment only became available in Rwanda within the last decade, so the change in vernacular understandings of cancer might also change rapidly in the coming years. Indeed, Ignace had begun treatment for diabetes in January 2012, just three years prior to our meeting. Interestingly, though, Ignace did not name an infectious etiology for diabetes. As he put it, he did wonder about basic realities produced by cancer "For how long will I be treated, and what will my life and that of my family be like before I am cured?"

In the end, it did seem that Ignace sought unifying theories of disease. When asked what he thought about the care at Butaro, he claimed to be satisfied with the services, and said that the patients who came before him told him that they had come in poor condition but subsequently recovered and went home. For Ignace, this confirmed the truth that "if you start treatment on time you can recover, and when you come to late you don't recover, and this can happen for all other illnesses [not only cancer]." Ignace's beliefs demonstrate the fact that not all Rwandans attached significance to cancer for its temporal constraints, but rather had experiences of many illnesses for which timing of diagnosis and treatment were important.

There was another patient battling breast cancer, 51-year-old Rose, who was adamant that she had no idea about the causes of cancer, and that she had been unconcerned about her original breast abscess. During our interview in March 2015, she mentioned that she had been a patient at Butaro for the past four years, having

initially developed an abscess [this time *inkabya*] on her left breast. Later on in Rose's patient trajectory, in August 2014, physicians at Butaro noticed a small abscess [*akabyimba*] in her left armpit that she herself had not noticed. She remembered how the team had told her that they must remove the abscess, and she had urged to them to refrain from doing so: "I said it doesn't hurt me, don't remove it. But they said, 'No, we must remove it.' So they referred me to Butare [*Centre Hospitalier Universitaire de Butare*], where a doctor would remove it." The physician at CHUB examined her but couldn't find the abscess, so it was never removed. At the time of our discussion Rose was uncertain whether the team had excised the abscess yet or not. When she answered my first question about the consultation of any traditional healers in the negative, she reiterated that she hadn't sought out any such treatment as her husband had also been unalarmed by her breast mass: "When the abscess was still small I showed it to my husband and he said, 'This is nothing, not an illness.' But when the rain would fall I would feel itchiness in my left breast, wanting to scratch it."

Later on, Rosine had a left mastectomy. She avowed that she had suffered stigma as the only woman in her cell[39] to have lost a breast—when she began treatment and started losing hair, having her skin darken, and her nails peel, people stopped visiting her. She told me, "They would only come to laugh at me, and go tell other people, who would also come to laugh at me [*guseka* = to laugh in mockery]. Once I met a woman in my village and she told me there is no one whose breast can be removed and still live afterwards, so go eat all you have" [*Nta muntu bakuraho ibere ngo abeho. Genda urye utwo ufite twose.*]. But I later learned that in addition to a difference of approach between hospitals, and her husband's perspective, history also mediated

[39] Rwanda is currently divided into areas that descend in geospatial expanse category as follows: province--> district-->sector-->cell-->village.

Rose's hesitancy to have her "abscesses" removed via any lumpectomy or axillary lymph node dissection. Rose said to me, "When I was young there was a woman who lived in Kabaya sector; she had a swelling in her breast and people said she had *inzibyi* [type of abscess]. She went to Gisenyi Hospital; they removed the breast and she died." It seemed possible that such a stark and disturbing memory reverberated through Rose when she developed her own "armpit abscess" (enlarged lymph node) and "breast mass." Perhaps this informed her own hesitancy about having her enlarged axial lymph node removed. Another older breast cancer patient, 62-year-old Elise, recalled how she had developed an abscess in her left breast [*ikibyimba*] which she had effectively ignored for a year, despite having learned on the radio "how cancer attacks the breast." Even so, she didn't consider her abscess an illness because she "had no pain," nor other symptoms, and had been healthy her whole life.

IV. The Contagion of Cancer: Tumors and their Rumors

Now I wish to turn to the etiologies and associations that patients described when talking about cancer. The second argument I set forth here is that ideas around contagion and transmission that have emerged in the Rwandan encounter with tumors are quite culturally specific and relate back to the issue of *kanseri* as a disease category and experience that implicates both infectious and non-infectious elements. Often it was clear that on the ward, in clinic, and beyond, within people's broader families, villages, and communities, malignancy was being framed as contagious, but not infectious: contagion in the absence of a microbe or virus is invoked. This move suggests that if Rwandans are compelled by the notion of malignancy as threatening kinship networks and communities through a mechanism of contagion, it is as much a

metaphysical one as an etiological one. It is also crucial to recall that this social fact operates in a society in which extreme violence was recently an abiding fact of everyday life. Finally, the rich use of metaphor as part of the semiotic practices that accompany Rwandan tumors will be evident from my data. These metaphors are often focused on the material, physical, and familial depletions that cancer produces, as well as on broader relationships to the ecological and natural landscapes that bear upon daily life. Their regular use indexes a certain reality. While the state has taken care to frame oncology as a gift of modern, high-tech care to a fragile post-genocide populace, and to rapidly increase its access to such care, the erasure of entrenched local ideas about the intractibility and inevitable destruction and disfigurement—physical, social, and moral—wrought by malignancies cannot be achieved at an equal pace. And yet, in a fascinating manner, Rwandan onco-citizens participate in the marking of cancer as a disease that defines a new technomodern moment, and a profound rupture with a past marked as premodern and exploited, soaked in violence and divisionism. They do so by invoking cancer as an illness that "comes on its own"—no one sent it, and it indeed seems to function as the "emperor of all maladies" (Mukherjee 2010), laying its sovereign hand on victims with little regard for age, gender, ethnicity, personal or family history.

Many Rwandans stated that they had "no idea" about the origins of the disease, although a good number expressed knowledge about the major danger of it spreading from its original site to other parts of the body if not treated on time; some also volunteered that the risk of pain increased the longer you let a tumor sit without intervention. Sometimes a patient would report that it was widely known in his or her village that HIV+ patients were at greater risk of developing cancer than the general

population. Thus, by 2014-2015 at Butaro, many patients from all over the country were educated about cancer, to the extent that they knew that time was of the essence with respect to treating a malignancy. This widespread knowledge is part of a new vernacular understanding still in the making; most patients continue to present with cancers in advanced stages—a reality that has not yet changed radically since 2010 when I began spending time at Butaro, and one that is representative of the situation on the continent at large (Livingston 2012). Certain patients believed that physicians had no time to explain the causes of cancer to them, and while they were angered by this, they refrained from asking for greater explanations about their disease.

Some patients spoke about the physical pain that they had developed with their cancers; it was also evident that within villages there was regular talk about how cancer as an illness involving a great deal of physical pain. However, while pain was certainly a serious issue for most cancer patients, they did not foreground it ahead of other concerns. Rather, it was the inability to access certain treatments, poverty, and the threat to one's capacity to support family and educate one's children, in particular, that vexed the majority of patients. However, when pain was introduced into the conversation, sometimes there was a kind of doubling involved: cancer was invisible until it was visible and debilitating; it could be painless and then become very painful as a tumor grew. As one older woman with breast cancer said, "It's an illness that causes a lot of pain that is not visible to the eye, because many come here when they are already debilitated. If your child has this illness, you as a parent may not notice until later." One teenage patient told me how cancer produces so much pain that "people can lose hope" [*bakiheba*]. Another woman said that cancer was sinister precisely because you could have it for years and be pain-free, and therefore

completely unaware of it. Thus, cancer was also an invisible contagion that plagued the body while its victim remained ignorant of its invasion.

Let us recall the context of experimentation in thought and practice that marks the cancer war(d) in Rwanda. Often, it seemed that patients were working through possible etiologies of cancer as they spoke to me, interrogating their ideas about the connection between witchcraft and cancer in the moment, and perhaps about wounds and cancer, in the face of new knowledge they had assimilated about cancer risk factors. Let us consider the case of Dana and Pacifique: she, a middle-aged woman who was the full-time caregiver for her mentally disabled husband, who was then grappling with a form of bone cancer. At first, both of them stated that they knew nothing about cancer—Dana emphasized that she didn't know any other cancer patients and thus lacked a good point of reference. Pacifique invoked the wound-cancer link and proffered up a historical causal chain to explain his current cancer: in 1990 he was cultivating land for someone in Kigali when a neighboring shop was raided by thieves. He ran to help stop the thieves, and during the scuffle the latter threw some hand grenades. The only one to survive the incident, Pacifique sustained a head injury, and thereafter developed epilepsy and a mental disability. Some years later, he fell during a seizure and burned his left foot. More recently, a lesion had appeared on the same foot, eventually diagnosed as bone cancer. So, Pacifique explained to me the culprits for his cancer: "It is an illness caused by another illness. You see I had the wound and epilepsy before the cancer, so they caused the cancer. If I had not had epilepsy and burned my foot I would not have cancer there now." In this story it was evident that cancer was an occurence that layered over and developed in a wound, an injury understood as one

literally deriving from the violence and unrest that had marked Rwanda in the 1990s and in prior decades.

My research assistant and I decided to press further, asking Pacifique what he thought the causes of breast cancer might be. He said he was ignorant of any such causes, and here Dana interjected, also articulating the idea of a connection between wounds and cancer, saying that a breast wound that does not heal becomes cancer. Further, if one had a wound that was intractable despite treatment, one could conclude that it had morphed into cancer—however, she affirmed that this was her own thinking on the matter, and not a widely held belief in the community.

Dana offered yet more detail—she believed there were environmental factors behind the intractibility of Pacifique's wound. As she put it, when Pacifique was home he would go to look for grazing grass for their animals, and in the process his wound would be exposed to dew, dust, and grass [*ikime, ibitaka, ibyatsi*]. These natural elements would enter his wound and that was why it had not yet healed. Further still, Dana recounted, Pacifique had been a smoker in the past—having heard on the radio that tobacco use was a risk factor for cancer, she imagined that this had also contributed to his cancer. Pacifique himself concluded that cancer was a disease that damaged the body [*konona* = to damage]; through it the body was altered, and killed in a "bad way."

Sometimes there were ideas about environmental factors precipitating cancer that I only heard from one patient at a time: for instance, the notion that rust [*ingese*] could cause cancer. One 55-year-old woman with colorectal cancer said she had learned this from a health counselor [*umujyanama*] at CHUB (*Centre Hospitalier Universitaire de Butare),* while on her own, she had no idea about the causes of cancer.

As it was explained to her, this rust could come from a cooking oil tank, or polluted food. Many patients said that cancer was beyond their sphere of knowledge, but that it was something sent by God. While it could be a punishment from God, it wasn't always conceived as such, but simply as a "thing" (*ikintu*) sent by God. Many patients, men and women across a broad range of ages, talked about cancer as a disease that "comes on its own,"[40] or "comes on its own, whenever it wants," personifying cancer and giving it an omnipotent character. A number of patients affirmed that they knew nothing about cancer, but had asked after arriving at Butaro and been told by physicians that even they were uncertain about cancer etiolog(ies), yet poorly understood.

On other occasions I witnessed the expression of a certain helplessness in the face of cancer—its cause was unclear, and one could just see it unfold before one's eyes [*Nabonye biza gutya.* (I just saw it happening.)]. One young man in his early 20s related how he had heard on the radio that cancer was caused by a virus ravaging the body of a person. He was uncertain about the mode of transmission of said virus, but he had heard people in his village say that cancer comes and attacks the breast and uterus of a woman. It was likely that he had heard about cervical cancer on the radio and thus identified an infecitous virus as the major etiology; however, he did not articulate an understanding of HPV as a sexually transmitted virus, and expressed uncertainty to how the virus was transmitted. Thus, he displayed an understanding of cancer as transmissible and contagious, but didn't immediately conclude that this tranmission was infectious, according to prior knowledge of infections.

[40] Pt 36: "I have no idea. I just know it's an illness which comes on its own [*indwara yizana*], because it attacks babies, children, young people, everyone."

At the other end of the spectrum, a 74-year-old woman affirmed that cancer was "not transmitted like AIDS." In fact, she wished she had AIDS instead, "because at least those who have HIV gain weight!" She said this emphatically, thus referencing the weight gain associated with ARVs (antiretrovirals). When she talked about the "transmission" of AIDS, she too used the verb "*kwandura*," essentially always used to define a passive action/(always used in passive form), best translated as "to receive or catch an illness," whether it be through the air, through forms of bodily contact, or through hereditary transmission. Significantly, *kwandura* can also mean "to be dirty, soiled, or stained" or "to be contaminated or infected." Thus, while *kwandura* could simply denote catching an illness, it also had other layers of meaning denoting dirt, contamination and infection which were carried beyond the experience of infectious disease into the experience of cancer. This part of the lexicon also suggests that Rwandans make a conceptual connection between catching an illness and catching dirtiness, such that broadly speaking, illness, like dirt, is "matter out of place" (Douglas 2005:35). Mary Douglas also concluded the following: "This idea of dirt takes us straight into the field of symbolism and promises a link-up with more obviously symbolic systems of purity" (ibid.). Because so many patients used the verb *kwandura*, I argue that in Rwandan culture, both diseases in general and cancer are understood as a violation of the body's purity.

Accounts of cancer's contagious aspect or transmissibility (through blood and kin) were especially fascinating because I witnessed patients thinking these issues openly, taking into account both local cultural logics and rumors or suspicions they had encountered. Céline, a sweet-faced 18-year-old battling leukemia deduced that cancer was not a transmissible illness because she had witnessed suffering patients on

the Butaro ward younger than herself. These were "small children" with the illness, and "their parents don't have it"; therefore it could not be transmissible. Yet, moments later, she shared a rumor she had overheard from the hospital cleaners, who were discussing a common occurrence whenever the oncology ward was saturated with patients beyond its intended capacity. The cleaners would seek to borrow mattresses from other wards in Butaro Hospital, but staff members in those other wards would claim that they could not lend them because cancer, which had not been transmissible in the past, had become so in the present. In recounting this anecdote Céline also used the verb *kwandura*, to receive or catch an illness. As for the contagious nature of cancer, Céline was not convinced about this rumor: "I don't think so because they wash our sheets and those of the doctors together." When I asked Céline if she had discussed cancer etiologies with any of the physicians treating her, she insisted that they had been uncertain of the causes, and adamant that there was yet no way to protect oneself from cancer, though research was ongoing. As for pediatric cancer, its existence was a recent discovery for many in the community. Céline was not alone in being struck by how cancer could plague young children—a number of parents of pediatric cancer patients at Butaro expressed their shock over this fact. Some recalled how they had witnessed elderly individuals succumb to what the community collectively called cancer even if no one knew which type of cancer. One mother of an eight-year-old dying from acute myelogenous leukemia (AML), Francine, told me: "My friend, I cannot know where it comes from. For me it is an illness which just appears out of nowhere."[41]

[41] My friend, I cannot know where it comes from. For me it is an illness which just appears/come out of nowhere [*Mbona ari indwara yizana*.].

To return to the connection between cancer and infectious disease, Francine was among those who conceived of cancer as "an epidemic": "Cancer has become an epidemic. Before, we would hear about one person with cancer in the whole district, but now it is many people who have it." She used the word "*icyorezo*," which means epidemic or scourge, and is typically used by Rwandans to talk about AIDS.[42]

Fear about the transmissibility of contagious tumors could also morph into fear that threatened familial bonds, and this speaks powerfully to malignancy as a moral contagion. One mother, Elina was concerned about whether she was at risk of contracting cancer from her 25-year-old daughter, Alice, who was beginning chemotherapy for uterine cancer. At one point Elina asked my research assistant and I if this was a danger, so that she might take action to protect herself. Of course, we assured her that cancer patients were not contagious and that she was not at risk. This wasn't a story of rupture in kinship ties and caretaking—unequivocally, Elina was devoted to her daughter and eager to see her respond well to chemotherapy. She had been vexed by what she had often heard about cancer in the past, in her village and among kin—that it couldn't be cured and essentially was equivalent to a death sentence. Yet when I met her, comfortable with her surroundings at Butaro, she was full of hope. Furthermore, doctors on the ward had promised Elina that Alice would recover from her cancer. This statement, along with encouragement from other patients on the ward regarding the good care at Butaro, and the start of Alice's chemotherapy, put Elina at ease. She told me, "When someone reassures me I trust

[42] Of note, Rwanda has a relatively low HIV prevalence rate at 2.8%. In 2014, UNAIDS estimated the prevalence rate for adults aged 15 to 49 as 2.8% [2.5% - 3.2%]. See [http://www.unaids.org/en/regionscountries/countries/rwanda]. Accessed April 8, 2016.

him. I am no longer afraid. I'm no longer afraid, and also, God is here."[43] Thus Elina also placated her own fears by concluding that the cancer ward was a sacred place.

The materiality of the social (Farmer 2001) was acutely evident in the familial conflicts and ruptures that sometimes occurred in response to cancer. Recall Jean, a little boy suffering from leukemia, and his mother Eve. Like many receiving care at Butaro Cancer Center of Excellence, they were not from Northern Province and had traveled a considerable distance from their region to reach it. Formerly, Eve had farmed with her husband, but she told me that she was now separated from him. Early on in our conversation she explained to me that when Jean's illness had begin in December 2012, she had immediately wanted to take him to a health facility, but her husband had been opposed to the idea. Eve insisted upon her plan, and he banished her from their home. She took Jean and two of her other three children, and moved to her parents' home, where they were still living when I met them. After the initial separation, the husband didn't give Eve so much as a transportation ticket, or food, nor help or support of any other kind. Further, he discouraged her by asking why she was bothering to seek care for her son when he clearly wasn't going to recover. As she recalled, he said, "Don't ask me for anything, and if I have something, you won't get any of it from me!" Later on he told Eve to seek financial support from Partners In Health, and manage on her own. She in turn worked for other people, cultivating their land in order to earn money for transportation fares related to Jean's treatment.

Further yet, when Eve started bringing Jean to Butaro, her husband hid Jean's mutuelle (national health insurance) ID card, and his medical record booklet, as well as Eve's national identity card, to prevent them from returning to Butaro Hospital. Eve

[43] Pt 25's mother: "[Furthermore] God is here [*Kandi n'Imana irahari*]."

informed the two community health workers (CHWs) serving her village, who subsequently came to her home to ask the husband to return the documents. He refused, and the saga soon implicated the chief of the village [*Chef d'umudugudu*]. The CHWs reported the husband's seizure of said documents to the chief, who then demanded the documents back, using threat of force. Eve didn't wish to elaborate further, but the chief succeeded in seizing the documents for her. Ultimately, she said, "my husband told me 'If you don't want to leave the child [Jean] at home and not seek care for him, leave here and go to your parents' home. Later on if you change your mind, come back to me.'"

While the village chief resolved the issue of the documents, and Eve was able to take Jean back to Butaro, she reported a generally negative attitude from residents of her village. They were often discouraging, making statements to the effect of "If you want, stop by there [Butaro]; [but] such illnesses do not get cured at all. It [cancer] throws you too far to come back. It exhausts you for nothing." In a heartbreaking moment, Eve concluded by saying that sometimes Jean would hear such discouraging comments and ask his mother whether it was true that he would never recover. She would reassure him that he would. Ultimately, it was only Eve's brother and mother who offered her support, in the form of bus fare to and from Butaro.

Indeed, perhaps unsurprisingly, the transition from knowing cancer as an incurable disease to relearning it as one that could be successfully treated at Butaro did not come without doubts and moments of jealousy. Let us recall four-year-old Antoinette, a Wilms' Tumor patient, and her mother, Dancille, whose story serves as another vivid example. The latter recounted how the view of cancer as incurable in her village was so deeply embedded that visitors to their home would spread the word of

Antoinette's suffering and others would ask in a mocking manner, "Is her daughter going to recover?" implying that it was a waste of time and money to treat her given the inevitable fatality of cancer. Further, neighbors gossiped about how Dancille and her husband were rich given the fact that they had sought treatment for their daughter abroad (at Mulago Hospital in Uganda for radiotherapy, for instance). They wondered with great suspicion about how the family had earned the substantial funds to be able to travel for care. We shall return to this kind of local response in Chapter 4. Dancille explained how she disliked having to talk about cancer at all. In addition to the negative responses in her village towards Antoinette's illness and treatment, she was also traumatically marked by a time at which she had lacked the financial means to access cancer care: her own mother had been diagnosed with cervical cancer in 2012—she was a patient at her local health center and at CHUK (Centre Hospitalier Universitaire de Kigali) before being referred to King Faisal Hospital (the private, state-owned hospital in Kigali). Owing to an absence of funds, Dancille and her older sisters took their mother home to die.

Dancille's story exemplified another type of tragedy marking the experience of cancer and oncology in Rwanda: so often, a lack of financial means could make treatment inaccessible and hasten the death of loved ones while, at the same time, successfully accessing cancer treatment could spur a jealousy, doubt and suspicion in one's community. Nonetheless, Dancille was encouraged by the high quality of care that Antoinette received on the ward as a pediatric cancer patient, and said, "I think that she will recover because the pediatrician takes care of them."

Here and there, patients would mention that they had "learned" or "heard" that cancer could be transmitted in families, and therefore categorized as a hereditary. One

young man said to me, "For example, if your father had a cancer, you as his child can be attacked by cancer. Or if your mother had cervical cancer, you, her daughter, can get it. Before people died from cancer without knowing what from—for example, someone could have a wound [*igisebe*] and die from it." The term he used to denote the heritability of cancer was "*zo mu miryango*," meaning "for within families"; *miryango* is the plural form of *muryango*, which means family or lineage. An older woman from Northern Province who was grappling with breast cancer wondered, and asked me whether cancer could occur within families: "When someone in the family has had cancer it can be transmitted through blood like asthma. Isn't that possible? Asthma is transmitted through blood too. If your grandparent had it, you may have it too." She also used the term "*kwandura*," to receive or catch an illness, to talk about this potential hereditary basis of cancer.

As for familial transmission (and contagion), did meet a few patients with a history of cancer in their families. One of these was Grace, a 55-year-old woman, and mother of seven, receiving chemotherapy at Butaro for breast cancer following a right breast-mastectomy in Kigali at CHUK (Centre Hospitalier Universitaire de Kigali). She had traveled to Rwanda from her native Burundi, and was more educated than the typical patient at Butaro, having completed secondary school. When I asked for her occupation, she said that she divided her time between house chores and the education of her children, in which she was quite devotedly involved. She was already a widow—her husband had passed away in 2013, having suffered from complications of a rare cardiac tumor. I actually discovered Grace on the ward one morning, having met her a few months prior in Kigali while I was investigating the civil society scene

around cancer and therefore visiting the office of one of the few and key groups, Breast Cancer Initiative East Africa, Inc (BCIEA).

At that initial meeting, we had talked about how BCIEA and its founder, Ms. Philippa Decuir, had supported her in moral and material ways following her mastectomy. For one (and Philippa showed me the inventory that day), BCIEA had procured a number of prostheses and bras with built in prosthetics to be distributed (at a certain cost) to Rwandan had undergone mastectomies. In fact, BCIEA had funded Grace's transportation from Kigali to Butaro. Because of our prior meeting, she felt connected to me in a certain way, and her speech, shaped by my interview questions, flowed easily. Fairly early on in the interview, I asked her about her conception of cancer. She hid her softly featured face in her left arm and burst into tears as she said, "I have a terrible experience with cancer! I am the seventh person in my family to suffer from cancer. My husband, brother, father, my maternal and paternal grandfathers, and my maternal grandmother all died from cancer." She went on to lament that in Burundi there was no treatment; that she and other cancer sufferers had to seek care abroad and inevitably this impoverished them and hence their families.

As a result of her tragic personal history, Grace had an unusually intimate and deep experience of the disease. When I asked her who served as her caregiver she explained that she was taking care of herself: "I always come alone because this illness of ours lasts for a long time and then people get tired." This comment revealed Grace's understanding of the extended chronicity of cancer, and the ways in which it was a disease that exhausted the energy of entire families such that eventually, as she implied, one could no longer rely on one's kin for regular provision of care. Her relatively greater knowledge about cancer also engendered a more detailed set of

clinical anxieties—she emphasized how she was also "worried because I don't think I will recover because I have not gotten radiotherapy. I told the visitors today that we need radiotherapy here and they promised we would have it soon." Here she was referring to the delegation from the Dana Farber Cancer Institute, which happened to be visiting Butaro on the day that I interviewed her. In broad strokes, Grace's story evidenced the fact that local knowledge about cancer was heavily mediated by class and educational background, and furthermore, that there were individuals with a familial history of cancer who therefore had an older, deeper knowledge of cancer. Her more detailed understanding of the clinical protocols for breast cancer made her worry about the impact of not accessing radiotherapy on time, and she asked me if I might be able to influence the leaders of BCIEA in the hopes of receiving financial aid from the organization, in order to return to Mulago Hospital for radiation. In short, Grace's experience and education had also led her to find BCIEA and benefit from its aid and moral support, within a very small civil society sector.

While BCIEA was working on initiatives to improve knowledge about breast cancer with Rwanda's majority population in rural areas, many of its advocacy efforts—like the annual breast cancer walk—were based in Kigali. With the relative concentration of capital, more educated citizens, and clinical resources in Kigali, it was not surprising that knowledge about the biomedical aspects of cancer, and engagement with civil society were greater there than in rural areas. On the other hand, Partners In Health had been active in community sensitization around cancer since 2010. In summer 2010 I had been part of the team that traveled to various health centers in the district to educate community health workers about breast and cervical cancer.

V. The Interpellation of Onco-Citizens

As a third intervention, I argue that the Rwandan state interpellates onco-citizens of the onco-nation through public education campaigns focused on cancer, the HPV vaccination initiative, and radio programs. I want to reiterate that Rwandans are experimenting with ideas about malignancy in the face of new encounters with oncology—these ideas draw on various symbolic repertoires as well as deeper histories and entanglements with disease, suffering, and violence. In this version of my chapter I focus on patient narratives although in future iterations I will incorporate more material from state-sponsored campaigns, speeches, local media, and the like.

The new and ongoing formation of citizens of an onco-nation was evident in how patients discussed recently acquired biomedical knowledge—like James, a middle-aged man with chronic myelogenous leukemia. To his mind, there was no obvious cause of cancer. However, he had recently heard on the radio that cancer was the result of "unusual functioning of the body's cells." James was among those patients I encountered who vehemently dismissed any association between cancer and witchcraft. He recounted to me, "One day my wife tried to tell me that I might be a victim of witchcraft [*uburozi*] but I refused [this idea] as I knew there was no way I could have been affected [by witchcraft]. This is why I decided to go to health facilities." Certainly, given the phrasing, we might wonder if James was simply refuting the possibility that he himself had been a victim of witchcraft, but not that there could be a connection between witchcraft and cancer more generally. We will return to this issue in Chapter 4.

Another such patient was Edouard, a 34-year-old HIV+ widow with Kaposi's sarcoma who sold tires and spare automobile parts for a living. He recounted that, earlier on in his treatment course, an American physician at Butaro had explained to him that "every person can have cells that develop abnormally and can cause cancer anytime; she said to me, 'Even I can have it.'" The biomedical concept of abnormal cells and a widespread risk of cancer were new to Edouard, and previously he had not held any deep conviction about cancer. He said, like many other patients, "I had no idea about cancer," and expressed a distant anecdotal experience of cancer through listening to the radio: "I had heard of a doctor or a president here and there who had died from cancer. I knew it was a bad illness. I heard all this on the radio." His story offers another example of the pivotal role that the radio plays in Rwanda in terms of sensitizing the population to cancer, and oncology services. It is one of the major modalities through which the state interpellates Rwandans as onco-citizens, offering its poor, rural, traumatized populace knowledge about a disease that implicates a number of previously absent technologies, and one that is emblematic of developed modernity. As evidenced by other stories (though not Edouard's), the radio was a major mechanism through which the state told its citizens about the gift of oncological care.

Like many patients described previously, much of Edouard's knowledge derived from his immersion as a Butaro patient. Like many other patients and parents who had spent time at Butaro, he found it quite remarkable that children could have cancer although their parents had always been cancer-free. Their reactions to pediatric cancer illuminated yet again a major current reality: Rwandans are busy working out their understandings of the causes of cancer at various levels, whether they be

instrumental or thoroughgoing. In this case, they were working through issues of the transmission of cancer, and while they made no explicit mention of transmission through bodily fluids like blood, it may well have been that a prior experience of mother-to-child contractability of HIV informed their initial expectations of malignancy. Building on that knowledge, sedimented by extensive state-sponsored ARV treatment access and public education campaigns around HIV/AIDS, many Rwandans at first wondered how the child of healthy parents could develop cancer. Given the reality of a first contact with oncology and the biomedical treatment of cancer that is still unfolding in Rwanda (and certainly was in 2014-15), one cannot read this conception of heredity and cancer as an instantiation of recently assimilated biomedical knowledge. Such responses to pediatric cancer may also demonstrate a prior, vernacular understanding that disease, more generally, could develop as a result of a familial or heritable trait.

Edouard was also one of those patients who succinctly articulated a new understanding of the temporality of cancer, experienced by many patients at Butaro: "The only problem [*ikibazo*] I have is that you can have cancer but you're ignorant, and once you know it you don't have the financial means [*ubushobozi*] to get treatments. Because you don't have pain, you learn about your cancer too late, after having gone to many places for care." Edouard's comment was of a very personal nature, because he had consulted a variety of healers over the course of a few years, without any cancer diagnosis. In fact, he had first developed KS lesions in 2003, and from then on until 2007 he had pursued treatments with various traditional and alternative healers. It was only in 2007 that he started seeking biomedical health care, and in 2010 that he was ultimately diagnosed with KS.

Despite the years of suffering and seeking treatment for what had turned out to be KS, Edouard was convinced that "cancer kills, and it does so suddenly." He went on: "For this reason, I always ask myself what is the guarantee of these medications? Will they cure me completely? However, they tell us that you can take these treatments for a long time." His case serves as a good example to examine the doubt that marks such new Rwandan experiences of oncology, a new field of care which, despite its technologies and countrywide network, cannot quickly transform the reality that many Rwandan cancer patients do die suddenly from obscene tumors because they enter this developing oncology network belatedly. Yet, crucially, Edouard did not interrogate the efficacy of chemotherapy because he was a firm believer in witchcraft as the ultimate cause of cancer. Rather, he had already concluded that witchcraft and cancer were unrelated:

> Of course there are people who say there is a relationship between witchcraft and cancer. But I, as a person who has sought care from traditional healers, I don't see any relationship. If there were a relation between the two, witchcraft would kill you or disable you so you could not walk. Also if it were true, we say that victims of sorcery die as soon as they are injected but I was already injected multiple times at Butaro and did not die.

Edouard's experience with traditional healers was among the major reasons that he disavowed the possibility that witchcraft maneuvers could be a causal agent in cancer. His final conclusion reveals the extent to which, unsurprisingly, biomedicine and witchcraft have long overlapped with one another in the local moral worlds (Kleinman 2006) of Rwandans. Judging from further conversation with Edouard, vaccines also counted as "injections" in this lexicon, and in Rwanda, vaccines have been present since the Belgians seized colonial administration of the country from Germany, in 1916, during World War I.

We might recall Anatole, who in speaking about his 5-year-old son, Evariste, expressed the belief that no one had been able to prevent microbes from entering Evariste's wound and leading to cancer. He was also fairly certain that cancer could develop on its own, in the absence of a wound. In contrast, there were patients who had learned about the crucial nature for prognosis of early diagnosis and treatment. One such patient was 22-year-old Bosco, a married hairdresser struggling with colorectal cancer. He also expressed the notion that cancer may develop with no clear etiological basis as he said to me, "I think it is something that comes on its own." But this was complicated by what he had learned from his care team at Butaro: "Because they told me I had a large abscess, I thought any disease can become cancer if not treated on time. They also told me cancer had grown in my abscess owing to my late seeking of treatment." Hence I was witness to Bosco working through the temporal urgency of cancer, though interestingly his first move was to say that any condition left to develop with a lack of appropriate treatment might morph into cancer. It made me wonder if he saw cancer as an all-encompassing scourge, the final stage of many neglected disease processes. Certainly, the variation in tumor types (and hence the anatomy affected), age, ethnicity (Hutu vs. Tutsi) and regional affiliation among cancer patients confused the etiological picture—even innocent children with short life histories could be devastated by a tumor.

There was one 49-year-old patient, Françoise, who while receiving chemotherapy through an IV in her right arm, also told me that she had "no idea" about the causes of cancer. Yet, she refused any connection between cancer and sorcery:

> Myself I have no idea about causes of cancer and I do not think it is in any way related to sorcery…But, people in the community think that their cancer is

> related to sorcery, bewitchment or poisoning. They seek care from traditional healers and change from one to another until the patient dies.

In Chapter 4, I shall lay out the difference between sorcery, witchcraft, and poisoning in the Rwandan cultural system. Françoise identified herself as an outlier not subscribing to the etiological ideas about cancer held by most Rwandans in her local community, and she was very troubled by the consequences of these pervasive beliefs. She considered herself "lucky" to be "literate and knowledgeable…able to seek care." She saw the persistent lack of knowledge about cancer as a "big problem." Another way she expressed was as follows: "People in the community may think that they have poisoning when in fact they have cancer, and go to a traditional healer and take those medicines." To Françoise's mind, the only way for her and her social entourage to "protect" themselves from cancer, and "avoid it," was to learn its "causes," which were, she said, still unknown to her. She was also vexed by what she saw as her inability to "protect [her] children from cancer." Ultimately, Françoise wished to become "a knowledge giver who informs other people [about cancer]." Her language suggested that cancer was transmissible and could be avoided, even if its ultimate causes were not infectious nor clearly understood.

However, Françoise affirmed that Butaro, in many ways a hub of knowledge about and experiences of cancer which could then circulate when patients returned home across Rwanda, was difficult to access as a patient. Namely, it was difficult to get a transfer from a health center to a local district hospital, or to obtain one to go from that hospital to Butaro, essentially both a district hospital and a referral center for any patients suspected of having cancer. The transfer is a bureaucratic document and procedural move facilitating patient mobility within a decentralized national health system, and also meant to ensure that pathologies are dealt with appropriately in this

system, based on the level of complexity, material resources, and specialized expertise required. For instance, in Françoise's case, when she first presented with symptoms to her local health center, she was told that she was likely suffering from a case of amoeba, and with that diagnosis selected, she had to be treated at the health center level and could not receive a transfer to a higher tier in the health care system. One of the major lessons that I gleaned from Françoise's comments was that the diffusion of biomedical knowledge about cancer among Rwandan citizens was slow, and this perpetuated the pattern of initially seeking out traditional healing, and eventually, at a later date, presenting to a health center or hospital with already advanced cancer. She implied clearly that the vernacular body of knowledge and belief around traditional healing, poisoning, and witchcraft needed to be entirely replaced with a new, equally robustly and widely understood biomedical body of knowledge.

Indeed, in some cases, enduring strong beliefs about the correlation between cancer and poisoning complicated the efforts of parents who had managed to bring their children to Butaro for care. These parents had entered the space of modernity that Butaro represented, as an institutional space metonymic of the broader ambitions of a technologically-invested sovereignty enacted through onco-nationhood, but often their family members stayed away from Butaro and never entered this yet exceptional space, and overall, yet resisted the injunction to become onco-citizens. Martha, a young mother whose eight-year-old son Abe was receiving treatment for leukemia, spoke of her conflict with the entire paternal side of Abe's family. Her husband, Abe's paternal aunt, and paternal grandparents all believed that he was a victim of *uburozi*, by which he meant poisoning (*uburozi* actually encompasses all three types of witchcraft, which I define and explore in Chapter 4, so context is important in

distinguishing between them). Martha had rented a house in Rusomo, Butaro's nearest cell[44], so that she and Abe could remain in the vicinity of the hospital while the team worked on his diagnosis and eventual treatment plan. She was certain that if they were to return home, the family would take Abe to a traditional healer, despite her efforts "to teach" her husband by describing how at Butaro, they were surrounded by other Rwandans with *kanseri*. He and the relatives remained vehemently against her seeking care for Abe at Butaro; as such, Martha was convinced that they had to stay put rather than visit home until Abe had completed some form of treatment. How then, had Martha, a cultivator (like the majority of patients) and pastoralist/animal domesticator (primarily of cattle), learned about Butaro? In her sector she was friendly with a generalist physician; after Sam's illness had begun he asked her whether she had heard of Butaro. Martha recalled having heard the name on the radio, but nothing more. He then explained to her that Butaro was a place where clinicians could diagnose and treat cancer. She had then brought Abe to Butaro, and was waiting for the team to clarify his diagnosis following inconclusive test results at CHUK (Centre Hospitalier Universitaire de Kigali), before pursuing treatment. She remarked how upon her arrival at Butaro she had been surprised to realize how many people of different ages had cancer.

Encounters on the ward often reminded me that the decision to open the first public cancer center at Butaro, in the rugged, cooler, higher-altitude Northern Province, did have an enormous social and material impact. While patients and clinicians from various parts of the country or Kigali often lamented Butaro's location

[44] Recall that the Rwandan government has organized the country as follows (starting with the smallest unit of territory and ending with the largest): Village, Cell, Sector, District, Province. The District is the basic political-administrative unit of the country.

owing to the bumpy travel and distance reaching it entailed, it is a real beacon of advanced care in a rural setting. One need only think back to the many interviews cited in this chapter to recall how Butaro was so often articulated as a place where poor Rwandan farmers and their family members first learned about the possibility of treating cancer with success, and found not just clinical care but also hope—"Butaro" and its "cancer doctors" were terms that circulated in villages and sectors so quickly that Butaro had more patients than beds within a couple months of its opening in 2012.

Indeed, many patients spoke of how their time at Butaro had quickly produced a new sense of hope, an antidote to the long embedded understandings in their communities of cancer as a disease that killed people quickly and was incurable (cancer was often described as "*indwara idakira*," an incurable disease). On the ward, Rwandans learned that "they can cure us of cancer," to quote one elderly woman with breast cancer. She had also heard on the radio that Butaro featured clinicians from abroad who were able to treat cancer. In essence, it was clear that while cancer could threaten familial bonds and livelihoods to a devastating degree, the disease also implicated a kind of "first contact" phenomenon, as has long been described in the anthropological literature—recall Paul Farmer's seminal work on the sociological impact of introducing ARVs to Haitian communities in the early 1980s (Farmer 2006) or earlier work on first contact with the peoples of Papua New Guinea. Many patients reported how they had asked a Rwandan physician, somewhere in their trajectory of care implicating multiple sites and interventions, about the causes of cancer, to hear that ultimately it was a disease that "comes without any reason," or "on its own," as we

saw previously[45]. But while patients understood that the American doctors at Butaro offered a knowledge of how to treat cancer successfully, they did not portray them as clinicians who radically revised their views of the etiology of cancer. As we saw before, these physicians sometimes told patients that anyone could get cancer at any age, including they themselves; interestingly, Butaro physicians had not agreed upon any unified educational script about cancer etiology to present to inquisitive patients (as most of them were).

VI. Conclusion

In this chapter, I have shown that Rwandans talk about cancer using a lexicon of infection and transmission. In particular, they imagine tumors as "abscesses," implicating an infectious process that has taken over an enduring wound. As such, the vernacular view is that cancer is actually a higher order process that builds on processes of infection and transmission. It comes forth when an abscess or wound is not properly cared for and healed. This reality complicates the strict division between infectious and noncommunicable diseases that the national public health system, in collaboration with transnational partners, generally maintains, leaving aside public education efforts around one of the virus-associated malignancies, cervical cancer. My data speak to the manner in which the experience of infectious, acute disease is imbricated with an experience of the chronic, non-infectious character of cancer, but also to the ways in which Rwandan citizens have a sophisticated and deep engagement with the historical presence and embodiment of both kinds of disease. This set of

[45] One woman described cancer as "an illness which comes without cause/reason." [*Ni uburwayi bwizana*.]

conclusions also has substantial implications for efficacious pursuit of public education efforts around cancer in Rwanda.

Chapter 4 Witchcraft as the Underside of Modernity

Historical ethnographies have detailed the encounter between indigenous and missionary medicine under colonialism, whose ruptures altered both with effects that endure today (Comaroff and Comaroff 1991; Hunt 1999; Vaughan 1991). In my broader project, I attend to the historical roots of Rwandan beliefs about cancer by situating current symptomatology and beliefs within the larger purview of local ritual healing and etiological idioms, past and present (Hagengimana and Hinton 2009; Lestrade 1955; Taylor 1992). Classic studies of cults of affliction have led me to consider how new and syncretic rituals in Rwanda's nascent oncological landscape congeal processes of social reproduction and often draw also on older signs and practices (Devisch 1993; Evans-Pritchard 1976; Turner 1967). Delineating Rwandan symbolism and symptomology around cancer will reveal how the gendered body relates to social action—and how values are constructed in a context of major sociocultural transformation (Comaroff 1985; Weiss 1996). My work is also driven by the exhortation to recognize African biomedicine as a distinct epistemological and sociocultural form rather than as a mere importation of Western biomedicine and technologies (Livingston 2012; Wendland 2010), and seek to respond to the dearth of studies on African practitioners of biomedicine with my portrait of Rwanda's first generation of oncology specialists.

In this chapter I explore the status of ideas about witchcraft among Rwandan cancer patients, which fall into three distinct types—sorcery, poisoning, and bewitchment [*ibitegano, ibitamikano*, and *ibihuherano*]—each denoted by a distinct term. The shared word for a witch or sorcerer is *umurozi*; it may also be used for a "poisoner."

In sum, an *umurozi* [plural *abarozi*] might use any of the three methods of witchcraft to attack an individual, or all of them in combination. Anyone can become an *umurozi*. The generic verb is *kuroga*, which applies to all three types of witchcraft. *Ibitegano*, best translated as sorcery, encompasses the malevolent use of substances, visible or invisible, or objects. In the case of a substance, it can be one that a victim literally steps over, unknowingly. If an object is used, it may enter and have to be removed from the body of the afflicted person. If a material substance is deployed to harm someone, it may consist of animal feathers, a tree, or crushed powder from the bones of various animals. *Ibitegano* can lead the afflicted individual to have either a physical or mental ailment, or suffer from both at once.

The second type of witchcraft is *ibitamikano*, for which the best English equivalent is poisoning. It involves a toxin placed in the food or drink of the intended victim. The sign of being poisoned thus can be a stomachache of unknown cause despite biomedical investigations, which may yield abnormal results without a clear cause or etiology. *Ibitamikano* rarely leads to a mental ailment, but usually causes one to suffer a physically and, at worst, die very quickly; it is thought to be very efficient in its power to harm. The majority of poisoned victims, I was told, become insane, or mentally incapacitated; this is best exemplified, perhaps by a previously intelligent child, at a normal developmental stage, suddenly becoming mentally ill or mentally challenged.

The third element in this typology of witchcraft is *ibihuherano*, best translated as "bewitchment." It involves the use of evil spirits, which can be sent to afflict someone from afar. As an example, one informant cited the distance between Kigali and the smaller city of Cyangugu, about 143 miles. Locals affirmed that it was rare for

ibihuherano to cause a physical illness in the victim at hand, but if it did, the condition would kill one immediately; but it does lead to erratic behavior as, for instance, when a bewitched lover begins to stalk the object of their affections. While in theory an *umurozi* can put any of these witchcraft methods to use, some are only capable of *ibitamikano* (poisoning), which doesn't demand too much intelligence, or contact with the selected victim. Other *abarozi* are able to use both *ibitegano* (sorcery) and *ibihuherano* (bewitchment), but in this case will tend to mostly use *ibihuherano*, mostly owing to its discretion from a distance.

Witchcraft has steadily figured as a major object of study in the Africanist anthropological literature since the early days of British structural functionalism, famously incarnated in Sir Edward Evans-Pritchard's *Witchcraft, Oracles, and Magic among the Azande*. In that seminal account, Evans-Pritchard famously stated,

> "Witches, as the Azande conceive them, clearly cannot exist. None the less, the concept of witchcraft provides them with a natural philosophy by which the relations between men and unfortunate events are explained and a ready and stereotyped means of reacting to such events. Witchcraft beliefs also embrace a system of values which regulate human conduct." (18)

The notion that witchcraft as a cosmological system existed to explain events of misfortune and tragedy, including physical illness and death, reflected a structural functionalist reading, and also emphasized witchcraft as a social framework integral to social reproduction, a theme that has remained central in Africanist anthropology. Indeed, he described the extent to which ideas about witchcraft permeated every area of Zande life—agriculture, fishing, hunting, domesticity, law, morals, healing, and so forth. One particular anecdote in Evans-Pritchard's analysis should be recalled given its relevance to my later analysis of the status of witchcraft and cancer in Rwanda today: that of an Zande boy knocking his foot againts a wood stump and blaming the

accident on witchcraft. The boy explained to Evans-Pritchard that witchcraft was the reason he had failed to see the stump, and also why his wound had "festered and remained open" (ibid.:20) rather than heal quickly as a regular cut would. In fact it was often that Rwandan patients told me that their kin insisted that they had been victims of witchcraft given in the face of their intractable tumors, resistant to treatment and slow to heal at least somewhat, let alone be cured. The other oft-cited example is that of the granary which collapses while people are sitting under it—according to Evans-Pritchard the Zande knows that termites ate away at the granary supports and that people were sitting under it to avoid sun and heat, but it is witchcraft that causes "these two events [to occur] at a precisely similar moment in time and space" (ibid.:23).

For illnesses and other afflictions believed to be the result of witchcraft, sorcery, or poisoning, Rwandans continue to call upon traditional healers. Many of the patients on Butaro's inpatient oncology ward had sought treatment from such healers before entering the national biomedical system in any consequential way, and a number of them told arresting stories about their encounters with healers in the distant past, for ailments or problems long predating their tumors. The widely used term for a traditional healer is *umuvuzi ba gihanga. "Umuvuzi*" (plural *abavuzi*) is a healer or doctor, though in present day Rwanda one hears the word "*umuganga*" used for a biomedical doctor. "*Gihanga*" refers to the former king of Rwanda, known as the *Mwami*: "one to whom everything belonged," as one young woman remarked. Yet it is also related to the verb *guhanga*, to create, because the *umuvuzi ba gihanga* uses vegetables, plants, and other natural entities to create the materia medica of his healing practice. Another term for a traditional healer is "*umuvuzi gakondo*," with *gakondo* literally meaning "tradition" or "origins." "*Ubuvuzi gakondo*" is traditional

medicine. While an *umuvuzi ba gihanga* uses products of nature to heal, an *umuvuzi gakondo* is different because his healing implicates traditional cults and related beliefs beyond the physical matter of the earth. Interestingly, it is commonly believed that an *umuvuzi (*healer; plural *abavuzi*) can become an *umurozi* (a witch/sorcerer), in which case the same person can cause suffering for his victim and know how to heal it. *Abavuzi* cannot be readily identified in the community, but they are known as being able to treat victims of all three types of witchcraft. Within one's community it was possible to suspect a person of being at once an *umurozi* and an *umuvuzi*; the potential of this dual status is well known across many African cultures. I also learned the term *abavuzi ba Kinyarwanda* to designate a "healer" more generally, but it was not a term that I heard patients use particularly on the ward or in clinic.

Now I turn to how Rwandan patients and their family members articulated ideas about the relationships, or lack thereof, between witchcraft, traditional healing, and cancer. Many were adamant that there was no connection between witchcraft and cancer, and that, consequently, they had only sought biomedical care and eschewed traditional healers. Out of the 45 patients with whom I did in-depth interviews in 2014-15, 31 said they had never consulted traditional healers for their cancers, 12 said they had, and for two it remained unknown to me or the patients did not want to disclose. Middle-aged women with breast cancer, **especially** those with some secondary school education, tended to say that they had ignored the advice of relatives to consult traditional healers. Many emphasized that they had "known" early on in their illness that traditional healing methods could not help them, and immediately refused them. I also was witness to other kinds of claims about the impossibility of witchcraft lurking behind tumors. There were mothers who said they could not claim their children had

been poisoned because they lacked the requisite "proof." This fitted into the larger set of beliefs about *ibitamikano* (poisoning), which was always carried out in secrecy and invoved simple, discrete actions, like adding a few drops of poison to someone's beer. Recall James, the middle-aged man grappling with chronic myelogenous leukemia, about whom I wrote in Chapter 3. He said that neither he nor his parents believed in the existence of witchcraft (*uburozi*) at all: "If witchcraft existed there would be few people left in the world because there are so many conflicts among people. If there was witchcraft, people would kill each other constantly." He was further convinced that indeed, many rural Rwandans feared and believed in the power of witchcraft, and therefore often avoided healthcare facilities. He cited the example of a man bloated with liver disease, who believed himself to be a victim of *uburozi* and consequently not seek adequate treatment. James drew the conclusion that such people "die of illnesses of which they could be cured." However, many patients (both men and women) spoke of how they had initially pursued traditional healing methods but stopped after experiencing no benefit or visible improvement. One 37-year-old from Kigali battling colorectal cancer, Illuminé, told me how he had consulted three different healers (*abavuzi*) in fairly short succession when he had first fallen ill, two in his native Eastern Province, and one after he relocated to Kigali near the end of 2013. One of his domestic workers[46] had told him about about the first healer, who was known for his success in treating stomachaches (*igifu*). This man gave Illuminé oral medications (*umuti*) which he took for two months, but his symptoms did not change nor disappear. Later he went to a second healer who was said to treat poisoning (he used the plural form *amarozi*, to

[46] Most patients at Butaro were poor subsistence farmers from rural areas who carried out all domestic and agricultural labor on their own. This man was clearly wealthier than the average Rwandan.

mean poisons).[47] That healer told him that he had eaten poisoned food, and prescribed him a concotion he made out of honey and unknown herbs. As Illuminé insisted, "Even if you see the medicine, you cannot tell what it is." He spent four months in that healer's care but again his health did not improve.

After moving to Kigali he consulted a third healer in the Kanombe neighborhood (where Kanombe Military Hospital is located), who believed that he was suffering from sorcery (*ibirozi by'ibitegano*). He then gave Illuminé a powder mixed with water (*udufu*), which turned "red like beets and smelled bad," which he spent four months taking as instructed. Illuminé explained that he continued to take the medicine from that healer under the influence of neighbors who asserted that he was a victim of *urusyo*, which he explained as the effects of sorcery somewhere in the body causing major hardness owing to an object imported magically. *Urusyo* is also translated as "grinding stone" in standard dictionaries, and locals confirmed for me that *–syo* is a stone on which one grinds sorghum. Interestingly, and harkening back to Chapter 3, I also later learned that *igisyo* denotes a large abscess which can appear anywhere on the body. Essentially, Illuminé believed in the plausibility of *urusyo* and continued the treatment prescribed to him, but he was also anxious to make progress with his gastrointestinal symptoms, so in January 2014 he returned to a health center in his original area within Eastern Province. From there he was referred to a district hospital, and the rest of his treatment narrative involved only care in the biomedical realm. When I pressed him on whether there was a relationship between cancer and witchcraft, he said that he didn't think so, but he felt that if biomedicine failed to heal a

[47] Recall that (singular/plural nouns) the meanings: *uburozi/amarozi* means poison, or toxin vs. *umurozi/abarozi* which means a witch or sorcerer.

sick Rwandan, people were quick to conclude witchcraft (*uburozi*) as the culprit.[48] Indeed, he had also sought the services of three healers *after* visiting his local health center, where the team was unable to "figure out what was wrong with [him]"; "it was a desperate attempt," he said of the recourse to healers. Illuminé's story serves as an excellent demonstration of the dialectic between traditional medicine and biomedicine that marks the current landscape of oncology in Rwanda. Also, in certain instances a generalized vocabulary of healing is shared across these two systems. For instance, when Illuminé was telling me about the ten chemotherapy infusions he had received to date, he referred to them as "*imiti*," the plural of "*umuti*."

Of course, I cannot discount the idea that informants may have viewed me as a representative of the biomedical system, as a white foreign researcher and medical student, and were therefore cautious about sharing with me their ideas about or experiences with witchcraft and vernacular forms of healing. My critics might contend that this kind of reticence around witchcraft was especially plausible given the deep structures of respect for authority and social hierarchy in Rwandan society which pattern individual behavior and of course shape social dynamics in any hospital, refracted along lines of power, class, race, and gender. In my defense, however, the twelve patients who had consulted traditional healers were quite forthcoming about their experiences, as were patients and locals with whom I had spoken in earlier years (2010-2014). Further, beyond the relationship of trust that I always aimed to build with patients, there is a certain openness to the sociality between doctors, nurses and patients at Butaro, given the overarching mission of educating and patients and communities that is sustained by the institutions that govern it (the Ministry of Health,

[48] "They say it is witchcraft." ("*Baravuga ngo ni uburozi.*")

Partners In Health, Dana Farber Cancer Institute, Brigham and Women's Hospital, Harvard Medical School). This crystallizes in dialogues between clinicians and their patients about traditional healing, its inefficacy, the dangers of temporal lags with respect to tumors and treatment, and so forth, so that witchcraft does not appear to be as much of a taboo on the Butaro ward as it may be in other clinical settings of biomedicine in Rwanda. That said, there were rarer moments in my fieldwork when an interlocutor would unequivocally state that traditional healing was dangerous and potentially harmful to the body—one young man told me that "*imiti ya kinyarwanda*" (traditional medicines) could damage stomach tissues. Further, in a quintessential moment of asserting himself as an onco-citizen, he said, "everything which does not meet [standards as set by] the National Bureau of Standards can harm a person," declaring his adherence to a national ideology which foregrounds technology, science, and rationalized standardization. He further recalled an episode from his childhood during which he had applied a traditional herbal preparation (made from "*umuravumba*," which is the shrub *Iboza riparia* or *Tetradenia riparia)* to his forehead in the hopes of curing a headache, but had ended up instead with swelling and a visit to the local pharmacy. Since then, he had been afraid of traditional methods and even at his local health center had been told that it wasn't good to use them. Hence his avoidance of traditional healing was based on a negative experience but also on obedience with respect to warnings heard in the clinical spaces of biomedicine.

One 43-year-old with breast cancer, Stéphanie, who like many, insisted that she had avoided traditional healing completely, said that certain people in her village talked about cancer as being pure "*uburozi*." She also stated that many people in her community knew that HIV+ individuals had a "greater risk of developing cancer," and

some believed that cancer could be a chronic disease. As such, it was clear that in her village, conceptions of cancer as the result of *uburozi* and as a consequence of HIV, as a chronic disease and as an acute killer, co-existed. Overall, my research suggests that in most of rural Rwanda, the biomedical and witchcraft (poisoning, etc.) frameworks are both invoked in conversations about and explanatory models of cancer. Unsurprisingly, then, my data also features many patients who consulted traditional healers and many who sought care strictly within the system of public biomedical care. I cannot speak here of a syncretic practice, because most patients who were treated by healers regretted the inefficacy of such treatment and the loss of precious means invested. One mother of a young boy with leukemia recalled how she had gone twice to traditional healers to procure herbs ("*ibyatsi*") in the form of a lions' cream ("*amavuta y'intare*") to apply to his swollen eye, but it "did nothing."

I did not encounter any who continued traditional treatments once they had learned about modalities like chemotherapy and surgery, as new beneficiaries of such interventions. Furthermore, clinicians at Butaro and at the other hospitals in the cancer network were eager to raise awareness of cancer and educate Rwandans; in policy and coordination meetings traditional healing was always cited as an ongoing problem, sustaining the constant figure of a late-stage cancer patient presenting to their clinics with already quite advanced disease. A 32-year-old patient said that if a doctor were to tell her that cancer were the result of *uburozi*, she would understand, but she had never heard this from any physician. She implied that only in that case would there be a clear reason to pursue traditional healing methods. This was certainly a good example of how respect for the knowledge and authority of

biomedical physicians could be expressed by patients. Sometimes patients would relate their historical encounters with traditional healing. Another older breast cancer patient, Anne, recalled how she had consulted traditional healers many years prior, during her third pregnancy (she had eight children) after developing intense abdominal pain. She went to a healer, took the concoction he prepared, and recovered. Anne made a point of telling me that she had purposely *not* asked the healer the reason for her poisoning ("*uburozi*") because she "knew the healer wouldn't know the reason behind it—the healer is not a teacher who shares what he knows." When she spoke about having been poisoned, she repeatedly used the verb "*kwandura*," but in the sense of "to dirty," or "to soil." Recall that I cited this verb many times in Chapter 3, with its other definition, essentially, to catch or receive an illness. In essence, Anne used this verb to talk about the contamination that poisoning had wrought in her body, but in the previous chapter I examined its many utilizations to denote the development of cancer, whether it "came on its own" or was "transmitted" in a family between kin of different generations. Thus, the lexicon for cancer straddled both ideas about witchcraft and ideas about heritability, as well as the articulations of Rwandans grappling with the question of any infectious aspect of cancer and its contagious nature, or lack thereof.

Anne's narrative also demonstrated something that was true with many of the patients I interviewed—cancer was not a unique event that ruptured an individual's lifelong trajectory of health and illness in an especially remarkable and altering manner, as it is so often depicted in societies of the global north, where practices of meaning making and political solidarity derived from the experience of suffering from cancer, and survivorship abound. In the north, a cancer survivor inhabits survivorship

in a very identitarian way—often, indeed to the benefit of cancer patients, fundraising efforts, and public awareness campaigns—because cancer is experienced as an illness replete with fear, uncertainty, toxicity, and disfigurement, which marks its subject (or victim) in an indelible way. Yet in Rwanda, many of the cancer narratives I collected were long and circuitous—my informant would often share a personal historical trajectory beginning with some of her earliest engagements with healing and healthcare throughout the life course. This usually happened in response to one of my opening questions, about when she had noticed the first signs or symptoms of cancer. Therefore, it certainly made evident how most of these patients were preoccupied with working out the causes for their cancers, but also that they were experimenting with the temporality and causality of cancer. As for Anne—she remembered that after the poisoning episode she had suffered years before, she had developed major pain in her legs. It had felt "as if her legs were tied" and she was soon unable to walk. For that ailment she ultimately received care at a local health center, where she obtained "pills and injections" which healed her legs. At the health center she was told that there was a problem with the blood vessels in her legs. Thereafter she returned to the health center regularly for the same treatments, over the course of five years, during which she managed to continue cultivating her land daily. For Anne, these two distinct experiences in her more distant past—the poisoning and her recovery, in addition to the leg treatment at the health center—were both part of the history of her current cancer, and conditions that eventually brought her to Butaro. Actually, a part of this had to do with Anne's trajectory of care—it was providers at the health center who had noticed something (presumably on her breast, though she was not at all explicit) and suggested a transfer, in June 2014, to Butaro Hospital, telling her that it was "a place

where they treat cancer." Thus, a multi-year experience with a local health center became part of her cancer history because it had ultimately led her to Butaro—space and time in the longue durée were subsumed into the experience of cancer. However, Anne was resolute in her opinion that the episode of *uburozi* and her cancer were entirely distinct occurrences, and that none of the three types of witchcraft bore any relationship to her cancer. Ultimately, cancer was simply an illness that "develops from the body."

There was also the issue of cancer's symptoms resembling those of bodily pathology resulting from witchcraft acts, such as major pain and cachexia (weakness and wasting of the body due to severe chronic illness). As one teenaged leukemia patient explained to me, although she was certain that there was no connection between cancer and witchcraft, she understood the "confusion" that could lead Rwandans to think otherwise. "Some people go seek traditional medicine because cancer attacks you in the same way as witchcraft...People say that when you are a victim of sorcery, and have stepped over it [the ensorcelled object], you have pains in the legs, the hands, [or] in your joints. This is why when people have cancer they are confused and go to seek traditional treatment." This comment foregrounded the fact that pain has a long natural history in Rwanda, as it does on the African continent more broadly (see Livingston 2012). Thus, the symptomatology of witchcraft and of cancer were shared, through the experience of pain—I also heard older women speak to this effect. Hence we have another example of how local interpretations of suffering related to cancer might first be integrated into the vernacular system of belief around witchcraft, even in the face of public awareness campaigns and other efforts to educate the citizens about cancer. Francine, the mother of a little girl with leukemia, who also

figured in Chapter 3, where I quoted her declaring cancer to be "an epidemic," mentioned cachexia (I am using the medical term) as a shared feature of attacks by "evil spirits," and cancer. "Cancer can have the same signs as evil spirits," she told me. Indeed, she recalled how her daughter had suddenly started losing weight, seeming to "waste away" before her mother's eyes. Yet overall, she believed that witchcraft as a system of belief was "ending," because it was "used less and less." Another patient told me that she couldn't deny the ongoing existence of all three forms of witchcraft; she just didn't think they had anything to do with cancer.

Françoise, the 49-year-old primary school teacher and head undergoing receiving chemotherapy for colorectal cancer whom we met in Chapter 3, was among those patients who affirmed that ideas about poisoning were still quite present in most communities, and a major culprit in delaying cancer sufferers from seeking biomedical care. She believed that in her community, most people with tumors would assume they were victims of poisoning, and seek care from one traditional healer after another, until inevitable death. Stating that she had "no idea about the causes of cancer," Françoise was nevertheless certain that it wasn't "related to sorcery," and she recounted how the advent of Butaro's cancer center had impacted how she made decisions for herself and her family. She remembered the inauguration day of Butaro Hospital—probably of the cancer center in July 2012 and not the overall hospital in January 2011—with news of it circulating on the radio and in newspapers. "We heard that Butaro was built by Americans and specific for cancer." And sometime in 2013 or 2014, Françoise had noticed that one of her sister's breasts was larger than the other, and she felt a lump in it, "something hard." She encouraged her sister to head to

Butaro in search of care, which she did in March 2014, at which point she underwent a mastectomy and was then transferred to Kibagabaga Hospital in Kigali. Françoise did not volunteer more details about her sister's condition (it was March 2015 when we met); rather, she elaborated on how, thanks to public education efforts around cancer, residents of her community knew about the risk to women of breast and cervical cancer. She recalled how during the national HPV vaccination campaign (it began in 2011), health center nurses had come to the school where she was head to vaccinate a cohort of girls. While there they "taught everyone about breast and cervical cancer." In addition to the vaccination campaign and many discussions with school-aged children, Françoise confirmed that community health workers (CHWs) in her region were also teaching people about those two cancers. Biomedical knowledge about the warning signs, risk factors, and appropriate responses to these women's cancers had thus been penetrating her community over the past few years, as a counterpoint to the yet engrained forces of poisoning and other forms of witchcraft. For Françoise, proof of this was locally abundant—"many women can tell you that they've lost one of their breasts. And when vaginal bleeding starts, women know it is probably cervical cancer." Furthermore, Françoise noted a development in her region's political climate around health—local leaders regularly told the residents of their communities to purchase an adequate health insurance plan (which in many cases meant being formally enrolled in the national health insurance system) so that they might seek care for any illnesses "before it is too late." Thinking back to prior years, Françoise believed that there had been individuals in her community dying from cancer, but she just "hadn't known it" at the time, being unaware of the signs of cancer. Indeed, she was especially attuned to the fact that it would take years yet for Rwandans to deeply assimilate knowledge

about cancer and the appropriate biomedical interventions to be pursed in a timely fashion. As she said, "Some people still neglect small signs."

In effect, Françoise's observations spoke to the very active development of cancer care and awareness, for breast and cervical cancer but also for other malignancies, across the country. It was also true that she was from Northern Province, which includes Burera District—the first district in which Partners In Health had launched a cervical and breast cancer prevention campaign (which I worked for and was a part of) beginning in 2010. Her recollections also remind us about the extent to which cancer has become part of a national rhetoric about health and individual responsiblity for it. Onco-nationhood becomes pertinent once again as we think about the impact of cancer public awareness campaigns, and the HPV vaccination campaign, through which the state interpellates a new citizen who is meant to be vigilant about signs of cancer and become, as necessary, the beneficiary of high-quality, life-saving treatment for it.

The dialectic between witchcraft as an explanation for tumors, and a new oncology infrastructure sometimes produced serious ruptures in kinship ties and nuclear households. Recalling the story of Martha, the mother of 8-year-old leukemia patient Abe, offers us a fitting example of this fact. She recounted how her husband, along with his sister and parents, were convinced that Sam had been a victim of *uburozi*, or poisoning, of which his illness was a direct consequence. As such she had separated herself and her son completely from the rest of the family and was renting a house a hill down from Butaro so that Sam could complete his treatment without any disruption. Otherwise, she had been certain that her husband would insist on taking Abe to a traditional healer and interrupt his course of oncological treatment. In vain,

she had explained to her relatives that there were many patients with *kanseri* at Butaro, suggesting once again that a transition to biomedical understandings of cancer was going to be slow in arriving, and perhaps particularly so for Rwandans who did not gain a first-hand, sensually close experience of clinical oncology at Butaro or other similar wards. To this point, Flora's husband and his family members had never been to Butaro themselves.

In certain cases a patient would describe how members of his immediate family had urged him to consult traditional healers, and yet how he had resisted this suggestion. One such patient was the calm, articulate 26-year-old Frank, who was receiving chemotherapy for diffuse large B cell lymphoma, a diagnosis the team at Butaro had made recently, after many months of uncertainty for Frank. When I met him he was still managing to work as a primary school teacher, though he lamented that prior to his illness he had also been a beekeper and entrepreneur, selling honey as well as wood to bakers. He was one of the rare patients who articulated a substantial family history of cancer and early on in his illness had suspected that he might have cancer for this very reason. His maternal grandfather and first cousin had both died of cancer, the latter at Butaro. His paternal grandfather had suffered from cancer but had undergone treatment in India and Liberia and lived for a few years before passing on. As such, his view of cancer was as follows: "It is a killer disease...anyone I knew with cancer died." He had heard about Butaro's cancer center on the radio, and he had implored his doctors for a transfer to Butaro on many occasions, while receiving care at regional health centers and one hospital, in addition to Kanombe Military Hospital in Kigali. Of note, Frank's parents had wanted him to seek traditional medicine, but he was quick to refuse. In fact, they had procured treatments from a traditional healer and

placed them in Frank's room. One day soon afterwards, he simply "threw them out" while his parents were absent. In fact, he'd been particularly wary of the medicinal preparations because his first cousin, who worked at one of the district hospitals in Frank's native Western Province where he had first sought care, had warned him that they could cause hepatitis. One of the preparations had been for oral intake and another one was an ointment to be "smeared on the skin." Frank also spoke of being concerned about the high concentration of the medication—he thought they might cause him problems owing to high acidity.

Frank did not think that witchcraft and cancer bore any connection. However, while his parents had "accepted that I have cancer," his other relatives all thought that he had been bewitched by the evil spirits of dead forefathers.[49] The suspicious party believed to have afflicted Frank with the evil spirit forces was his yet living paternal uncle, because he had worshipped ancestors in the past.[50] But Frank was certain that this constituted a fallacious accusation—it was "a lie" which he "did not believe." He cited the fact that he met his uncle regularly and furthermore, that his cousins (said uncle's children) had visited him at Butaro as well as at Kanombe Military Hospital in Kigali during an earlier period in his clinical trajectory. Ultimately, Frank summarized what he saw as the distinction that allowed certain inviduals in his social entourage to accept cancer as a biomedical disease with witchcraft etiologies behind it: "Only people who went to school accept that it's cancer because they look at the results." Thus, he concluded that formal education was the distinguishing factor between those Rwandans who recognized tumors as constituting a pathological affliction resulting

[49] *Bamwe bavuga ko ari ibintu byo mu miryango bantererereje*.

[50] Frank (pt 14) used the verb *guterekera* = to worship (exclusively for ancestors' spirits), a practice which can generate positive or negative effects on others. '*Guhimbaza Imana*' means to worship God.

from witchcraft and therefore requiring traditional forms of healing, and those who had come to recognize it as a biomedical pathology, measured with a different form of rationality. In this rationalized framework cancer progress was assessed through clinical exams and laboratory tests, and the disease itself was responsive to newly visible modalities like chemotherapy and radiation. Frank's appraisal of witchcraft and cancer in the community again suggested that to a certain extent, Rwandan citizens were quite quickly assimilating knowledge about cancer as a biomedical illness, in the context of gradually expanding public oncology and public awareness campaigns. The tragedy of Frank's story also came through in the comment of my research assistant, Ignace, who said that he had met Frank on the ward about nine months prior to my conversations with him, in May 2014. At the time Frank had been full of hope for his recovery, and Ignace vividly recalled his optimism. But now he seemed deflated, and was losing faith that his condition would ever improve. When he had asked one of his Butaro physicians about the cause of cancer, he'd heard in response that the cause was yet poorly understood. Rejecting witchcraft entirely and declaring himself ignorant of cancer's etiology, Frank's psyche was gradually succumbing to the disablements and ruptures that cancer had wrought upon him.

Occasionally, patients would simply speculate on the relationship between cancer and witchcraft—one elderly woman wondered if one was a victim of witchcraft with a leg affected and subsequently amputated, couldn't that cause cancer? Another woman of the same generation, Fleurette, explained that at the first appearance of her symptoms, before seeking care in biomedical facilities, she had speculated that she was a victim of *uburozi*, but avoided any consultation of traditional healers. Further, in 2011

her child had died from had seemed to be a mere fever, while hospitalized at CHUB (*Centre Hospitalier Universitaire de Butare*) in Southern Province. Fleurette had also wondered if her child was a victim of poisoning, but had chosen not to consult traditional healers ("*buvuzi bwa gakondo*"). When I pressed her to explain to me what had made her so reluctant to consult traditional medicine, she replied placidly that she simply did not like traditional healing, and that there was no particular logic or reason behind her feelings on the matter.[51] Notable, however, was the fact that Fleurette, in addition to being a cultivator, was a community health worker for her village and therefore more aware of biomedical interventions than the average rural Rwandan citizen. In fact later on, she mentioned that perhaps there was a reason for her aversion to traditional healing. There was an old woman in her village who was sick and cripped, with a "visible head abscess," who thought she was a victim of witchcraft. Fleurette said, "For that reason she does not go to seek treatment from health facilities. I think that maybe she has a bone cancer or blood cancer and if she went to seek treatment at a health facility, she would get well. This is why I dislike traditional medicine. That woman constantly has abscesses on her head." She made this conclusion quite emphatically. It seemed that the combination of her own experience as a cancer patient at Butaro, as a CHW in her village, and in watching members of her social entourage deteriorate with tumors were all coalescing to transform her vague negative suspicion about the efficacy of witchcraft and traditional healing as an explanatory framework into a strong antipathy to these beliefs.

[51] Pt 11: She said, "*Ntibindimo*," which translates as "I simply don't like all this," as she meant to communicate that there was no particular reason behind her dislike.

Fleurette was one among many patients I interviewed who disavowed the relevance of witchcraft for understanding cancer. Another such individual was Paul, a 64-year old farmer, the owner of three sheep and three cows as he declared proudly, suffering from colorectal cancer. He related that early on in his illness he had followed the advice of some older peers, some of whom were *abavuzi* (traditional healers) and some not, collecting grasses and plants (*ibyatsi*), grinding and crushing them, and drinking the resulting substance. He drank a whole "basket" of such grasses over the course of three months before heading to a local hospital, but they had no effect. He remembered that the peers advising him had thought that he was suffering from a tapeworm infection (*inzoka*), or stomach pains and bloating (*ibijinga*). Paul was not simply convinced that there was no connection to be made between witchcraft and cancer—he asserted vehemently, "Poisoning and witchcraft do not exist at all! If someone is sick I advise him to go and see a doctor. The only dangerous thing in the world is cancer!" Furthermore, he was vocal about the fact that he had *never* actually believed in poisoning—in the past when people would suggest to him that someone with a tumor had been poisoned, he would immediately refuse the idea. In the present day, he explained, if someone were to suggest to him that an individual with a tumor was a victim of *uburozi*, he would be quick to tell him that the individual "has cancer" and should be taken to a health facility.

Paul's trajectory made evident the fact that sometimes, Rwandan patients would recount the utilization of traditional medicine but vehemently deny any prior deep-seated belief in forms of witchcraft like poisoning, and in the present strongly against any association between witchcraft and cancer.

Within communities, there were deeply settled beliefs about the material conditions of witchcraft and poisoning which complicated the issue of placing cancer within this framework, or even made its inclusion impossible. One major example of this was a widespread belief among Rwandans that once a person was poisoned (recall *ibitamikano* as the term for poisoning), he could no longer successfully receive any kind of treatment in the form of injections—rather, an injection would lead to a rapid death within approximately two days. This belief was regularly invoked by many patients with whom I became well acquaintated, as evidence of the incompatibility of biomedicine and poisoning—poison could not be cured with biomedical means. Another such patient was Edouard, the 34-year-old HIV+ widow with Kaposi's sarcoma who I introduced in Chapter 3. He also volunteered the fact that he had received multiple injections at Butaro without dying as evidence for the fact that he had not been a victim of sorcery. Further, he thought that if there were a relationship between witchcraft and cancer, "witchcraft would kill you or disable you so you could not walk," but instead many cancer patients seem to suffer for months on end and remain mobile. He affirmed that there were many Rwandans who believed in a link between witchcraft and cancer, but he could not agree with this given his extended and quite negative experience with a few forms of traditional healing[52], in which he had invested amounts of his overall means to no avail.

One mother, Juliette, whose eight-year-old girl was plagued with leukemia, immediately denied any connection between *ibitamikano* and her malignancy, adamant that had her daughter been a victim of poisoning, the "many injections" of

[52] Edouard had pursued a series of treatments with two different groups of healers—*abagorozi*, who are a group of healers who broke off from the Seventh Day Adventists and formed their own sect, and members of the Masaï tribe in Kigali, who also sold their medicinal concoctions.

chemotherapy would have already killed her. Indeed, the intravenous lines through which chemotherapy coursed into the vasculature of thin, fragile bodies, usually through a port lodged in the hand, over the course of many slow hours, were considered "injections." Juliette further insisted that members of her community were curious about her daughter's illness, but she would simply tell them that the diagnosis was as yet unknown. There were other ways in which the materiality of cancer care and its intensity, so new and yet unknown to much of the population, shaped what people assumed about her daughter's illness, and how Juliette responded to them. She explained that at one point, members of her community had speculated that she was taking her daughter to traditional healers for her illness, because "one cannot go each week to a health facility." Hence it was also clear that Rwandans were yet uncovering the pragmatic and material conditions of oncology's practice, and of the very intensity that characterizes cancer therapy. They had no prior experience of chronic illnesses requiring weekly visits to a hospital on which to anchor what they heard from cancer patients ad their close kin. As Juliette asserted, "It is because nobody has been sick for a long time. Everyone who is sick goes to a health facility, gets treatment and gets cured. If not, then they are referred to a hospital and also get cured. So they wonder why I come here every week." One might immediately wonder why the Rwandan experience of HIV/AIDS, as a condition that cannot be cured and which requires that patients take medication (antiretroviral drugs, or ARVs) for life, was absent from Juliette's account. This reference point was likely missing owing to the successful decentralization of HIV/AIDS treatment in Rwanda—community health workers (CHWs) monitor HIV/AIDS patients in their communities and the national ARV access and adherence

rates are quite high (here I am relying on official statistics).[53] This kind of story speaks to the fact that the technologies, temporalities, and overall clinical infrastructure that oncology requires are difficult to imagine without a first-hand experience of them as a patient or as kin accompanying a patient. It also drives home a more obvious point—while Rwandans have an experience of cancer that stretches back many decades in the historical record, the national oncology program is still at the vanguard of health care development in Rwanda. With respect to the biomedical healthcare infrastructure, most Rwandans only referenced diseases for which it had been possible to obtain a treatment and cure within the space of one clinic visit.

"Pregnancy of Snow," "Dirtiness," and the Persistence of Bewitchment: Diagnostic Imagery and Healing Systems for Choriocarcinoma

Certain Rwandan patients I met did articulate bewitchment as a major part cancer etiology. I was particularly struck by the story of one 33-year-old woman with choriocarcinoma, a tumor of the uterus that develops out of the cells that normally become a placenta, during pregnancy. A baby may or may not develop with this cancer present. Her name was Danielle and she had traveled a long way from her home in Western Province to Butaro far in the north. A farmer and mother of two small children, she was an especially effusive and loquacious interlocutor. With her large saucer-like eyes set on me, she launched into a long narrative about her illness, barely pausing for a breath, as if she was relieved to finally have a devoted listener. She began the story in 2009, during her first pregnancy; at one point she developed "extraordinary" pain in her lower abdomen. Danielle was quick to orient me to the

direction of her thought process, stating "they did witchcraft on me,"[54] with the "they" signifying unknown individuals in her community. She hurried to a local health center for a prenatal examination that yielded no abnormal results, and thereafter she was transferred to a nearby district hospital where she spent two weeks and received analgesics and "24 injections" according to her recollection.

After being discharged from the hospital and returning home, her abdominal pain only increased further. In vain she would "pour water on [her] belly" and drink a four-liter jerrycan of water at through the night. Witness to her ongoing suffering, her husband concluded that she must be a victim of witchcraft, but at the time Danielle had thought this quite unlikely. There was no reason for anyone to have bewitched her—she had only been married for two years, and she consistently gave water and food to anyone who came to visit her. Further, she felt she had no conflicts with any individuals. Her husband persisted in his belief of malfeasance towards her, citing the fact that she had already been to multiple health facilities with "intelligent experts," but had yet not experienced any improvement. Moreover, he was especially convinced of this after a neighbor had visited him to tell him the following: she had heard two other women in their village boasting that they had bewitched Danielle. The women had stated maliciously, "Although she [Danielle] is pregnant, she does not have a baby in her womb. Instead there is an animal [in the womb] and she will die thanks to it!"[55] Even with this information as well as pain that was becoming unbearable and a fever, Danielle repeatedly refused her husband's imploring suggestion that she seek treatment from traditional healers.

[54] "*Barandoze*."

Afterwards, Danielle's husband invited two pastors from their Protestant church, and two friends of hers to their home to pray for her, also hoping that this group would convince her to pursue traditional healing. They visited, and having convinced her, visited ADEPR (The Pentecostal Church of Rwanda) to procure the medicine. ADEPR is an assembly of Protestant churches in Rwanda, including Pentecostal ones, and indeed "Pentecostal" is specifically in the name. There is also a separate Pentecostal sect bearing a similar name, but Pentecostalism has a minimal presence in Rwanda, and most Rwandans understand ADEPR as referring to the association of many Protestant sects. This apparent syncretism between traditional forms of healing and Christianity, and the fact that a Pentecostal church could be the site for procuring medicinal products outside the public biomedical framework, demonstrates a reality about "traditional healing." As a cosmology of healing, it too is a dynamic system of belief which citizens actively produce within the social and political context of post-genocide Rwanda.

Danielle took the concoction, but all she remembers is that she vomited over and over again. She vomited "frog eggs which were viscuous" and at a glance resembled "the cooking vegetable oil [I] had swallowed." Her abdomen had felt as if it was burning, and her whole body felt hot. Her husband called the man who had prepared the medicine, and he instructed the husband to remove her from the compound where they were living, in order to move her further away from the unknown person who had bewitched her, as said person was presumably near their home. Before moving away at all, though, that night Danielle's father-in-law came to visit her, accompanied by another woman who was a neighbor. Danielle recalled how after they had left her room she had poured water on her abdomen, but she believed

that the neighbor had watched her from behind the fence to her house and witnessed this action. She was convinced that the neighbor had then gone to the women who had bewitched her to report how she used water to soothe herself, because later in the day her husband asked her if she'd been out of the house and poured water on her abdomen because he had heard her habit being discussed in town! As she put it, that was when she suddenly decided that she was "really a victim of bewitching." She continued to take the traditional medicine that had been procured for her, which always made her very thirsty so that she remembered "living on" fresh milk (*inshyushyu*) and fermented milk (*ikivuguto*), as well as meat sauce. She continued to vomit copiously and prayed to God: "God is a skilled workman,"[56] she told me.

Danielle recounted her story to me at great length, dense with many details, so I will summarize the rest of it and then consider the centrality of witchcraft in her explanatory model for choriocarcinoma. We are still reviewing events that occurred in 2009. Essentially, Danielle's husband was concerned that she had not had a prenatal check-up in a long time, so she returned to her sector's health center. The nurse there let her go home despite her thin frame, but advised her to pursue better nutrition to build her strength and be able to "push the baby out." On December 15, 2009, with the onset of labor pains, Danielle went to the health center and gave birth. Her child was small owing to the health problems and weight loss she had experienced. Fast forward to February 2014, when Danielle did not have her menses, and again had intense pains in her lower abdomen. She said, "Because I had been bewitched before I was then afraid of poisoning. So I took time to pray but after praying I had my menses only for one day although I would usually have it for six days. I thought to myself, this is

[56] Pt 16: "God is a skilled workman." [*Imana ni umukozi w'umuhanga.*]

unusual." Yet the following day she experienced profusely heavy vaginal bleeding and returned to her health center. They confirmed that she wasn't pregnant and hospitalized her in the center, an unusual occurrence, but refused to transfer her to a hospital. To convey to Danielle that something was awry, the nurse on duty commented to her that she seemed to be "two or three months pregnant with 15 babies!" After another brief interlude at home with more bleeding and ample praying with fellow Protestants from her church, Danielle went to a different health center where she was diagnosed as having suffered a miscarriage.

From there Danielle was finally transferred to Kabgayi Hospital in Southern Province, far from home. There she underwent a first abdominal ultrasound which catalyzed her eventual diagnosis with choriocarcinoma. She described the scan as showing that she had "snow" (*urubura*) which was "making noise in my abdomen." She had never known a woman with snow in her stomach, though she did recall the story of a woman who, instead of a baby, had three things removed from her stomach: *intamyi (*part of papyrus leaves*), ikiyongoyongo (*a black-headed heron*),* and *urubura* [snow or hailstones].[57] Undoubtedly, out of all the patients I got to know, Danielle had perhaps the richest vocabulary to describe her cancer and her clinical trajectory. She begged the surgeon to remove "the snow" without surgery or a C-section, if at all possible.

[57] *Ikiyongoyongo* (a black-headed heron, or a bird with a long neck usually near a river or lake; eats small fishes); *urubura* (snow).

Conclusion

In late August 2014 Danielle was discharged from Kabgayi Hospital and referred to Butaro for further care. She recalled that she hadn't known where Butaro was and so had inquired with various people in her community while she worked on procuring the fare and a plan for public transportation. It was at Butaro that she actually received the diagnosis of choriocarcinoma: "They did ultrasound and x-ray [on me]. When the results came, Dr. Clément said that the snow [*urubura*] had caused the cancer [*kanseri*]. I calmed myself and told the doctors to pray for me. They were shocked that I had cancer." Thus, what Danielle conceptualized as "snow" after her first abdominal ultrasound became the causal agent for *kanseri*, a term she learned at Butaro.

Danielle read the "shock" of her physicians as a sign that she had a serious illlness, and by the time I met her she had crafted her own theory of the etiological basis of choriocarcinoma. These were her major conclusions:

> Cancer is dirtiness. The dirtiness is that snow, it is pregnancy of snow. The snow decayed my uterus and this resulted in cancer...There is cancer that comes from witchcraft (*iterwa n'uburozi*), and there is cancer which develops in the body without any cause—for example, breast cancer. In my case I know for sure that I stepped over things and they intended to kill my baby. And they found I was not pregnant, and those things I stepped over caused my cancer (*ibintu natambutse*).[58] There is a man whom I think is behind all of my problems because he came and told my father that he was able to treat me. I told my father, please don't give any money to that man; I will pray and go to the hospital instead. I refused to be treated by the man, so conflict ensued. Then my father banished me, and since then he does not visit me.[59]

Danielle's equation of cancer and dirtiness was especially striking and fits well into the conclusions I drew in Chapter 3 as to how Rwandans constantly utilized a lexicon of

[58] [*Ibintu natambutse*] = I stepped over things. [like *ibitegano* = witchcraft substances which you step over to be poisoned/bewitched].
[59] *pt 16: "Yangize igicibwa."* = He banished me.

infectious disease with the invocation of abscesses and infectious transmission to describe and make sense of cancer. Her history also revealed another reality on the ground—it was not only incongruent beliefs about witchcraft (Danielle and her father believed in the power of witchcraft) within an immediate family that could cause rupture but also disagreements over the best method and course of treatment to pursue. Further, when she spoke of "stepping over things" and this leading to her cancer, she was referring to *ibitegano*, or sorcery. Recall that this form of witchcraft encompasses the malevolent use of substances, which can be visible or invisible and intangible, or objects, which may have to be subsequently removed from the body of the victim if there is to be any hope of a cure. It was clear that Danielle had been extremely marked by the experience of seeing her uterine malignancy visible on an ultrasound scan, and she had spoken at length about the subsequent gradual "removal of the snow" with treatment at both hospitals. The material characteristics of the ultrasound picture were likely another reason that she inferred having been a victim of *ibitegano*, given that this is the type of witchcraft that can involve implanted physical objects causing illness in a targeted person. Thus, in a novel way, a technology that was still new or difficult to access for most Rwandan patients, that of x-rays, had been integrated into the semiotic order of witchcraft and produced empirical evidence for *ibitegano*. This certainly can serve as a potent example of an unintended consequence of introducing high-tech oncological care into rural Rwanda—the modalities of care involved may well be interpreted in a manner that allows for them to be embedded into a long-standing vernacular belief framework organized around witchcraft. And yet, Danielle was careful to distinguish types of cancer derivative of witchcraft from those that "develop in the body without any cause—for example, breast cancer." Why

might she have singled out breast cancer as a major malignancy free of any etiological entanglement with witchcraft? We might speculate that this was because breast cancer is one of the major cancers seen these days in Rwanda, and that Danielle could not imagine so many corresponding acts of witchcraft as plausible. In addition, it may have been a direct consequence of asking physicians about breast cancer causes during her care trajectory, and learning that causes were yet unknown or unclear. Further yet, mammography is minimally accessible in Rwanda owing to a very small number of the specialized machines, and therefore very few patients have ever seen mammographic images of breast tumors. At a deeper level, we might wonder if there was something especially sacred or delicate about the womb in Rwandan culture that meant that pathological states of the uterus were assumed to be related to malevolent actions.

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