

IMPROVISING MEDICINE

An African Oncology Ward in an Emerging Cancer Epidemic



JULIE LIVINGSTON

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In memory of Dikeledi Mloi

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PREFACE

 In 2006 I returned to Botswana after an absence of some years, to begin research on a book about pain and laughter. On my first weekend back, a dear friend invited me for lunch at her home. She said she had been saving something for me, and she handed me a huge, flat, brown envelope. Inside were the CT scans and X-rays of her dead cousin, whom I had known long before as an energetic teenager. On the CT images, a massive tumor could be seen pushing through the colored slices of his head. She was unsure what to do with these pictures. It seemed wrong to throw them out, but they also were too upsetting to look at. Instead, she gave them to me, along with the story of his cancer. She told me she was sure I would find a way to put them to good use. In the coming days, other friends began to offer up cancer stories. Soon these stories led me to the pain and laughter I sought, but also to a great deal more.

This book is about a small cancer ward in Botswana. At this ward is a white, European doctor who tends to suffering, (mostly) black patients. The air is hot (in summer), and the sun bright. Some of the nurses are big, angelic mothers with wonderful rolling laughter. In the country next door, a murderous tyrant reigns. Uh oh. You might be worried already. She's written *that* book—the one Binyavanga Wainana warned us about in his deadly hilarious satire “How to Write about Africa.” The book wherein some undifferentiated Africa lies marked by depravity, affliction, and beauty, awaiting the salvation of an equally unmarked “West.”¹ But take heart, and please do not misread the chapters that lie before

you. This is *not* a tale of white physicians come to save the poor Africans, if only they can overcome their ignorance and superstitions. We will not journey into “the diseased heart of Africa” to gaze at the spectacle while congratulating ourselves for caring.² There will be no hyenas or elephants, or even any big, red African sunsets. Africa will most certainly not be “pitied, worshipped, or dominated.”³

Cancer, if you think about it, just doesn’t lend itself to that kind of story. Cancer, like biomedicine itself, is neither an exclusively African problem, nor a particularly Western one. The problems of pain, death, illness, disfigurement, and care that lie at the heart of this book are basic human ones. But like all such experiences, they unfold on the ground in particular ways. Nor should cancer lend itself easily to the tales of redemption via biomedicine that make up the fantasies of global health. Thankfully, some cancers can be cured. Most, however, cannot. Oncology, like all domains of medicine, offers more than cure—it can help to extend the lives of patients, and it can palliate the afflicted, easing pain and discomfort. But these rewards are hard won if they come at all, gained through costly practices of poisoning, cutting, and burning. Any close look at oncology, as so many readers already know, necessarily means contemplating the deep ambiguities of biomedicine and our uncomfortable relationship with technological longing.

I myself cannot remember a time before cancer, before people I loved melted away and entered the agony of slow death, before surgical scars, and wigs, and bottles and bottles of pills. I also cannot remember a time before oncology. I was raised in the home of an oncologist who ran a cancer research lab. American, European, and Israeli cancer scientists and cancer doctors regularly visited our house, where oncology was a religion of sorts. Some of my dearest friends survived their cancers because of oncology, and for their continued presence I am immensely grateful. Yet, in the face of many deaths I have witnessed since childhood, I have also questioned oncology’s rituals, its liturgy, and the excesses to which blind faith and desperation can lead. For many years, I noted its cultural, political, and economic power. I carried on in this manner until 1997, when, to my surprise, I found myself peeling apart cancer and oncology for the first time, so thoroughly interwoven had they been in my imagination.

In September of that year, for the first time in my life, I saw untreated, advanced cancer—that is, cancer without oncology. It was a horrible epiphany. I was in Botswana, visiting patients with a home-based care

team, when I encountered a massive, florid growth that was killing a boy who slowly, silently writhed in agony. I stood stunned by the spectacle, unsure what I was seeing. My friend and co-worker, Dikeledi, whispered the word *cancer* in my ear, with a familiar gravity. I eventually saw many such scenes, and in the process came to understand that while cancer with oncology was awful, cancer without oncology could be obscene.

In the late 1990s in Botswana, these cancers seemed somehow ephemeral. Most people with an interest in healthcare in southern Africa were focused elsewhere—on HIV/AIDS. The politics of health were centered on gaining access to the new antiretroviral therapies (ARVs) that were suddenly extending the lives of people with HIV in the global north. Because such drugs were not available in Botswana, being far too expensive for the ministry of health to afford, many people wasted and died. What was to be done?

When I returned to Botswana for an extended stay in 2006, the situation had changed markedly. Antiretrovirals were now available, and the programs to distribute them were scaling up and continuing to enroll patients. But suffering, illness, and death had not disappeared, of course. Clearing away the cloud of AIDS revealed the landscape of cancers, which were attaching to a newly established oncology. But longing for oncology is not the same as longing for ARVs, as you will discover in this book.

The story before you necessitates the revelation of many personal matters and intimate details—a cancer ward is such a place where life is cut open, raw and exposed—but you won't find the X-rays my friend gave to me. They are simply too private. Similarly, you will not find photographs of cancer patients or their relatives. You will have to rely on my words and your imagination to grasp the humanity in the pages that follow.

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Schaan, Isabella Schaan, and Patrick Monnaese made our stay on Kgwa-kgwe road much more fun.

This book is the product of a conversation sustained over the course of several years with my dear friend and intellectual comrade Steve Feerman. Many of the questions I ask here were initially his, and so, too, many of the answers. Steve has patiently read drafts and been my most consistent interlocutor since I began this research. I am immensely grateful to the Wissenschaftskolleg zu Berlin for giving us an entire year together in Berlin. In addition to Steve, the other members of the body-antibody group—Lynn Thomas, David Schoenbrun, and Nancy Hunt—have been extraordinarily generous and rigorous readers and listeners over the course of the research and writing, and I offer them my most heartfelt appreciation. There aren't words enough on this planet to thank Jennifer Morgan, brilliant scholar and beautiful, intuitive human being that she is, for all that she has contributed to this book, including but certainly not limited to the close reading she provided of the manuscript. João Biehl, Vinh-Kim Nguyen, Dietrick Niethammer, and Nancy Hunt read the entire manuscript and offered wonderful support and smart advice. Working with Ken Wissoker, of Duke University Press, has been a true joy, and I consider myself extremely fortunate to have him as my editor.

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This book is dedicated to the memory of one very dear, departed friend, and to the too many loved ones lost over the years. It is also offered in deep celebration of those who are healed.

The Other Cancer Ward

 In the oncology ward of Princess Marina Hospital (PMH), Botswana's central referral hospital, a light breeze is blowing the curtains in the female side of the ward. It is that cool pause in the morning before the dry heat settles in for the day in Gaborone, Botswana's capital. Ellen is sitting up in her bed, dressed in her nylon, butterfly-print nightgown, retching into a vomitus—an enormous, lidded, stainless-steel basin. Piled on the stand next to her bed are cards, boxes of juice, bananas, and other gifts from relatives and friends. The two pairs of underpants and spare nightgown she laundered in the bathroom down the hall are draped across the headboard of her bed, drying. Next to her lies Lesego, age sixty, and a former teacher. With her enormous glasses perched on her nose, Lesego is silently reading her Bible. This is her fourth year as a cancer patient, and she is used to the rhythms of the ward. She knows that soon Tiny will come, rolling the metal breakfast cart through the aisle, pouring a tin or plastic mug of tea with milk and sugar for each patient, and dishing out plates of *motogo*, a sorghum porridge. It isn't a Tuesday or a Thursday, so there won't be a hard-boiled egg and tiny mound of salt.

Across the nursing desk in the men's side of the ward sits Roger, age twenty, whose left eye is swollen shut from a lymphoma. He is trying with little success to drink a small carton of strawberry-flavored Ensure (a nutritional supplement), as Mma T encourages him in that matter-of-fact, joking way that nurses so often use to cajole their patients. A few

moments ago, he, too, was bent over his vomitus. Already he is melting away. Strangely enough, Roger's half-uncle, Mr. Mill, a white Motswana farmer with multiple myeloma, had vacated that same bed only the evening before Roger arrived. The ward is full right now, as usual, with twenty-one patients total—one extra bed has been crammed into the female side of the ward, the only ward in the hospital that refuses to house patients on the floor.

The cancer ward sits at the end of a corridor that is lined with long, narrow wooden benches. There patients and their relatives sit waiting to see the highly impassioned and, by all accounts, brilliant, if at times irascible, German oncologist, Dr. P. Some rose long before dawn for bus or ambulance rides from villages deep in the Kalahari Desert. Others arrive from nearby urban homes, or large towns in Botswana's southeast. Many will wait five or six hours or more for their turn in the clinic office with the hospital's lone oncologist, who not only attends to an average of twenty-five (but sometimes as many as forty) outpatient visits in the day, but also manages the ward, fills out paperwork (in triplicate with carbon sheets between the copies), administers chemotherapy, and performs his own cytology in the evenings. After he climbs onto a chair in a vain but unrelenting attempt to coax the highly improbable ward television set to life, he drives home, where he will finish the day's paperwork after eating dinner.

Formerly a lawyer in Frankfurt, and a disillusioned ex-Mugabe supporter, Dr. P was already in his mid-fifties when he came to Botswana from Zimbabwe, where he had practiced oncology at Mpilo Hospital in Bulawayo for fourteen years. Leaving wasn't easy. His wife, Mma S, remains in Zimbabwe, but visits Dr. P some weekends, during which she loads up her car with supplies no longer available back home. Mma S has been around the world and has lived abroad. She knows it is one thing to travel, another altogether to leave her country (and the private ultrasound practice she has built) and live as an African exile, a *lekwerekwere* (African immigrant or outsider). Come what may, Mma S has decided to stay in her home.

Dr. P also writes a column, strident in tone, for one of the Botswana newspapers, using the forum to lash out against white mercenaries, Rupert Murdoch, and corrupt African politicians. He is more than willing to stand up in the staff meeting and proclaim PMH a Potemkin village! But his respect for Botswana runs deep. His sometimes explosive

temper and his bluntness—so out of place in Botswana—are by turns comedic, endearing, and infuriating to clinical staff, patients, and their accompanying relatives. Dr. P is chronically impatient and characteristically relentless in caring for his patients. Some days it seems the ward is running on the sheer force of his personality; occasionally it seems that it is running despite it. Each day he brings a crate of fruit to the clinic office, sharing bananas, grapes, peaches, plums, oranges, and apples, all in their season, with staff and visitors. He always wears a white coat in clinic. He enjoys nothing more than a joke made at his expense, except perhaps a political debate.

On one side of the corridor, opposite the clinic office, is the treatment room (also called the chemo room), with its sink and metal examination table. Various supplies, such as bags of IV saline and sterile dressing packs, are stored in this room, and occasionally the doctor uses this room to hold brief counseling sessions for the relatives of terminal patients, since end-stage prognoses are rarely discussed in front of the dying. Most important, chemotherapy is administered here, sometimes with three or four patients crammed in together on makeshift seating, their intravenous lines stretching like the legs of an octopus from a pole in the center of the tiny room. When one patient begins to vomit, the others often start heaving as well, and a nurse or the visiting ethnographer distributes pieces of paper towel and plastic bags. It is hot and stuffy in the treatment room, the air conditioner having broken long ago, but staff try to keep the doors shut, for the sake of the patients waiting on the benches. For some, even a peek into the treatment room or at the tubes of “the red devil” (doxorubicin, a chemotherapy drug) is enough of a mnemonic for the experience of chemo to bring on spontaneous waves of nausea and a panicky dread.

A decade ago the cancer ward was part of the Accident and Emergency Department of PMH. But the Botswana ministry of health predicted a rise in cancer and therefore refitted the observation wing of Accident and Emergency as the country’s one and only cancer ward, bringing Dr. P on staff to oversee operations. Mma M, the ward matron, bore the loneliness of leaving her husband and children in order to study at an Australian university, becoming the first—and, until recently, the only—nurse in the national health system with specialized oncology training.

In addition, a small radiotherapy outpatient practice was developed across town, at the Gaborone Private Hospital (GPH). There, two radi-



The clinic office and exam room.



The hallway by the clinic.



The chemotherapy and treatment room.



The entrance to the ward.

ation oncologists see public patients, whose treatments are paid for by the government and coordinated by PMH oncology. More recently, an oncologist was brought on placement through a partnership with the Chinese government to work in the medical wards of the only other tertiary hospital in the public health system: Nyangabwe, in Botswana's second city, Francistown.¹ Though some people do avail themselves of private doctors, particularly patients who receive medical insurance through their jobs, Botswana's system of universal care ensures that most people use the public system. As the hub of care and in coordination with these other sites, the PMH cancer ward remains the center of oncology in the country, and the only dedicated cancer ward.²

Improvising Medicine tells the story of this place—Botswana's oncology ward and its associated clinic—from its birth, in late 2001, to 2009. In the pages that follow we will observe patients, their relatives, and ward staff as a cancer epidemic rapidly emerges in Botswana, reflecting the surge in cancers across the global south. The stories of this ward dramatize the human stakes and the intellectual and institutional challenges of the cancer epidemic. They illustrate how care proceeds amid uncertainty in contexts of relative scarcity. They also offer fresh perspective on cancer medicine and illness experiences more broadly.

The argument I present is three-fold. First, improvisation is a defining feature of biomedicine in Africa. Biomedicine is a global system of knowledge and practice, but it is also a highly contextualized pursuit. Everywhere, doctors, patients, nurses, and relatives tailor biomedical knowledge and practices to suit their specific situations. In hospitals and clinics across Africa, clinical improvisation is accentuated.³ Second, though cancer produces moments and states of profound loneliness for patients, serious illness, pain, disfigurement, and even death are deeply social experiences. Understanding cancer as something that happens *between* people is critical to grasping its gravity. In this respect, what I seek to make visible in PMH's oncology is not uniquely "African." Rather, it is an imperative that is often papered over or under threat in the technobureaucratic rituals of European or American wards, but which is nonetheless still there, beneath the surface: *care*.⁴ I understand care within the context of debility and existential crisis as a form of critical "sociality based on incommensurate experience," to quote the anthropologist Angela Garcia.⁵ By paying careful attention to care within the ward—

how it is imagined, enacted, and distributed, the moments in which it succeeds or fails—I present an anthropology of value that conjoins the biopolitical, the ethical, the social, and the human in medicine.⁶

Third, cancer in Africa is an epidemic that will profoundly shape the future of global health, raising fundamental policy, scientific, and caregiving challenges for Africans and the international community alike. Cancer is a critical face of African health *after* antiretrovirals (ARVs). As such, cancer experiences in the ward expose the unfortunate fact that biomedicine is an incomplete solution. It can simultaneously be redemptive and exacerbate existing health inequalities. In other words, there will be no quick techno-fix for African health. And yet biomedicine functions as a necessary, vital, palliative institution in a historically unjust world.⁷

The PMH oncology ward presents a compelling microcosm of twenty-first-century tertiary healthcare in southern Africa. The expertise that supports PMH oncology was assembled, in part, from African and European clinicians fleeing economic and political chaos elsewhere in Africa, Chinese and Cuban physicians brought in through bilateral development-assistance programs, and a group of Botswana nurses still reeling from the pressures of the AIDS epidemic. Its establishment was prompted by the fact that cancer was an anticipated byproduct of the first national public antiretroviral program in Africa, a program designed around a public-private partnership between the pharmaceutical industry, the Botswana government, and international philanthropy. Its promise is crafted out of the social, political, and demographic imperative to care for the sick that lies at the heart of Botswana's unusually robust social contract. Its form is marked by the contingencies, grittiness, and empirical challenges of providing high-tech medicine in a public hospital where vital machines are often broken, drugs go in and out of stock, and bed-space is always at a premium. Its patients are drawn from the full spectrum of Botswana's population, where "Bushmen" from the Kalahari lie in beds next to the siblings of cabinet ministers, and village grandmothers sit on chemo drips tethered to the same pole as those of young women studying at the university. And its cycles of promise and despair unite oncology's emphasis on hope with an African ethic of care that stresses continuous engagement, effort, and attempt.⁸

Taking a cue from Solzhenitsyn's remarkable novel *The Cancer Ward*, about a post-Stalinist ward in Tashkent, I present the ward as both a

metaphor for and an instantiation of the constellation of bureaucracy, vulnerability, power, biomedical science, mortality, and hope that shape early-twenty-first-century experience in southern Africa. And as, quite simply, a cancer ward—a powerfully embodied social and existential space. In the process I will consider fundamental questions about the political and economic context of healthcare in Africa, the politics of palliation and disfigurement in the global south, the nature of decision making in clinical conditions of great uncertainty, and the social orchestration of hope and futility in an African hospital. I will contemplate the meanings, practices, and politics of care.

AN EMERGING EPIDEMIC

For all of its awfulness, cancer may sound like an esoteric distraction from more pressing concerns in African health. Yet epidemiologists have recently described cancer as a “common disease” in Africa.⁹ This is part of a general trend in the so-called developing world, where more than half of all new cancer cases are already occurring, a situation made all the more acute given that developing countries deploy only a tiny fraction of the money spent on cancer globally.¹⁰ And, as health experts have repeatedly stressed, the tide of cancer is rising steadily across Africa and the global south more broadly.¹¹ In Botswana’s cancer ward this epidemiological shift is palpable. Dr. P wistfully remembers his first years in Botswana, when oncology beds lay empty and he cycled through other wards of the hospital actively searching for cancer patients to transfer to his ward. By 2006, when I first entered the ward, this scenario was difficult to imagine. Each year since the ward opened, patient queues have grown and pressure on bed-space has intensified. This trend persists despite programs developed to treat routine cases of the most common cancer, Kaposi’s sarcoma (KS), at peripheral hospitals in the national network. But just how many cases of cancer are there, why are the numbers increasing, and what kinds of cancer are we talking about?

Cancer epidemiology is a complex business, given the expansive range of diseases under the cancer umbrella, as well as the need for laboratories with cytological and histopathological capacities to confirm diagnoses.¹² Africa has precious few cancer registries that feed into the International Agency for Research on Cancer (IARC) master registry of data collection. Basic medical certification is provided for only an estimated 13 per-

cent of the deaths on the continent, and gathering accurate population figures is difficult in many sites. Botswana opened a cancer registry in 1999, but problems in staffing and coordination have greatly curtailed its ability, though these difficulties are now being sorted out.¹³ Given the problems in collecting accurate data, most estimates of the burden of cancer in Africa are based on sentinel studies and on statistical models generated in a very few sites and then extrapolated to a broader population.¹⁴ The figures I cite, taken from a two-part report by a team of leading cancer epidemiologists headed by D. Max Parkin, therefore are tentative ones. In addition, though this analysis is recent, it is based on data that are by now nearly a decade old, so these numbers almost certainly understate the current situation. They should be read with these caveats in mind.

In 2002, the year the PMH ward swung fully into action, there were an estimated 650,000 *new* cancer cases in Africa. Men and women, not surprisingly, suffered from slightly different cancers. For men, KS was the most common cancer, followed by cancer of the liver, prostate, bladder, lymphatic system (specifically non-Hodgkin's lymphoma), and esophagus. For women, cervical cancer took the lead, accounting for nearly a quarter of all female cancers, followed closely by breast cancer, which was responsible for nearly a fifth of all female cancers. After these came KS, liver cancer, non-Hodgkin's lymphoma, and ovarian cancer, in descending order. Significantly, epidemiologists also noted, "The importance of infectious disease in Africa . . . means that as many as 36% of cancers in Africa are infection-related, exactly double the world average."¹⁵

In the southern African region, where Botswana lies, the 2002 age-standardized incidence rates were the highest on the continent: 213.7 for males and 163.2 for females. These figures calculate the number of *new* cases per 100,000 persons in a year, based on a standardized age pyramid, which allows for comparison across populations with differing age distributions.¹⁶ These rates were considerably lower than in North America, which had the highest incidence rates in the world: 398.4 for males and 305.1 for females. In North America, however, the comparatively high rates of cancer are partially accounted for by the proliferation of screening technologies that pick up early-stage asymptomatic disease. As Robert Aronowitz has argued, increasingly sensitive screening tests have resulted in what he calls "diagnosis creep" for some cancers, even as the rates for disease recurrence and fatality have remained stable.¹⁷

Southern Africa by and large lacks these screening programs, and as a result does not usually “count” cancers that have not progressed to the point where they produce symptoms.

Given this, perhaps equally telling is a comparison of the cancer mortality rates for these two regions: 158.5 (southern African males) versus 153.0 (North American males) and 106.3 (southern African females) versus 112.1 (North American females).¹⁸ Mortality rates here represent the population’s average risk of dying from cancer within the year. And so we can see that in 2002 while North Americans were much more likely to be diagnosed with cancer than southern Africans, they stood nearly equal chances of dying from the disease. For some population subgroups, the comparison is even starker. As Parkin and colleagues recently noted, “Even leaving aside the huge load of AIDS-related Kaposi’s sarcoma [one of the most common cancers in these two sites], the probability of developing a cancer by the age of 65 years in a woman living in present day Uganda (Kampala) or Zimbabwe (Harare) is only about 30% lower than that of women in western Europe, and the probability of dying from a cancer by this age is almost twice as high.”¹⁹

In Botswana partial epidemiological data, combined with anecdotal evidence and tallies from the ward and clinic, suggest that in PMH the most frequent cancers in men are KS, cancer of the esophagus, the prostate, head and neck, lung, and non-Hodgkin’s lymphoma; in women cancer of the cervix, KS, breast cancer, non-Hodgkin’s lymphoma, head and neck tumors, and cancer of the esophagus are most common. From this range of cancers, we can begin to discern two intersecting trends that combine to create a rising epidemic of cancer in the country.

Many of Botswana’s cancer patients suffer from virus-associated cancers that are facilitated by HIV-related immunosuppression. These viral cancers include, but are not limited to KS (human herpes virus 8); genital cancers, of the cervix, vulva, anus, and penis (human papilloma virus); non-Hodgkin’s lymphoma (Epstein-Barr virus, which is also associated with nasopharyngeal carcinoma and Hodgkin’s disease); and head and neck tumors (often associated with human papilloma virus). A minority, but a significant number, of HIV patients will contract a virus-associated cancer either before being initiated on antiretroviral therapy or during the process of partial immune reconstitution. This should not be surprising. Experience in the United States has already shown that cancer and

HIV enjoy a troubling synergy, a dynamic underscored by the fact that three viral-associated cancers — KS, non-Hodgkin's lymphoma, and cervical cancer — serve as AIDS-indicator illnesses, which are complicated by the development of antiretroviral therapy. In 2003 program officials at the National Cancer Institute predicted the African cancer epidemic, and African oncologists and health planners, along with other members of the international oncology community, have been warning of rising incidence rates for some time.²⁰

Before ARVs were available, many of Botswana's patients died *with* a cancer, but *from* other AIDS-related infections, while some died from rapidly growing cancers like high-grade non-Hodgkin's lymphoma. Since late 2001, when Botswana's ARV program began, however, many patients have survived HIV only to grapple with virus-associated cancers made all the more aggressive and difficult to treat by HIV co-infection. Botswana, where nearly a quarter of all adults have the HIV virus, is the site of the first public antiretroviral program in Africa, a model for programs now scaling up in neighboring countries. Yet, while ARVs are critically necessary and welcome in Botswana, they nonetheless expose the deadly relationship between cancer and HIV.

At the same time, the establishment of oncology services to assist patients with the new HIV-related cancers has helped to identify a significant population of patients with cancers not necessarily related to HIV — such as prostate, breast, esophageal, and lung cancer — who previously might have gone undiagnosed and untreated. The current cancer epidemic is deeply enmeshed with the HIV epidemic, but it is not only a subset of it. Breast cancers, for example, have long been present in the country but are now rising to a much greater level of recognition by both clinical staff and the general public. It is also quite likely that breast cancers are rising in overall incidence. Certainly, more and more women with breast cancer have been coming through the doors of PMH oncology. We cannot know the extent to which a long-standing burden of disease is now being unearthed through the expansion of services and public awareness, and the extent to which actual rates are rising. Most likely, it is a combination of the two. Over the past several decades Botswana has experienced rising rates of obesity, earlier onset of puberty for girls, lowered fertility rates, greater use of synthetic estrogens, and bottle feeding — all of which increase the risk of breast cancer. At the

same time, new services mean that more women with breast lumps and wounds are being referred to PMH oncology for diagnosis.

BOTSWANA, CITIZENSHIP,
AND UNIVERSAL CARE

Though historically overshadowed by tuberculosis, malnutrition, and, later, AIDS, cancer in Botswana predates the ward. Dr. Alfred Merriweather worked for over five decades in the country, becoming one of Botswana's most respected missionary doctors, as well as the first speaker of parliament in newly independent Botswana. Here, taken from his memoir published in 1999, is Merriweather's description of the female ward of the Scottish Livingstone Hospital in Molepolole, on his very first day in 1948, in what was then a twenty-four-bed mission hospital.

The elderly woman in the next bed was a pathetic case, one of very many I was to see in the years to come. She was in the late sixties very pale due to severe anemia, and she had experienced vaginal bleeding for over a year. She was asked how many children she had and replied, "I have had twelve but God has taken seven of them." We found the cervix of the uterus to be a friable mass of bleeding tissue eating its way into the vaginal wall and the bladder. She had advanced cancer of the cervix, the commonest cancer in Botswana, associated with early sexual activity and large families. . . . I always feel that this is one of the cruelest diseases a woman can have, for death is slow with many complications.

In the bed next to this cancer case was a young woman also with an inoperable cancer this time of the skin. She had a black swelling on the sole of her foot which had begun to ulcerate and in the groin a mass of enlarged glands. I had not seen such a tumor before and was told that it was a malignant melanoma, a very aggressive cancer. "I suggested we remove the ulcer on the skin as a palliative measure," said the doctor, "but like most of our patients she refused any surgery. She will only last a few weeks as the cancer is now widespread through her body."

Next to her was a woman, just skin and bone, probably in her mid forties. She had presented herself at the out-patient department with a history of having difficulty swallowing meat which started some months ago and gradually increased so that she could not swallow her staple diet of porridge. Latterly even to swallow water was a problem. She was

starving to death. She had cancer of the gullet which, like cancer of the cervix I used to call a “cruel” disease. Such cases appear regularly in all our hospitals and the outlook is grim.²¹

Two decades after the scene that Dr. Merriweather recounts, in 1967, PMH opened to serve the new city of Gaborone and as the referral hospital for the estimated 630,000 citizens of a then newly independent Botswana. Over the next five years, 193 cancer patients received inpatient treatment in the wards, with cancer of the esophagus and the cervix still being among the most common forms of the disease. Dr. Johnson, the PMH surgeon at the time, felt certain that the cases he uncovered through a manual search of inpatient records represented an underreporting of the true extent of the disease.²² Some patients refused admission and the recommended surgery, and many more, no doubt, never made their way to PMH in the first place. With most cancer patients who did come arriving with late-stage malignancies, many were denied admission because their disease was too advanced for treatment. At the time, PMH treated only a small fraction of the inpatient cancer cases in the country—nearly 1,500 between 1960 and 1972.²³ This would change in the years to come.

By the mid- to late 1990s, PMH was literally overflowing with patients. But the cancer ward was yet to open, and neither the English term *cancer* nor the Setswana term *kankere* were in common use. In those years I often saw cancer patients in the context of my research or during my leisure time, both of which took me into private homes. I sat with one friend while she sobbed for hours about the impending death of her only son, age five, from leukemia. He had recently returned from South Africa, swollen and bruised from several months’ treatment at Chris Hani Baragwanath Hospital. Located in Soweto, it was the largest hospital in the world and had served Africans under apartheid. His grandmother had gone with him, sleeping each night on the floor next to his bed, while his mother remained in Botswana to work. Another friend’s mother lay slowly dying of ovarian cancer on a mattress on the floor of her crowded two-room house. One time I accompanied staff from the clinic in the village where I lived to bring a packet of ibuprofen to a teenage boy lying on a mattress on the veranda of his home; his knee was swollen to impossible proportions from a bone cancer, a stunning spectacle that underscored the impotence of our small plastic bag of pills. His mother and aunt appeared to watch his every breath, as his agony suspended time.

In the 1980s and 1990s, before the ward was built, some cancer patients were sent to Zimbabwe or South Africa, where the Botswana government paid for them to receive oncology treatment in public hospitals. Many were not diagnosed until their disease was so advanced that they did not qualify for treatment referral. In other cases patients or their relatives decided not to pursue the prospect of referral abroad. In the 1990s, because of HIV, many Batswana were dying horrible deaths despite hospital care, and confidence in the biomedical system was flagging.²⁴ No doubt many of the relatives of these cancer patients suspected, quite often correctly, that even if their patients made the arduous journey to a foreign hospital, they might die anyway, but would also suffer as a result of being far from the comforts of home and family.

Even now, the government continues to send Batswana cancer patients to South Africa for specialized care unavailable in Botswana. Each week a government van brings women with cervical cancer for brachytherapy (internal radiation) and young patients with leukemia for induction or consolidation chemotherapy, which requires isolation conditions that are impossible to obtain at PMH. And many Batswana continue to look to South Africa as a place with more sophisticated and powerful medicine than is available in their own country. The ministry of health, will not, however, pay for other, more expensive treatments with lower likelihood of success, like bone marrow or organ transplantation, despite their availability in South Africa. For the state, achieving the greatest good for the greatest number sometimes means pushing back against the imperative of what the medical sociologist Mary-Jo DelVecchio Good has called the “biotechnical embrace.”²⁵

While Batswana still travel for care in South Africa, and indeed many patients look longingly across the southern border, Zimbabwe, to the northeast, presents a different story, one that throws Botswana, its history, and PMH oncology into relief. In December 2006, when Beauty’s voice became hoarse and her throat painful and swollen, she and her husband feared the worst. Her laryngeal cancer had been in remission since 2000, when she was treated at Mpilo Hospital in Bulawayo. This time when she fell ill, her local primary hospital referred her south, to PMH. Though it was their first time in the ward, when they arrived Beauty and her husband found familiar faces. Dr. P discovered his own handwriting on her Mpilo discharge cards and called Dr. K., who had handled her initial radiation treatments, for a lunch-hour consult. Even though Beauty

and her husband had traveled south to Gaborone and PMH, rather than northeast to Bulawayo and Mpilo Hospital, she experienced a surprising continuity of care when the recurrence was unfortunately confirmed and treatment began.

A few years after Dr. P decided to leave Mpilo Hospital and head to PMH, he was joined in Gaborone by a Zimbabwean radiation oncologist, Dr. K, who had trained in Cuba and then worked with Dr. P at Mpilo for many years. By late 2003, the political and economic situation had become highly unstable in Zimbabwe, so Dr. K reluctantly crossed the border to join Dr. H, a white South African radiation oncologist, in running the new radiotherapy practice at the Gaborone Private Hospital. This was the first and at present is still the only site for external radiation in the country; public patients were sent there on the government's dime. Unlike the public hospital, the private hospital was lucrative, with radiation treatments costing the government up to thousands of dollars per patient.

Dr. K and Dr. H both drove BMWs and wore much nicer shoes than did Dr. P, who was known to use a stapler to repair his sandals. This gave Dr. P, who came of age as a left-wing protester in 1968 in Germany, some deep ideological satisfaction. Before lunch most days, Dr. K or Dr. H came to PMH for a quick consult to coordinate care for the government radiotherapy patients. Eventually Dr. Z, a Congolese pathologist, and Dr. G, a Liberian surgeon at Mpilo, would also make their way from Bulawayo across to PMH. And so Dr. P, the lone hematologist and oncologist at the hospital, found himself consulting with a cluster of colleagues with whom he had worked in the heyday of social medicine in Zimbabwe. Unfortunately, Botswana's gain was Zimbabwe's loss—something both Dr. P and Dr. K felt acutely. No lunchtime consult was complete without a brief exchange of news about Zimbabwe.

Botswana is unique in the southern African region (indeed, the continent) for its steady development trajectory, stable democracy, and system of functioning social-welfare programs, including its national healthcare program. At independence from British colonial rule, in 1966, Botswana was a deeply impoverished labor reserve serving South African industry, surrounded on all sides (but for the tiny Zambezi River crossing into Zambia) by institutionally racist colonial states. Since then, the discovery of vast diamond wealth and prudent investment by a stable, democratically elected government have meant rising standards of living,



Map of Botswana in the region.

as well as significant investment in primary healthcare, clean water, nutrition, and infrastructure. Botswana's path to middle-income status was not some accident of history. For over four decades, Botswana's political leadership has proven remarkably adept, patient, and forward thinking in charting the course of development, stability, and peace under challenging circumstances.

Perhaps the most challenging circumstance has been the HIV epidemic, which wounded Botswana to its core. For about a decade, beginning in the mid-1990s, Botswana had the highest rate of HIV infection in the world. Human resources were devastated as the young sickened and died, and vast resources had to be redirected into healthcare at the household as well as the government levels. The AIDS epidemic and its attendant illnesses and deaths posed moral crises for Botswana, and a tremendous amount of soul-searching took place.²⁶ Now, with nearly a quarter of the adult population infected, HIV continues to pose signifi-

cant challenges, but much has been learned, even if many dear friends have been lost.²⁷

Healthcare (including oncology) is provided as a public good for citizens under a program of universal care. Most notably, Botswana has not accrued foreign debt, and so has been spared the predations of structural adjustment. Botswana accepts advice and assistance from others, but it is also a nation that makes its own decisions and speaks its own mind when it feels it appropriate. The pioneering ARV program was established through a partnership with the Gates Foundation and Merck pharmaceuticals, eventually expanding to include the contributions of Bristol-Myers Squibb, Harvard University, the President's Emergency Plan for AIDS Relief (PEPFAR), and the Global Fund. But the ministry of health has played the central role in dictating the terms of this arrangement, running the program within (as opposed to alongside) the national health system.²⁸

As a result, Botswana do not have to grapple with the heart-wrenching dilemmas or intense economic pressures of unequal access to life-saving therapies like ARVs or oncology that abound elsewhere on the continent.²⁹ The privatization of public health across Africa has had a devastating effect on healthcare, a fact that erupts in the ward each time a noncitizen arrives for treatment and must bring cash to cover the costs of care.³⁰ Often these patients come because care is unavailable at home, as in 2008, when Zimbabwean patients arrived at PMH reporting that there was *nothing* in the hospitals in Bulawayo — *not even a panado* (paracetamol or acetaminophen).

None of this is to suggest that Botswana is without economic or political inequalities or tensions, which often map onto minority ethnic status, gender inequalities, class politics, or regional economic differences within the country.³¹ These are significant problems, though they remain somewhat outside the scope of this book. Nor does it mean that all Botswana are wealthy. They are not. While the state has invested in public infrastructure and safety nets, the gap between rich and poor has also grown steadily since independence, and just under a third of the population lives below the poverty line.³² Many who appear to be gainfully employed are deeply in debt to Botswana's thriving credit economy.³³ There may be Mercedes-Benzes parked in the lot at PMH during visiting hours, but there are also many patients who have real trouble borrowing the funds necessary for bus fare to their clinic appointments.

Nor can one be certain about the future availability of healthcare. Because of the global economic crisis, the Botswana government warned, in 2009, that it might be unable to enroll new patients on ARVs after 2016.³⁴ In 2011 the country was rocked by a massive public-sector strike, in which many health workers walked off the job to protest their conditions of employment. Nonetheless, having built an extensive primary-care system essentially from scratch throughout the 1970s, 1980s, and 1990s, the Botswana government has prioritized the expansion and improvement of access to tertiary care in recent years. Thus, new services like oncology have been developed within PMH, one of only two tertiary-care centers in the public healthcare system, as stop-gap measures while new broader institutional capacities are being developed.

Plans for construction of a more up-to-date and capacious national referral hospital are now under way, as part of the establishment of the country's first medical school. This medical school will enroll citizens of Botswana, thus developing a cadre of local medical and research expertise. Because of long-standing national policy, nearly all the nurses in the national health system are Batswana. But at the time of this writing, the vast majority of doctors, particularly specialists, are not. There are some notable exceptions, of course, like Dr. O, an extremely skilled Moptswana maxillofacial surgeon, who also ran the dental clinic, or Dr. R, who is pioneering a women's health center through a partnership between PMH and the University of Pennsylvania. Other younger Batswana medical officers—like Dr. C and Dr. S, both of whom worked many months in oncology during their rotations through the various wards of PMH—have gone abroad for specialty training with plans to return. But for now, most specialists and many medical officers (“residents” in American terminology) tend to come from other parts of Africa and from Europe, Asia, and North America.³⁵ And for the foreseeable future, PMH remains Botswana's hospital of resort.

CANCER

Perhaps no disease is so iconic for and familiar to American and European readers as cancer. This unfortunate fact provides the opportunity for readers from these places to know Botswana and its patients as part of a broader community of biomedical practice and bodily experience. In one sense *Improvising Medicine* traces a remarkably familiar tale of

cancer as experienced outside the elite oncology centers like Dana Farber or Sloan Kettering. The PMH ward will be instantly recognizable to anyone who has spent time with cancer. Just as in American or European hospitals, the therapies are intensive and aversive, and the cure often elusive, but hope animates the daily dynamics. Patients often feel alienated and intimidated by hospital bureaucracy. But individual clinicians, fellow patients, and especially nurses have the power to humanize the illness experience. Errors in this hospital are common, just as they are in biomedical institutions throughout the world.³⁶ Cancer patients and their caregivers in Botswana face the same existential, temporal, and moral questions that trouble cancer patients everywhere: the temporal urgency of oncology; the deeply aversive yet potent nature of therapeutic interventions: chemotherapy, surgery, and radiation; the uncertainty of the future; the threat of nihilism.

Yet amid all this familiarity, this sameness, lie critical questions of resources that are more easily revealed in a public hospital in a middle-income country, where triage is not left to market forces (masked through the oracular bureaucracy of health insurance), but rather must occur within an explicit pragmatics of universal access. Even within the ethos of collective compassion evidenced in robust medical citizenship, cure, despite its elusiveness, is often given precedence over a more expansive form of care. The PMH ward lacks the amenities—the powerful anti-emetics, the morphine pumps and fentanyl patches, the breast reconstructions, the professional counseling and informational literature—meant to smooth the rough edges of oncology, one of biomedicine’s most brutal, if hopeful domains of practice.

Oncology is predicated on a temporal urgency. As any patient (not only in Botswana) will tell you, a cancer diagnosis hurls one into a therapeutic pipeline at great speed. Dr. P recognizes that cancer patients cannot wait to be seen, without serious consequences. At PMH he is committed to seeing all the cancer patients who require attention on the day they arrive, rather than booking appointments with waiting times of weeks or even months for the newly diagnosed. He could send the patients away and ration his time so that his workload would be reasonable, perhaps fifteen patients a day. But then those patients who would be waiting to see him would only be getting sicker, their prognosis more tenuous, their pain more profound, and success even more elusive. “I won’t save myself any work in this way unless the patient dies in the

meantime while waiting for their appointment, and this is utterly unacceptable,” he told me. Yet, since there is only one oncologist, the temporal urgency means that each patient gets little time to discuss their problems with the doctor, and so the humanistic side of oncology is, unfortunately, greatly curtailed.

Questions of therapeutic intervention and futility also take on a different tone here. The desire to intervene in cancers, to extend life, to palliate through surgery, radiation, or chemotherapy is fueled by a daily look at the natural course of disease progress. A context, as in the United States, wherein many cancers are treated aggressively when they are still microscopic or asymptomatic engenders a public conversation about iatrogenic effects of aggressive therapies and their value. In Botswana, where florid, disfiguring growths and horrible pain drive patients with late-stage cancers into the clinic for diagnosis each day, the palliative nature of oncology for the terminally ill is more clearly recognized as a public good, and stage 0 cancers or precancerous growths are not part of the popular experience of the disease.

The clinical science that drives therapy is also familiar, if radically pared down. In Botswana, perched on the periphery of the metropolitan oncological imagination, we see cancer diagnosis performed in an institution where histology is uncertain, where crucial technologies often break and cannot be repaired for weeks or months on end. This is a hospital that lacks a magnetic resonance imaging (MRI) machine, mammography, and endoscopy, where the lone oncologist performs his own cytology on a donated microscope after clinic hours, and where genetic screening and nuclear medicine are impossible. Cancer medicine lies at the cutting edge of the biomedical enterprise. Yet cancer medicine as it is practiced in Botswana, in many ways a best-case scenario for African public health and clinical medicine, bears a strange relationship to the research agendas of academic medicine and the private pharmaceutical industry. Oncology here does not match “evidence-based medicine” or “best practices” as developed in the West. The technical, biological, and social conditions of medical care in Botswana differ greatly from those from which knowledge and standards of care are derived. Dr. P must continually improvise and work empirically as he treats patients with tuberculosis *and* cancer, late-stage presentations, and HIV co-infections in a context that lacks some of the drugs, equipment, expertise, and diagnostic technologies that are standard in Western hospitals.

The existential angst and reflection among patients and their loved ones trace common threads. Yet the content of patient expectations, the forms of prognostication, and the ethics of clinical decision making follow slightly different logics than the American model, which privileges patient autonomy, presumes a baseline familiarity with cancer and its trajectories, and ponders the ambiguities of technologies like feeding tubes and respirators. The HIV/AIDS epidemic in Africa has already generated tremendous debate over biomedical ethics. The cancer epidemic raises a new set of questions—about rationing, prognostication, and futility. For example, here is a typical scenario: five patients each need between four and six units of platelets. Yet the hospital blood bank only has five units total to dispense. How is Dr. P to decide how to distribute the platelets? Should each patient receive at least one unit? Or should all units go to the neediest case? The one with the best prognosis? Should the Mma Kgabo, who has failed to show up for two scheduled rounds of chemotherapy, be denied a share of the precious platelets as punishment for her “noncompliance”? Should Mr. Mill, whose prognosis is bleak, be denied platelets, even though he is the only patient actively bleeding? I will grapple with a range of such questions and also describe how relatives and clinical staff negotiate with one another to locate therapeutic futility for the dying in a setting that lacks bed-space, hospice care, and adequate counseling resources.

The PMH oncology ward is an improvised setting. It leaves much to be desired, as its staff readily acknowledge. Examining processes of making do, tinkering, and ad-libbing help us to better understand the nature of biomedicine in Africa and the work of African healthcare workers, for whom improvisation is inevitably the *modus operandi*. Yet the story of this ward is not only one of cultural difference or of poverty, but also of innovation and care, and of therapeutic futility. Botswana cancer patients and oncology staff are part of a global therapeutic community—as they improvise, they also dislodge some of the master narratives of cancer in the global north. This book calls into question some of the prescriptive, heroic narratives and basic assumptions about illness, death, hope, and medicine that many American patients, their clinicians, and family members often take for granted. Like David Rieff’s recent memoir about Susan Sontag’s final year of cancer, or Lucy Grealy’s *Autobiography of a Face*, this book doesn’t offer easy answers as to how families, patients, or practitioners should respond to grave illness. Nor does it shy away from

the microprocesses of biomedical care—the nasogastric tubes, bone-marrow aspirates, wound care, and the suctioning of tracheostomies. Rather than portraying these routinized procedures as minor details, subordinated to the main events of diagnosis and cure, this book shows how cancer experience, hope, and futility are built up through such uncomfortable practices. By stepping outside of the familiar contexts in which heroic narratives, prostheses, pink ribbons, and invocations of cutting-edge research sanitize cancer experiences in the popular imagination, readers will find new ways to contemplate what it is to be seriously ill, extremely uncertain, and seeking relief.

A reminder. The cancer ward is a dramatic place animated by pressing existential concerns and aversive bodily experiences. But among the dramatic deaths, the arguments, the sudden crises, the curious events, and the quiet tears, it is also a tedious and boring place. In the clinic Dr. P sees patient after patient after patient. He performs fine-needle aspiration after fine-needle aspiration, breast palpation after breast palpation. The same blood work and then chemo regimen are ordered over and over again for the KS patients. Nurses and nursing assistants must fill out endless paperwork and computer forms and must routinely translate the same basic explanations and instructions. They must suction tracheostomy after tracheostomy, change diaper after diaper, and make and remake beds. Patients and relatives must spend the better part of a day sitting on the benches, clutching small pieces of cardboard with numbers written in magic marker to establish their places in the queue. To make matters worse, many patients cannot eat before their appointments, because they either lack the money to purchase a meal, or fear the nausea that will follow their treatments. Some cannot afford to waste money on a meal they are certain to vomit up. And so they spend these waiting hours simultaneously bored, anxious, and hungry. In the chemo room, syringes are lined up, drugs pushed, and the patient queue moved through as names are called.

For patients who are staying in the ward for days or weeks at a time, there is no working television, nor are there magazines or books to break up the long days. Patients who are ambulatory might walk outside and sit in the shade, or go to purchase juice or snacks or cell phone airtime from the small, corrugated-iron tuck shops that line the hospital parking lot. But aside from these limited diversions, there is not much to occupy patients or to link them to the outside world except for visiting hours:

7-7:30 AM, 1-2 PM, 4-5:30 PM, and 7-7:30 PM. Many patients have relatives and friends who go to great lengths to be at their bedsides during these brief opportunities to visit. But many others have come to the ward from villages and towns many kilometers away, and their relatives may lack the time or money to visit often (or at all). Many patients are simply too sick to be bored, but they still might be homesick. Chatting with the nurses or the relatives visiting a patient in a neighboring bed or receiving a brief call or text on their cell phone may be their only links to the lives from which they have come. It is very difficult to appropriately convey this tedium in writing. In the pages that follow, I spend more time describing moments of crisis and action, than those of tedium and loneliness. But as you read I ask you to remember the many hours you yourself have no doubt spent waiting, sometimes for unpleasant or worrisome experiences, in highly bureaucratic and uncomfortable government institutions. Recall your own boredom in repeatedly performing the same monotonous tasks. Or think about the nights you have spent away from home knowing that life there was going on without you. And know that these kinds of experiences, too, are fundamental to cancer everywhere in the world.

THE METHOD, THE WRITING

The chapters that follow are based on intensive ethnographic research and are built on my long-standing knowledge of and engagement with healthcare and bodily vulnerability in Botswana.³⁷ During my work in Botswana—from November 2006 through May 2007, from June to July 2008, and in May 2009—I was granted privileged access to Botswana's oncology ward and clinic.³⁸ There I met patients, their relatives, and clinical staff as an American researcher and professor studying the nature of cancer medicine and care in the country, and as someone with a particular interest in questions of pain and palliation.

My methods were ethnographic, which means I spent many hundreds, if not thousands of hours observing and taking careful notes, and also participating in the daily activity of the ward. Thankfully, I was never a cancer patient at PMH, so my participation was inherently partial. I cannot fully understand the ward from the position of someone lying in one of the beds. Nor was I a doctor or nurse charged with performing the skilled and difficult work of oncology. But this does not mean that I did

not participate—only that my participation was shaped by my abilities and limitations. I shadowed the hospital's doctors, the nurses, and nursing assistants as they performed their daily tasks.

While staff in PMH oncology worked hard, the volume of patients created significant labor pressures, and it quickly became impossible to merely sit by and observe. I often accompanied patients to radiology or to consultations with specialists in other parts of the hospital, acting as a combined porter and liaison—helping to clarify why Dr. P was sending them for consult. I drove patients across town (often in Dr. P's car) to consultations at GPH, in order to save them the trouble, discomfort, and expense of a taxi or bus. I ran errands, often carrying drug orders to the pharmacy and syringes of cytotoxics back to the treatment room. I stood by during procedures as an extra pair of hands. For example, as patients underwent invasive diagnostic procedures (lumbar punctures, bone-marrow aspirates, etc.), I would sometimes help to hold them steady. Or I would assist a nurse cleaning a wound by helping to hold instruments or supplies that she could not touch while maintaining her sterile field. One patient who came regularly for transfusions would request that I come to hold her hand while the needles were inserted painfully into inguinal veins. Others wanted me to sit with them, maintaining eye contact, while they suffered the panic of respiratory distress beneath their plastic oxygen masks. While I sat in the clinic taking notes, patients, relatives, and staff often drew me into their diagnostic and prognostic conversations as a linguistic and cultural translator, given my knowledge of Setswana language, Tswana medicine, and biomedicine. Other times patients or relatives would use me as a sounding board. They recognized that I, unlike the busy staff, was someone who had more time to answer questions about the purpose of various technologies or about the nature of cancer, to listen to their existential angst, and to provide encouragement or at least recognition of the challenges of their predicament.

In addition to research in the ward, I worked in other domains of PMH in order to better situate cancer care, and questions of pain and palliation, within the larger institution. On occasion, I was present during the night or weekend shift in obstetrics and gynecology, or on the medical wards. There I had a small taste of the alternating exhaustion and adrenaline-fueled emergency response that the medical officers and nurses face as they regularly rotate through night duty. I attended rounds and staff meetings in the medical wards and in obstetrics and gynecol-

ogy, and sat with two of the hospital radiologists who patiently showed me how to identify metastases on X-rays. In the evenings I viewed slides with Dr. P, who doubled as the hospital cytologist, learning the rudiments of this diagnostic vision. I observed the colposcopy clinic with Dr. T, at that time the head of gynecology, where suspected cervical cancers were diagnosed. I visited some patients in their village homes or in the interim home, a twenty-bed dormitory where ambulatory patients resided while undergoing their several-week-long radiotherapy treatments. There I conducted thirty-five interviews, in Setswana and English, with patients about their cancer experiences. I also deepened my extant knowledge of Tswana medicine through interviews with local healers, some of whom I had worked with during previous research on the history of debility and care.

In addition, I sat briefly on a palliative-care task force organized by the ministry of health. I accompanied Dr. P on a small plane to a peripheral hospital in the southwestern corner of the Kalahari to do oncological outreach. I attended rounds and clinic in a provincial hospital on several occasions and sat in the HIV clinics in various sites observing cancer referrals in creation. This ethnographic and interview work is enriched by historical research that locates African oncology and transnational oncology in a longer time frame, as part of the necessary background story of the ward.

In moving from the private homes and public spaces of village and town life, which comprised my previous research, and entering the cancer ward, I was practicing a form of “hospital-based ethnography.” In order to understand how biomedicine is contextualized, it helps to spend time in its core institutions, hospitals.³⁹ Ethnographers recognize that the hospital is an intensive space where critical moral, political, and social questions arise regularly and with great urgency, and where broader political, social, and moral forces in society can be witnessed in a condensed fashion.⁴⁰ In other words, this ethnography describes oncology as a set of grounded practices occurring within a particular infrastructural, social, and epidemiological setting, rather than as a therapeutic ideal or model emerging out of cutting-edge research. I do not question evidence-based medicine or standards of care that emerge from careful metropolitan research; instead I witness how staff at PMH need to adapt this knowledge to their institutional setting like a round peg to a square hole. At the same time, this ethnography uses the limited stage of the ward as a venue to

contemplate the broader meanings of care in twenty-first-century southern Africa. In order to protect the privacy of the patients whose stories are told here, I have changed their names and at times altered certain distinguishing details about them, while retaining the inherent logic of their medical and social specificities.

This book is written in the first person, but this is not a journey of self-discovery. Instead I keep myself in the scene because my presence in the situations described undoubtedly shaped what happened, and to write myself out of the text in the language of dispassionate science or journalistic voyeurism would be misleading. I wrote in the first person to be a bridge between different kinds of readers as well.⁴¹ When I did ethnographic research in private homes, amid Tswana healers, and in village clinics in Botswana in the 1990s, I frequently recognized that everyone in the room except me understood what was happening. Life was brimming over with puzzles, and I was confused. Over many months, I groped my way toward enough social and cultural understanding to at least begin to grasp the depths of experience flowing around me. My research on cancer was quite different.

As I sat in the oncology clinic and ward with my black notebook and pen, I did not have this sense of puzzlement. Instead, I often felt like I was the only person in the room who really understood what was going on: the only one who knew enough about oncology or biomedical technologies (though far, far less, of course, than did Dr. P), enough about the hospital (though far, far less, of course, than Mma M or the other nurses), enough about Tswana medicine and forms of embodiment (though far less, of course, than many Batswana), enough about the intense challenges of care-giving in patient homes (though far less, of course, than most accompanying relatives), enough about the frustrations, pains, and fears of chronic illness and disfigurement (though far less than many PMH cancer patients) to perceive the miscommunications, the layers, the complexities of the daily dramas that unfolded in this clinical space. I felt like I had a holistic perception (albeit a somewhat superficial one) that transcended the intense, yet partial knowledge of everyone else. Of course, this hubris was often proven wrong: sometimes my assumptions were totally incorrect, and social or biological or institutional processes unfolded in ways that underscored my ignorance. Nonetheless, writing in the first person lets me convey some of this plurality of perspectives—to help you see this ward as a social space, a place

where different kinds of knowledge, concerns, people, and entities combine to shape the experiences of very sick people and their caregivers.⁴²

Lastly, this book is written in the first person because I hope to be a tool, a conduit through which you, the reader, can glean some dimension of the ward in a phenomenological sense. In other words, this book is concerned with forms of consciousness or knowledge that exceed the cognitive—forms that are sensory, bodily, affective. As my friend Ed likes to say, “You know more than you think,” and this is a good way to understand phenomenology.⁴³ Experiences in this cancer ward underscore the extent to which phenomenology can be rendered social. For example, it is one thing to say that Botswana is a very small place and that at times staff in the ward will find themselves unexpectedly treating friends, relatives, or acquaintances who are cancer patients. It is another to experience, as I did on a few occasions, the sinking *feeling* one has on looking up from one’s task to see a friend unexpectedly walk into the clinic as a newly diagnosed cancer patient, even while one tries to ensure that feeling is not conveyed on one’s face. It is one thing to read that cancer wounds can be necrotic, and quite another to make sure to chat with a patient while holding the plastic bag into which his or her dead tissue is being deposited. My own experiences were greatly diluted from those of the nurses, doctors, relatives, and, most important, the patients. But throughout I include excerpts from my field notes to convey some of this quality. I wrote my field notes continuously throughout my time in the ward each day, whenever a free moment arose. In the evenings I reviewed them, adding details I remembered but couldn’t elaborate on given the time pressures on the ward. Later I typed the notes into my computer, cleaning them up grammatically and occasionally making parenthetical connections that became clear to me as I reread them. I have placed quotations around all speech. Where I am certain I have someone’s words verbatim, I have offered an asterisk to indicate as much. Where I am less certain that I have the exact phrasing, I do not. These field notes, therefore, give greater proximity to the ethnographic moment, but they are a mediated, not a raw product.

Some of the writing in this book is quite graphic, but that is necessary. Disturbing bodily experiences are foundational to patient experiences and biomedical practices of cancer. It may be unpleasant or even frightening to read about rotting flesh or about the process of shoving a flexible tube up a patient’s nose, forcing him to swallow it so that he may be

fed. But cancer consists of such experiences. Their details are not gratuitous for the reader any more than they are for the patient. One strength of ethnography as a mode of writing lies in its ability to communicate these details as they are emplotted in experiences of illness and care. These details help to establish the stakes of illness and medical care, the disorienting immediacy of bodily experiences, and the forms of bodily consciousness that are produced through profound illness and practices of care. Nonetheless these are very intimate matters, and therefore I have taken great pains to include only those graphic accounts I think are absolutely essential to your understanding of the experiences at hand.

NOTES

*An asterisk by quoted speech indicates that I am certain I have the words verbatim.

PREFACE

- 1 Wainana, "How to Write about Africa."
- 2 Comaroff, "The Diseased Heart of Africa."
- 3 Wainana, "How to Write about Africa."

ONE ↓ THE OTHER CANCER WARD

- 1 Nyangabwe patients sometimes come to PMH on referral, either to be cared for during radiotherapy (in which case they are driven each day to GPH for time in the radiation machine) or for clinical consultation, but PMH patients do not go to Nyangabwe, unless they relocate north.
- 2 The diamond industry, Debswana, maintains two hospitals; the Botswana Defense Force (the national military) maintains another; and there is a private hospital in Gaborone, another in the final stages of construction, and many private clinics and doctor's offices for those with health insurance, deep pockets, or enough desperation or frustration with the public system that they are willing to pay for care.
- 3 Wendland, *A Heart for the Work*.
- 4 Kleinman and Hanna, "Catastrophe, Caregiving and Today's Biomedicine"; Theresa Brown, *Critical Care*.
- 5 Garcia, *The Pastoral Clinic*, 50. See also Tronto, *Moral Boundaries*.
- 6 Livingston, *Debility and the Moral Imagination in Botswana*; Biehl, *Vita*; Garcia, *The Pastoral Clinic*.
- 7 I am especially grateful to Vinh-Kim Nguyen for helping me to sort out this last point.
- 8 On oncological hope, see Good, Good, Schaffer, and Lind, "American On-

- cology and the Discourse of Hope”; Ehrenreich, “Pathologies of Hope”; Jain, “The Mortality Effect.” On the African ethic of continuous effort, see Whyte, *Questioning Misfortune*; Langwick, *Bodies, Politics, and African Healing*; Klaitz, *Death in a Church of Life*; Geissler and Prince, *The Land Is Dying*.
- 9 Parkin, Sitas, Chirenje, Stein, Abratt, and Waibinga, “Part 1: Cancer in Indigenous Africans,” 683.
 - 10 Ngoma, “World Health Organization Cancer Priorities in Developing Countries,” viii9.
 - 11 Farmer et al., “Expansion of Cancer Care and Control in Countries of Low and Middle Income”; Travis, “Cancer in Africa”; Morris, “Cancer?”; Lingwood et al., “The Challenge of Cancer Control in Africa”; Sloan and Gelband, *Cancer Control Opportunities in Low- and Middle-Income Countries*; Ngoma, “World Health Organization Cancer Priorities in Developing Countries”; Boyle et al., “Editorial.”
 - 12 Cytology is a method of diagnosing disease by examining cellular morphology. In PMH oncology, Dr. P extracts lymphatic or other fluid (through a process called a fine-needle aspiration or, less frequently, a bone-marrow aspiration or even a bone-marrow biopsy) and then presses the cells onto slides. These cells are stained, and he then examines them under a microscope, searching the slides for the presence of particular cellular structures that suggest what type of malignancy, if any, is present. With histology (or histopathology), a biopsy—a surgical sample of presumably diseased tissue—is processed into slices, placed on slides, stained, and then given to a pathologist, who examines the structures of the tissue sample under the microscope to identify any malignancy.
 - 13 Boyle and Levin, *World Cancer Report 2008*, 15–16.
 - 14 Songolo, Chokuonga, Motlogi, and Mogorsakgomo, *Botswana National Cancer Registry Report, 1986–2004*, 15.
 - 15 Parkin, Sitas, Chirenje, Stein, Abratt, and Waibinga, “Part 1: Cancer in Indigenous Africans,” 684.
 - 16 In other words, since cancer risks increase with age, age-standardization statistically realigns both southern Africa’s youth-heavy age pyramid and North America’s demographic bloat of aging baby-boomers to allow for comparisons across age cohorts, rather than across aggregate populations.
 - 17 Aronowitz, “The Converged Experience of Risk and Disease.”
 - 18 Parkin, Bray, Ferlay, and Pisani, “Global Cancer Statistics, 2002,” 82, table 3.
 - 19 Parkin, Sitas, Chirenje, Stein, Abratt, and Waibinga, “Part 1: Cancer in Indigenous Africans,” 683.
 - 20 Feigal and Black, “Cancer and AIDS”; Travis, “Cancer in Africa.” Through the past decade, CD4 cell counts have been used to triage patients in need of ARVs. The program in Botswana began by starting patients on treatment if their CD4 count was 200 or below, or if they had an AIDS indicator illness. Eventually, the cutoff point was raised to 250, then to 300. In practice, this requires that people be tested before they are symptomatic and that the CD4 machines be in working condition (they break down regularly). In other countries, where the ARV programs are patched together among various NGO and government

initiatives, there are still significant problems of access, even for those with low counts. Over time we can hope (but not necessarily expect) that ARV programs develop to the point where most patients are initiated on antiretrovirals while their CD4 counts are still high enough to help them avoid such cancers, as has happened in the United States. But even if African AIDS programs can overcome the infrastructural, financial, and other obstacles to pursue such a policy, experience in the United States has shown that the cancer problem will likely shift shape rather than simply disappear. In the United States, while ARVs have resulted in a crucial reduction in the numbers of HIV-positive patients with AIDS-defining cancers, over time there has also been a rise in those with non-AIDS-defining cancers. Shiels et al., “Cancer Burden in the HIV-Infected Population in the United States.”

- 21 Merriweather, *Desert Doctor Remembers*, 79.
- 22 Johnson, “The Cases of Cancer Seen at a Botswana Hospital 1968–1972.”
- 23 Macrae and Cook, “A Retrospective Study of the Cancer Patterns among Hospital In-Patients in Botswana, 1960–72.”
- 24 Livingston, “AIDS as Chronic Illness.”
- 25 Good, “The Biotechnical Embrace.” See also Keirns, “Dying of a Treatable Disease.”
- 26 Durham and Klaitis, “Funerals and the Public Space of Sentiment in Botswana”; Klaitis, *Death in a Church of Life*; Dow and Essex, *Saturday Is for Funerals*; Livingston, *Debility and the Moral Imagination in Botswana*; Dahl, “Left Behind?”; Ngwenya and Butale, “HIV/AIDS, Intra-family Resource Capacity and Home Care in Maun”; Heald, “It’s Never as Easy as ABC.”
- 27 Creek et al., “Successful Introduction of Routine Opt-Out HIV Testing in Antenatal Care in Botswana”; Bussmann et al., “Five-Year Outcomes of Initial Patients Treated in Botswana’s National Antiretroviral Treatment Program”; Ramiah and Reich, “Building Effective Public-Private Partnerships.” See also Brada, “Botswana as a Living Experiment.”
- 28 Carpenter, “The Social Practice of HIV Drug Therapy in Botswana, 2002–2004.”
- 29 Whyte, Whyte, Meinart, and Kyaddondo, “Treating AIDS”; Mulemi, “Coping with Cancer and Adversity.”
- 30 For more on the privatization of healthcare in Africa, see Turshen, *Privatizing Health Services in Africa*; Nguyen, “Government by Exception.”
- 31 Nyati-Ramahobo, “From a Phone Call to the High Court”; Werbner, “Challenging Minorities, Differences, and Tribal Citizenship in Botswana”; Solway, “Human Rights and NGO ‘Wrongs’”; Nyamnjoh, *Insiders and Outsiders*; Van Allen, “‘Bad Future Things’ and Liberatory Moments.”
- 32 Central Intelligence Agency, *The World Fact Book*, 2010, accessed 28 September 2010.
- 33 Livingston, “Suicide, Risk, and Investment in the Heart of the African Miracle.”
- 34 “Botswana: Bleak Outlook for Future AIDS Funding,” accessed 27 February 2012.
- 35 The best analysis of Botswana’s place within the imaginary problem space of Global Health is Brada, “‘Not Here.’”

- 36 Bosk, *Forgive and Remember*; Kohn, Corrigan, and Donaldson, *To Err Is Human*.
- 37 I also performed ethnographic and historical research on debility in Botswana in 1996, 1997, and 1998–1999. The results were published in Livingston, *Debility and the Moral Imagination in Botswana*.
- 38 This research was approved by three Institutional Review Boards: Rutgers University, Protocol # 01–355 M, “Pain and Laughter: A History of Sentience in Botswana”; Ministry of Health, Republic of Botswana, Reference No: PPMÉ-13/18/1 Vol 1 (224), “Pain: A History of Sentience in Botswana”; and the Ethics Panel of Princess Marina Hospital, Gaborone, Botswana.
- 39 Van der Geest and Finkler, “Hospital Ethnography”; Wind, “Negotiated Interactive Observation”; Mulemi, “Patients’ Perspectives on Hospitalization”; Long, Hunter, and Van der Geest, “Introduction”; Finkler, Hunter, and Idema, “What Is Going On?”
- 40 Van der Geest and Kaja Finkler, “Hospital Ethnography.” For excellent examples, see Kaufman, *And a Time to Die*; Rouse, *Uncertain Suffering*; Lock, *Twice Dead*.
- 41 I thank Seth Koven greatly for helping me think through the question of voice and epistemology.
- 42 By contrast, for an excellent patient-centered ethnography, see Mulemi, “Coping with Cancer and Adversity.”
- 43 Ed Cohen, personal communication. See also Rachel Prentice’s wonderful new book on embodied surgeons, *Bodies of Information*.

TWO ↓ NEOPLASTIC AFRICA

- 1 World Health Organization, “Cholera in Zimbabwe,” accessed 26 October 2009.
- 2 On xenophobia in Botswana, see Nyamnjoh, *Insiders and Outsiders*.
- 3 Farmer et al., “Expansion of Cancer Care and Control in Countries of Low and Middle Income.”
- 4 The Summers memo of 12 December 1991, when he was vice president and chief economist of the World Bank, has been excerpted and reproduced on numerous websites, including <http://www.jacksonprogressive.com>, <http://www.whirledbank.org>, and <http://www.mindfully.org>.
- 5 Hunger is an extremely pressing problem, one that greatly complicates ARV provision. See, for example, Kalofonos, “All I Eat Is ARVs.”
- 6 Stewart and Kleihues, *World Cancer Report*, 281–82.
- 7 Okeke, *Divining without Seeds*.
- 8 “Poverty Blamed for Blacks High Cancer Rate,” *New York Times*, 17 April 1991; Wailoo, *How Cancer Crossed the Color Line*; Hecht, “Africa and the Nuclear World”; Hecht, *Uranium from Africa and the Power of Nuclear Things*.
- 9 There is an extensive literature on these issues in Africa: Packard, “The Healthy Reserve and the Dressed Native”; Comaroff, “The Diseased Heart of Africa”; Vaughan, *Curing Their Ills*. And, of course, see Fabian, *Time and the Other*.
- 10 Livingston, *Debility and the Moral Imagination*, chap. 4.