

## CYNTHIA LESHOMO

Cynthia Leshomo was born to be a beauty queen. Her default facial expression is a pout. She rolls her eyes at the foibles of lesser mortals. She is exhausted by the needs of her adoring public. No one, she is quite certain, really understands the demands that are placed upon Miss HIV Stigma-Free.

But then, hers is a particularly challenging tiara to wear. The Miss Stigma-Free pageant was launched in 2003 by AIDS organizations in Botswana's capital, Gabarone, with the goal of trying to ease the shame and perhaps inject a touch of glamour into living openly with HIV. In a country with an epidemic as severe as Botswana's, this was no small task.

The first contest drew a modest, somewhat skeptical audience, and the inaugural Miss HIV Stigma-Free was built like a line-backer. She was no sparkling conversationalist, but she was unfazed by talking about her life with HIV, and so she won plenty of attention both at home and abroad. By the time Cynthia saw posters advertising the third competition in 2005, it had grown into a big, glitzy affair.

She was convinced this was the route she had long sought to fame and fortune. Cindy, as she is known to her friends, filled out an entry form and began to hatch her strategy. She started by checking out her competition. Gabarone is Botswana's biggest city, but it functions like a village, and it wasn't difficult to learn who else was aiming to be Miss Stigma-Free. A couple of the other

eleven contestants worried her slightly: some had gone public about living with HIV long before she had, and one had been a runner-up in the pageant the year before.

On the night of the contest, in muggy late February, five hundred people packed into a ballroom on the manicured grounds of the Royal Palm Hotel at the edge of the city. Music pulsed and klieg lights on the stage left the contestants with beads of sweat across their foreheads. First came casual wear; Cindy took the occasion to show off her long legs and high, round bum. Then questions from the judges about life with HIV: "Let's fight the stigma associated with AIDS, but not people with AIDS," Cindy said through a wide smile. Then traditional wear—and this was her moment.

Cindy walked slowly down the catwalk in a knee-length brown wool dress, carrying a clay water pot on her shoulder, swaying her hips. At the end of the runway, she sank gracefully to her knees, lowered the pot and reached inside. She lifted out a bottle of mineral water and a pill container. And there, in front of the crowd, Cynthia Leshomo took her ARVs.

She swallowed the tablets, gave the audience her most winning smile, restored the pot to her shoulder and glided back up the catwalk. There was still the evening-wear round to follow, but Cindy knew—as the stillness of the crowd was broken suddenly by wild cheers—that the crown was hers.

And indeed, an hour later, the flower coronet was placed on top of her long braids. Cindy clasped her hands to her cheeks in the beauty queen's universal expression of fetching disbelief. Stepping down from the stage, she embraced her older sister Tshenolo, and then turned to throw her long arms around Avo Avalos, the doctor who, a few years earlier, had told Cindy's family she had only hours to live. The doctor wept, the cameras flashed and the TV crews jostled for position. Cindy beamed.

Cindy is from Malokaganyane, a village in the arid south of Botswana near the border with South Africa. Born in 1970, she is the last but one of six children. Vivacious and sharp tongued, she was a ringleader in village games and she did well at school.



She has had, by the standards of the region, a life of opportunity. Her country is often heralded as an African success story: stable, peaceful and democratic since its independence, Botswana has some of the world's largest diamond deposits, and the government has channeled the mineral wealth into social spending. School was free when Cindy was growing up, and so was health care. Many people in Botswana work for the state; her mother was a school principal and her father a government driver.

The government paid for Cindy to travel to Pretoria to study for a college degree in commercial administration. She did well, although she never missed a party. She heard rumors about the spread of HIV, but she didn't worry too much. "I thought, 'I won't get it because I am young and beautiful and not of the class to be infected.'"

Botswana, in the mid-1990s, had a life expectancy higher than many nations in eastern Europe. But HIV was capitalizing on the most fundamental aspects of life in the country, and spreading with a speed that no one anticipated. The Batswana, as they are called, are a highly mobile people who traditionally divided their lives between a home in a village and a remote cattle post, tending to the herds that are the foundation of Tswana culture. By the late 1980s, Botswana was urbanizing quickly, and so people also moved between the city, where there was work, and the villages, where they maintained their family ties, a way of life that incorporated multiple relationships. Cindy was no exception. An upper-middle-class family such as hers has cows—*everyone* in Botswana has cows—and as a girl she went sometimes to camp at the cattle post in the bush. But by the time she was in her late teens she was determined to leave Malokaganyane for one of the rapidly expanding cities.

After college she got a job as a legal secretary at a private law firm in Pretoria. She was happy to stay in the South African capital, where life was much more exciting than in sleepy Gaborone. She earned a good salary, enough to keep her in the latest shoes and leather handbags and dangly earrings. There were lots of boyfriends, lots of parties, lots of wild nights in newly-free South Africa. And then she started to get sick: black lesions appeared on her face, and she lost more and more weight off an already lanky

frame. She saw a series of doctors, and each advised her to have an HIV test. She flatly refused. Pretty young women with college degrees didn't get HIV—the disease was for poor people, people back in the village with straw for a roof and chickens in the yard. Of course, deep down, she suspected HIV. “But there was so much stigma.”

*Stigma* is one of the most used words in the AIDS pandemic, a two-syllable shorthand for the shame and fear that cling to this disease. Stigma is not, of course, unique to HIV—it is a common feature of incurable, transmissible and deadly illnesses; lepers are banished to colonies, and crimson warnings are smeared on the doors of people infected with a plague. But there is a particular distaste saved for those diseases where the sick are viewed as the authors of their own misfortune, and a particular shame that comes with a disease most often transmitted by sex. Because HIV infection in Africa passes primarily through sexual contact, people who admit to having HIV (even when they contracted it from their husbands or, as in Cindy's case, from relationships that are entirely socially acceptable) are perceived both by others and by themselves to be admitting to sin or violation of community mores. Stigma, with the blame it implies, gives people a way to distance themselves from risk: it happens to “them,” not to me.

By 2000, when Cindy got sick and didn't get better, she was far from alone. Her country had the worst AIDS epidemic in the world: 37.5 percent of pregnant women in Botswana were testing positive. For a country with a population of only 1.6 million people, it called survival into question. The president, Festus Mogae, spoke of “extinction.”

In the early days of the epidemic in North America, when only gay men and heroin addicts had HIV, it was easy to shun people with the disease: these were marginalized groups, easily isolated, easily blamed. And even in Africa in the early years, only a small number of people had visible symptoms. But it is far more difficult, indeed largely impossible, to isolate a third of the population, or to argue that all of those people are guilty of something. And yet, in Botswana, the shame clung to AIDS in defiance of the 37.5 percent prevalence rate. When the government surveyed the population in



2001, nearly two-thirds said they would not buy vegetables from a vendor with HIV; nearly half said that a teacher with the virus should not be allowed to continue to teach.

Yet people weren't talking about it. Tswana culture is formal and conservative, reticent around both sex and death. If people referred to the new plague at all, it was as "that illness." When a friend or relative of Cindy's died, newspaper obituaries gave the cause of death as TB or influenza; people described the deceased only as "late." The gaudy condom billboards put up by international agencies around the cities were foreign, an embarrassment. "That was for others—it wasn't for me," Cindy explained, even though people her age were beginning to die in huge numbers. And even when she was tremendously ill, there was no way she was going to have an HIV test.

"All we were told is that you're going to die if you have HIV," she said. "If you died, you were buried the same day. People covered their faces in the mortuary when they went to collect a body." If she had it, Cindy figured, well, she'd die, but in the meantime, she wasn't putting herself or anyone else through the ordeal of living with that knowledge.

By late 2000, she was so sick that she had to go home to stay with her parents. Her mother took her to yet another doctor, and he too counseled HIV testing. This time, however, there was something different. "He showed me a bottle of Combivir"—a two-in-one antiretroviral pill—"and said, 'I am not saying you are HIV-positive but if ever you are, I will give you this bottle of Combivir and you'll be like Magic Johnson.'" This was a radical notion: that the treatment that could keep people with AIDS alive was available in Botswana. Available, that is, to people who could afford to pay \$350 a month. Presented with the bottle of ARVs, Cindy agreed to have the test. When it came back positive, her mother immediately bought the first month's supply of drugs.

Botswana's leaders had been, for some time, paralyzed by the scale and spread of the epidemic in their country. But now President Mogae demanded drastic action. Crack teams of international consultants were brought in to design a plan, millions of dollars were put at their disposal, and in 2001, a year after Cindy started

buying ARVs, Mogae announced the start of the first public AIDS treatment program in Africa. It was called Masa ("new dawn" in Setswana) and its goal was to provide every citizen of Botswana who needed AIDS treatment with free antiretrovirals. Although Botswana had the greatest percentage of infected people in Africa, it also had, unlike any of its neighbours, the money to buy the drugs and a solid health infrastructure to distribute them.

In addition to saving the lives of the sick, the Masa plan had another goal: ending stigma. Before Masa, most people thought as Cindy did: why get tested if there is no treatment and no cure—if you will be sent home to die, shunned by your family and neighbors? Better to die of some unspecified combination of respiratory problems and diarrhea, and leave HIV out of it. Centers offering free HIV tests had been opened up all over the country, but in the absence of treatment, they were often empty. People wouldn't test if there was no treatment. The prevalence surveys suggested that 300,000 people were infected, yet by 2003 only 80,000 had tested.

This was a problem in plenty of other countries, too. It was seen as essential to get people to "know their status," on the grounds that if they were HIV-positive, they could take steps to stay healthy and protect their partners, and if they were negative, they could take measures to stay that way. The theory was that the availability of free treatment would motivate people—in the tens of thousands—to test for HIV. And when people with AIDS began to get well in large numbers, then the stigma would begin to fall away: as AIDS was transformed from a fatal to a chronic illness, there would be less to cause shame, less to fear. The eyes of the whole AIDS world were on Botswana, waiting to see just how well it would work.

It didn't. After a year of free treatment, the numbers of people seeking HIV tests had barely crept upward. Some people were seeking out the treatment—but they were the desperately sick people who could not keep the secret anymore. Treatment hadn't ended stigma. It had barely dented it.

If any of the high-priced consultants who drew up Botswana's AIDS plan had talked to Cindy, they might have seen this coming. Yes, she had her Combivir, but a bottle of pills didn't soothe the



pain of being told she had a fatal illness at the age of thirty. Magic Johnson notwithstanding, she was *infected* with something, something she couldn't get rid of, something she caught having sex. She quit her job in Pretoria and lurked around her parents' house, feeling, she said, "like a black sheep, like I was cursed." Every time she swallowed a tablet, she thought about AIDS, about how she was now marked, stained, spoiled. The drugs soon made her well, but she still didn't tell her friends what she had. Here was the lesson for the architects of Masa: ARVs could make a person well, but they didn't end the shame of AIDS. Before long, Cindy was taking the medication money her mother gave her and going back to Pretoria, blowing the cash on booze and parties. "I'm still waiting to die but I don't die. So I'm just going to have fun—I drank until I dropped."

Within weeks of stopping the pills, she was sick again: her hair was falling out in clumps, her skin was peeling off. She got so sick her family had to keep her in diapers, and she decided she couldn't wait any longer for a death that was dragging its feet. "I thought, 'I'm going to suffer and going to die'—I just wanted to bring that day." She made a concoction of bleach, fabric softener, detergent and all the pills in the house, and drank it down.

She was in a coma for three days. She awoke in the hospital to the news that she had pneumonia, stomach tumors, tuberculosis and Kaposi's sarcoma. Her CD4 count was 8. Doctors told her family that this horrifying array of illnesses would almost certainly finish the job she had started with her poisonous homemade cocktail. Yet Cindy beat the cancer, and the tuberculosis; she got over the pneumonia and her lesions healed. "There's no one who went through what she went through and is still standing," Avo Avalos, her doctor, told me. "I was just lucky to facilitate her will to live. She's my inspiration."

Cindy said that when confronted with actual, imminent death, it didn't seem so appealing anymore. And she was lucky to be young and strong enough that when she decided, with her usual single-mindedness, that she wanted to live, her body could still fight back. She was filled with the sense that her life was spared for a purpose: "I still have to do something in life."

Soon she was out of the hospital and back on ARVs—taking them religiously this time. Her CD4 count slowly climbed. In the newspaper one day, she noticed an advertisement: an organization called the Coping Center for People Living with HIV/AIDS was looking for a receptionist, and would give priority to a person with HIV. Cindy got the job. “That was the turning point of my life. I met these people living with HIV and AIDS who accepted their status and were living life to the fullest. I thought, ‘My God, why not me?’”

At the center, she was soon given rudimentary training in public speaking, and she began to do small talks in workplaces, telling people how she was living healthily on ARVs. She loved the attention, and how people drank up what she had to say. She was the only college graduate who was publicly HIV-positive, and that made people listen. Now talking about HIV won her admiration, and that eroded the shame in a way ARVs never did. “I really had an impact on people.”

Audiences were drawn by the frank way she talked about contracting the virus. “I used to be naughty,” she said. “I used to change partners, I used to drink—I was young and vibrant and that was Cynthia.” Her honesty gave her a certain authority in talking about behavior change: she had changed, she said, but it is extremely difficult to persuade other people, for the simple reasons that none of the other options are nearly as much fun. “Just tell a kid to abstain—I can’t. I didn’t abstain. And I didn’t use a condom.”

Every beauty queen needs her cause, and Cindy threw herself into public education, focusing her advocacy efforts on rural areas. “In rural communities they still don’t know anything about transmission of HIV. People don’t have information and they end up dying.” Now, when she addressed a crowd at a village school or church, or in a *kgotla*, the traditional meeting place, people seized on the opportunity to ask this honest young woman all the things they really wanted to know. “People in rural areas ask me, ‘How did you get infected?’ And ‘Do you have sex?’” Yes, she told them. “‘I’m a human being, I do have sex, but in a safer way.’ They want to know, at funerals, do you cook the meal? I tell them that transmission of HIV is not through food.” There are many, many people who need to hear her message, she said.



Today some stop her in the streets, approach her at the mall, strike up conversations in the minibus taxi: everyone has seen her on TV. "They tell me I'm a role model, an inspiration." She often misses work because Miss Stigma-Free duties call; she serves as a treatment buddy to many people with HIV, accompanies those newly diagnosed to their first appointments at the clinic. She glides like a princess through the infectious disease center in downtown Gabarone, mouthing "hello" left and right, her cell phone pressed to her ear.

Because she is so well known, she said, lots of people turn up at her house for counseling. That's how she met her boyfriend, Carlos, who was sent by friends to see her after he tested positive. Cindy giggled when I asked—of course it's against the rules to date your counseling client, even when he's tall and dreadlocked and handsome in a smoldering sort of way. "But I'm a human being." These days she lives with him in his mother's house in a suburb at the edge of the capital, close to the big Riverside mall where she goes to keep an eye on the latest fashion trends.

Cindy said there is ever greater demand on her as more people get on treatment. When Masa failed to boost the number of people seeking HIV tests, the government took another radical step: in early 2004 it introduced the first-ever policy of routine HIV testing. Now health workers offer an HIV test to anyone who comes into contact with the health system—whether for tuberculosis or meningitis that may be related to AIDS, or an ear infection or a spider bite. People can decline the test, but researchers suspected that most would agree to take it. And they were correct: in the eighteen months after the new policy was introduced, 202,000 people were tested—a 134 percent increase over the previous period. By late 2006, the country had seventy thousand people on treatment, about 85 percent of those who need it, one of the highest ratios in the developing world. Finally, Cindy said, the normalization of testing and the sheer volume of people on treatment have served to erode some of the shame. "It's better now—for most people the stigma is not that strong. They're coming out and talking about it."

The Miss HIV Stigma-Free pageant was originally envisioned

as an annual affair, but after Cindy won, organizers realized that far more women were living openly with HIV than were men, and they decided to find a Mr. Stigma-Free instead—so she retains the title today. She revels in the fame her status has brought her, and yet she also has a clear sense of what the disease has cost her. If she were HIV-negative, she said, she would have stayed in South Africa and furthered her studies, but because she can get free AIDS drugs only in Botswana, she is stuck there. She reckons she could have a lucrative career in communications, if she could reach a market outside her small country. “Then I would be in a position to maintain myself. I want to study to be a motivational speaker like Oprah, and speak on issues of HIV/AIDS—I could make it to the top. I would have my own house, my own car, my own talk show, and be helping the nation.”

She has learned to speak the modest language of the pageant queen. “Today I am the happiest person if I save one soul,” she told me earnestly. The recognition, she added, means nothing. “I never thought I’d be famous like I am today,” she said in one breath, before adding in the next, “You know, at the end of the day I’m still myself. I’m still Cynthia.”