Dying Of A Treatable Disease

Working in Botswana reveals to a young American doctor the strengths and weakness of medicine in both countries—and shapes a set of difficult issues.

BY CARLA C. KEIRNS

WERE STANDING AT THE BEDSIDE of a frail young woman in a hospital in Botswana. She wore a white tank top and a much-washed blue skirt. Each time she inhaled, her labored breaths revealed her ribs, collarbone, and neck muscles. She was only twenty-three years old, with closecropped hair, and her deep brown eyes were sunken with dark circles below them. Each day her mother and sisters sat vigil; two young children waited for her at home. She reminded me of pictures I'd seen of famine victims. The women's ward in the one-story hospital was crowded, holding more than twice as many patients as it was designed for. Nonetheless, the ward was clean. The bed was made up with fresh linens, and the ward smelled of the pine cleaner used on the floor each morning.

I told her family that she would likely die tonight. Her brother asked if she could have been saved somewhere else.

As I looked at this slight, dignified woman who was breathing with so much difficulty, I thought of the patients I cared for back home in Philadelphia who'd died of the same disease, *Pneumocystis carinii* pneumonia (PCP). It's the most common opportunistic infection in people with HIV, no matter which continent they're on. I assured her brother that what could be done had been done, that if she'd been in an intensive care unit (ICU) in America, we wouldn't have been able to save her. I hoped this was a comfort. But I left my own question unasked: What might we have done if she'd come to us weeks or months ago, when the diseases were more treatable? Would she have lived then? Probably.

For more than a decade, effective treatment for HIV had been available to most North Americans who needed it. Those who came into my hospital back home with PCP usually had things going on in their lives that had prevented timely diagnosis or treatment. I thought of a specific patient there whose treatment had been complicated by a broken family, inadequate education, marginal housing, unemployment, and an addiction to crack. He died alone, unlike my African patient, who died surrounded by a dozen family members.

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Doctoring In Botswana

T WAS 2005. I WAS THIRTY-THREE YEARS OLD and three years out of medical school. I'd done my medical training in the United States, where I was used to treating predominantly older patients with chronic diseases. My aunt had practiced medicine in Mexico for twenty-five years, though, so I'd also visited her in hospitals there many times.

But now I was in a different environment. I'd come to Botswana to work in the women's medical ward of an urban hospital. The country had a fairly high African per capita gross domestic product (GDP) and spent substantially more on health care than neighboring countries. But in 2005, life expectancy in Botswana was dropping—from the seventies in the 1990s to age fifty-two—largely because of the loss of young adults to HIV. Other than a high HIV rate, the population was relatively healthy. In Botswana, primary care is readily accessible. Through village health workers, nurse-run clinics, and regional hospitals, primary care and basic hospital services are close at hand for the majority of the population. In terms of access to health care, the Batswana provide well for each other, especially compared to others in the region whose populations frequently find medical care out of reach for all but a few.

At this point in my young medical career, I was used to death. The ICU at my university hospital in Philadelphia had a high mortality rate, as is often the case where patients have serious, end-stage illnesses. But most of those patients were in their seventies, eighties, or nineties. In Africa, the typical patient I lost was a twenty-two-year-old mother of three who'd come to us in the final stages of HIV.

In her classic essay, "Training for Uncertainty," sociologist Renée Fox describes the cognitive and emotional development of medical students in terms of what is

"Could his sister have been saved if she'd been American, or wealthy, or had private medical insurance?" unknown to them because of inexperience or specialization and what is unknown to medicine as a whole. This set of distinctions has moral and practical consequences for all young physicians. They need to decide when to seek help (and of what kind) and when to recognize that the course of disease can't be altered, no matter what resources might be brought to bear. But physicians and nurses practicing in underresourced settings, whether in the first or

the third world, face a different source of uncertainty—the one my patient's brother raised. Could his sister have been saved if she'd been American, or wealthy, or had private medical insurance? His question traveled with me as I walked the wards with my African colleagues, as it still does in the United States when my patients are unable to afford the care they need.

A Course In Realities And Miracles

N BOTSWANA, IT WASN'T SO MUCH THE PATIENTS WITH HIV who made me think about my work in America in a new light as it was the familiar diag-L noses that we treated so differently below the Tropic of Capricorn. One night there, an American colleague asked me to look at an EKG as it printed out. The patient was having a heart attack—a big one. We began running through what we'd do to treat her in the United States. Aspirin: done. Oxygen: done. Nitrates? These drugs are the essential next step to improving blood flow during a heart attack, but they can dangerously reduce blood pressure. "What's her blood pressure?" I asked. There wasn't enough to measure. No nitrates then, unless we could provide compensating medication or procedures. We had neither. We looked each other in the eyes, and it felt like my own heart had stopped. We both realized that this fifty-year-old woman was dying—and there was nothing we could do to prevent it. It would have taken superior technology and resource-intensive first-world medicine to save her—intensive care and cardiac catheterization at least—and no guarantees even then. Our medical fingertips could touch the limits of what we could do then and there, and we could only admire what high-technology medicine sometimes—and somewhere else—could offer. She died within the hour.

When I returned to the United States, that woman went with me. The next time I worked in a cardiac ICU, I realized how much I'd taken for granted. We had

the ability to treat heart attacks, prevent complications, and bring back people teetering on the edge of death. But I also had less patience with what began to seem the excesses of the U.S. health care system. I thought about her, too, as I cared for hospitalized patients waiting for life-continuing hearts to be transplanted into them. Even if she'd survived her heart attack, she'd never have had that kind of technological second chance.

I took care of a man whose heart attack was much like that Batswana woman's; it cut off the blood supply to most of his left ventricle, the "Our medical fingertips could touch the limits of what we could do then and there, and we could only admire what hightechnology medicine sometimes—and somewhere else—could offer."

kind of heart attack that's still sometimes called a "widow maker." But unlike in Botswana, first he was flown to a hospital where they tried to open his blocked artery with catheters, then they attempted emergency cardiac bypass, then he was flown to our university hospital where he had an experimental device implanted that would support his failing heart until he could have a heart transplant. He spent twenty-seven days in our cardiac care unit until a heart "became available" following the death of another patient at a hospital across town.

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Philosophically, I'm never sure that these heroic measures—on which fortunes are spent for successes that are never whole or perfect—are the right thing for the medical system and the society of which it is a part. But I'm not able to face a dying man and tell him that. As a doctor at the bedside, I can't help but hope for my patient to get a new heart. Two patients with the same type of heart attack, both lost blood flow to their left ventricles. In the United States he gets catheterization, bypass, a left-ventricular assist device, and ultimately a heart transplant. In Botswana, for her, we don't even have the ability to give intravenous medicines to try to keep up her blood pressure to help her body get through the worst of her heart attack—something an ICU in the United States could have offered even thirty or forty years ago, long before advanced cardiac care. Yet I also think about the resources being expended here in the United States to treat patients with uncertain outcomes and the fraction of those resources that would have been needed to treat the "simple" heart attack in my fifty-year-old Batswana patient. These patientsthe Batswana woman and the American man-forced me to begin considering whether decisions made locally and globally about resource allocation promote justice, equity, and population health within and across nations.

When You Have To Say No

THINK ABOUT ANOTHER BATSWANA PATIENT AS WELL. She was thirty and had HIV that was being treated. But then her kidneys failed. Her mother asked if we were discriminating against her daughter in not providing additional care because she had HIV.

That wasn't the case. Sophisticated dialysis treatments and kidney transplants, her only chances for survival, simply weren't offered in Botswana. The country had decided that long-term dialysis was too expensive compared with the lives that could be saved by spending funds on antibiotics, clean water, and village health workers. It was a reasoned and rational resource allocation decision; nevertheless, it was a harsh lesson in the trade-offs between the deaths of patients we can identify and look in the eye and save at great cost and the many more faceless "statistical lives" we can save with good public health and basic primary care. Although we accepted that choice in principle, it was difficult for all of us to watch the young woman die, knowing that elsewhere she might have lived.

Acknowledging Futility

Here or there, some patients are beyond medical rescue. There was a Batswana woman in her fifties at our hospital whose cancer had metastasized; most of her liver had been replaced by tumors and had stopped functioning. Then she started bleeding internally. In the United States to-day we would give her blood transfusions to stabilize her condition, only to have

her die, inevitably, of her cancer in few weeks. But blood was limited in Botswana. Auto accidents, bleeding during childbirth, and exceedingly low blood counts in reaction to a common HIV medicine were frequent. These types of patients, who would need blood and who could perhaps be saved, were in my thoughts as I spoke with my African supervising physician. My American training was to "do everything" for this dying cancer patient, I said, but it seemed like the wrong thing to do in Botswana. A transfusion couldn't change her outcome, and it could be a matter of life and death to someone else. He smiled at my naïveté. "Among my people," he said, "at a time like this we pray." He also advised intravenous fluids and pain medicine to ease her passing.

When I thought about the chemotherapy, bone marrow transplants, or experimental treatments that this patient might have been offered in the United States, I suspected that she had good fortune *not* to be in a first-world oncology unit. Although trying to increase the length of her life would have been futile in any setting, we could learn from the composure with which my Batswana colleagues managed her dying and helped her to a peaceful death.

The Effects Of Shortages

A NOTHER PATIENT I REMEMBER AS I FIRST SAW HER, wearing a white dress printed with large pink and purple flowers; it was a Wednesday afternoon. She was twenty years old and had insulin-dependent diabetes. She arrived with diabetic ketoacidosis, a potentially life-threatening complication that occurs when the body doesn't have enough insulin. Although we didn't have all the technology we were used to, we were able to manage the situation. With insulin, fluids, and electrolyte replacement, she was back to normal within two days.

On Friday afternoon, we wanted to send her home, but she felt weak; so we decided to keep her until Monday to arrange further evaluation. On Sunday she died.

What had happened? Did she again develop diabetic ketoacidosis? There was no way to know. How was it possible that more than eighty years after the discovery of insulin we'd lost a twenty-year-old to diabetes?

Our women's medicine ward was built and staffed for thirty patients, but the bed count was fifty to seventy-five. Over the weekend, four nurses and two doctors took care of our "It was a harsh lesson in the trade-offs between the deaths of patients we can look in the eye and save at great cost and the many more faceless 'statistical lives' we can save with good public health and basic primary care."

overcrowded ward *and* the adjoining men's medical ward for 100 to 150 patients. Would we have been able to keep closer track of her if we hadn't been out of urinalysis dipsticks for months, if we could have gotten lab tests done more frequently, if we'd had more staff available-or if we'd tried harder?

Did the constancy of death, and the knowledge of global inequalities, allow the nurses and physicians in this African hospital to accept deaths that could have been prevented? Did introducing drugs and scanners generate false hope when we didn't have staff to provide the care of which we were, technically, capable? But this is the problem at home, too, where technology allows in principle for a level of care that staffing often makes impossible. Medical mistakes, missed diagnoses, and worsened outcomes are frequently linked to nurse-patient ratios that are too high, crowded emergency departments, and exhausted physicians-in-training.

Understaffing And Burnout

R ECENTLY INTRODUCED DRUGS IN AFRICA for HIV are crucial for saving lives—but they aren't enough. The hospital I worked in was understaffed, and the doctors and nurses I worked with were exhausted. Having been on the front lines for decades, they needed—and still need—reinforcements. In their 2007 book *Shattered Dreams? An Oral History of the South African AIDS Epidemic*, Gerald Oppenheimer and Ronald Bayer describe the same types of problems in neighboring South Africa, when the blessings of new drug treatments reveal the serious shortage of staff to administer them, leading to overwork, guilt, and burnout among dedicated medical staff members.

An African doctor in her thirties with whom I worked in Botswana had trained in the United Kingdom and knew personally that the working conditions were better abroad. Nonetheless, she said, she'd always wanted to come home after finishing her medical training. The year we worked together, her brother died of HIV, and I wondered if solidarity with others facing HIV in their families had brought her home. But she also wanted more time with her year-old son. Her work schedule was more than one hundred hours a week—about twice as many hours as those for young doctors in the United Kingdom. Add to that the daily risk of contracting TB and HIV, the frustrations of being unable to provide the best care because of supply shortages, and the dramatically lower salaries, and the question becomes not why do so many African doctors and nurses leave, but why don't more?

Health, Social Justice, And Infrastructure

To THIS DAY, WHILE FACING AN OVERWHELMING burden of illness, health care workers (and patients) in Botswana show determination, inventiveness, grace, and humor from which we all have much to learn. On balance, while I'd rather have my heart attack in the United States, I'd prefer to have late-stage cancer in Botswana.

In the years since I was there, Botswana has gained control over its HIV epi-

demic through partnerships between its Ministry of Health and international partners, including Merck and the Bill & Melinda Gates Foundation, reducing infection rates among young women by two-thirds. Although policymakers need to continue critical funding to find new drugs for HIV, TB, and malaria, Botswana's greatest success has been in solving some of the problems of distribution and human capital—of pharmacists, technicians, nurses, and doctors—to give the drugs and monitor treatment. The drugs won't help if there's no one to give them.

Ultimately, we have much to learn from each other. First-world medicine has served as a laboratory of technological and pharmaceutical innovation, finding

treatments and cures for many diseases. This vision of disease as an enemy to be vanquished contributes to American successes in diabetes and heart disease, but also contributes to failure to treat terminal cancer with a palliative approach when the time comes. From the third world, the Batswana have lessons to teach us in health planning, resource allocation, social equity, and respect for limits at the end of life. Some of these lessons are harsh—as is watching

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a young woman die of kidney failure—but others, such as universal access to care and extensive home care and disability services, are inspiring compared to American health care.

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