South Africa’s Moment of Truth

The continent’s richest nation is only five years into a new democracy. But is it already too late to escape an AIDS disaster?

July 1, 1999 By Mary Crewe

Gugu Dlamini lived in a small town in KwaZulu/Natal, a poor, mostly rural province in South Africa. Dlamini, 34, had HIV -- not unusual in a region where one out of every four people is infected. What was unusual about Dlamini was that she had become a member of the National Association of People With AIDS (NAPWA) and, on December 1, 1998, World AIDS Day, publicly announced that she had HIV. Having been assaulted by a neighbor who knew her status, she was apprehensive about how her community would respond to the news, but she was committed to doing her part for NAPWA’s new Acceptance and Disclosure campaign. Three weeks after she came out, her worst fears were confirmed: She was stoned and knifed to death outside her home because she had, in the words of her previous attacker, “disgraced the community.” Even before Dlamini’s murder, a number of people with HIV in the area had reported being threatened. One targeted woman says, “In this town, there is a belief that women are the ones who carry the disease over to others.”

KwaZulu/Natal has long been the scene of a low-grade civil war between extremists from the African National Congress (ANC) and the Inkatha Freedom Party, so the province is often tense with flare-ups of violence. Yet the brutal slaying of Dlamini -- allegedly because of her HIV status -- shocked South Africa’s AIDS community. According to Peter Busse, NAPWA’s national director, the murder is a glaring sign of how much remains to be done to end AIDS stigma in this newly democratic country. “We need to create a climate of openness,” he says, “so that when people do disclose their HIV status they do not suffer from any form of discrimination or intimidation.”

Despite the fact that an estimated 20 percent of South Africa’s 43 million people have HIV, no more than a hundred or so have risked disclosing their status beyond their small family circle, fearing hatred, hostility and now physical violence. NAPWA’s Disclosure and Acceptance campaign was intended to encourage the infected to come out and to break the pattern of silence and social conservatism that has shaped South Africa’s response to AIDS.

But this has not happened. In the weeks following Dlamini’s death, NAPWA received hundreds of messages of support from around the world but fewer than 20 from southern Africa. “It is as if people just did not care,” says NAPWA member Pauline Ledwaba. “Gugu died, and no one asked why.” Ledwaba works with a PWA support group in Johannesburg and is herself constantly ill with the disease, but she says that her family still insists that she has chronic tuberculosis. National

health ministry spokesperson Dave McGlew described Dlamini's death as possibly "one of the most devastating setbacks in our fight against AIDS."

Just five years ago, South Africa seemed poised to take on AIDS. Apartheid was dead; the first democratic elections had been held and the ANC, led by Nelson Mandela, swept into power. The new government promised equality, freedom and justice, a better life and redistribution of wealth. The HIV infection rate was still in the single digits, 7.5 percent. And with a per capita gross domestic product of about US$2,500, South Africa was five times richer than most African countries.

One of the new ANC government's first acts was to launch a National AIDS Plan, a comprehensive initiative emphasizing prevention and education but also calling for counseling, care and support for PWAs. The document was drafted in collaboration with nonprofit AIDS organizations, community groups, church leaders, unions, traditional healers and political parties. (I was a participant.) Mandela had spoken at the 1992 conference that led to the drafting of the AIDS plan, and it was widely believed that he would ensure that it was put into action. This confidence was rooted in Mandela's immense stature as a progressive leader, the country's post-apartheid optimism and its leading role in the economics of the continent. With its comparatively advanced infrastructure, health and education systems and greater technology, hopes were high that South Africa would escape the devastation of AIDS that countries to the north were facing. The new cabinet members had pledged to fight AIDS, and HIV campaigns were touted as an essential part of the new democracy. "A better life for all" was an ANC election promise, and people with AIDS had reason to believe they were included. What went wrong?

Much from the old apartheid days stood in the way of the new democracy's effective response to the epidemic. Though HIV first appeared in South Africa among white gay men, AIDS is now an overwhelmingly black, heterosexual disease. After years of economic marginalization, most black South Africans still lack adequate housing and jobs, water and electricity, food and education. The apartheid system of migrant labor and segregated homelands had fragmented the society and split apart families -- a pattern of dislocation that Slim Abdool Karim, one of the country's leading AIDS researchers, calls the "engine driving our epidemic." And a new constitutional guarantee of gay rights did little to challenge strong taboos against talking publicly about sex.

The National AIDS Plan, so promising on paper, stumbled at implementation. "We had all underestimated the incredible difficulty of getting materials and support out to the communities that needed them," says a former health official. "Even though we had so many more resources than other African states, this could not guarantee that we would be any better, [leading] to tremendous frustration." Problems in getting the plan up and running were compounded by South Africa's switch from a centralized white-controlled government and homelands to a new system of nine provincial governments, meaning, in effect, nine autonomous AIDS programs.

Yet as the *Weekly Mail & Guardian* wrote of Mandela, "Few people in recorded history have been the subject of such high expectations." He was to allay white-minority fears, promote a culture of learning, lower crime, help farmers, soothe business concerns, integrate South Africa back into the

world and maintain support at home. When Mandela spoke, it seemed, the nation listened. But Mandela failed to speak about AIDS.

According to Morna Cornell of the AIDS Consortium, a network of South African AIDS organizations, although “AIDS is the single biggest problem facing this country, Mandela, in four years, has never made a national speech on AIDS.” Despite the fact that the AIDS program was a “presidential-led project” -- a priority of the new government -- Mandela’s only major AIDS address until recently was outside the country, at a 1997 conference in Switzerland. Even that speech was vague, with the president saying, “Let us join in a caring partnership for health and prosperity as we enter the new millennium.” AIDS advocates, calling AIDS a “political disease,” have stepped up their criticism of Mandela’s silence.

But his spokesperson, Priscilla Naidoo, questions the critics. “I’m not sure what more he needs to do,” she says. “He has made every effort before and during his presidency to raise AIDS awareness.” And an official in the Gauteng province’s Directorate on AIDS and Communicable Diseases, who insisted on anonymity, says, “The government does get really tired of people with AIDS and their activists who think that AIDS is the only issue we have to address. Even if Mandela does not address AIDS directly, he has addressed it through all his calls for humanity, peace, justice and dignity. We must see what he says in a holistic way.”

In fact, most of the AIDS community’s anger has been directed not at Mandela but at the government’s powerful health minister, Nkosazana Zuma, who is from the same province as Gugu Dlamini, KwaZulu/Natal. A large and dramatic woman who exudes an air of confidence that some have described as arrogance, she is a former ANC exile and a well-placed FOT -- Friend of Thabo Mbeki, Mandela’s deputy president -- and expected to be, by presstime, South Africa’s president-elect. Zuma was a central player in the drafting of the National AIDS Plan, and just four years ago PWAs praised her strong stance against AIDS discrimination. Today she is in conflict with many of her former friends.

One AIDS advocate who worked on the National AIDS Plan recalls the days when Zuma showed concern. “She is a doctor, she had been in exile, I felt that she would push hard for the AIDS plan to be implemented. She was so committed in the meetings.” There is little dispute that Zuma cares deeply about improving the health care of all South Africans; spending for health care has jumped by 45 percent under her watch, and her department built 638 new clinics in just four years. But after endorsing the AIDS plan, she apparently did little to put it into action.

In the past few years, Zuma has been dogged by controversy. First came her decision to spend more than US $2.4 million of a US $11.6-million AIDS budget on an HIV-themed play, *Sarafina II*, a project canned only weeks after it opened, due to irregularities in the awarding of the commission and criticism from AIDS advocates over its content. Soon afterward, in its search for locally controlled treatment options, Zuma’s department threw its weight behind a little-researched “wonder drug,” Virodene. The compound was quickly discredited -- new evidence indicates that it may even hasten HIV replication -- and rumors of a government financial stake in Virodene led to investigations.

Last October, on the heels of this bad press, Zuma discontinued a popular program offering AZT to pregnant women -- a regimen that significantly reduces mother-to-child HIV transmission. This decision remains at the core of criticism of the health minister.

An estimated one in five pregnant women in South Africa is infected, and the pilot program would have provided a short course of oral AZT to several hundred. Though Zuma had never backed the project, three provinces had already allocated money for the Glaxo Wellcome-discounted AZT when she halted the pilots. Women's and AIDS groups erupted in protests, calling Zuma a "baby killer"; an AIDS organization and a political party have filed suit against the decision; and in defiance of Zuma, the program will move forward in the Western Cape, a province controlled by the opposition National Party. "It's very hard to know that there is a drug that might save my baby's life and not to get it," says Abigail Kunene, who hopes to enroll in a trial in Johannesburg. "It is harder when the drug is kept from us by the government we voted for."

In announcing her decision last fall, Zuma said that "AZT treatment will have a limited effect on the epidemic as we are targeting individuals already infected. ... The only cure is to prevent infection in the first place." She reasoned that providing AZT through a pilot program would signal to all HIV positive pregnant women that they had a right to the drug -- an expectation she said the government could not afford to meet. As one of her advisers, Ian Roberts, said, "There is not much point in running a pilot study unless you can implement its findings." And to truly prevent transmission, each woman would have to be provided with not only AZT but free infant formula and counseling -- a program whose price tag, while significant, would likely still be far smaller than that of caring for the infected children.

Zuma has chosen instead to focus resources on other forms of prevention and long-term strategies for treatment access. Her Medicines and Related Substances Act, which would allow the manufacture of cheaper generic substitutes for expensive patented drugs, has provoked the ire of U.S. trade negotiators. There is some irony in the infant-transmission issue blowing up in Zuma's face, since one of her greatest accomplishments as health minister was to institute free health care for all children under age six.

Although Zuma has said that her decision is open to review, she has yet to meet with the scientists who designed the program; at presstime, a meeting with AIDS advocates had been scheduled. Meanwhile, the controversy has gone international. An October 1998 issue of *Science* magazine reported that unnamed researchers were considering a boycott of the 13th World AIDS Conference scheduled for Durban, South Africa, in July 2000 -- the first to take place in the developing world. According to one independent AIDS consultant, such a protest would have little effect: "Zuma will be unmoved by a boycott. She will see it as a white, Western response and an indication that those people do not understand Africa and its constraints."

Within days of Zuma's decision to halt the AZT program, the government announced a new initiative, the Partnership Against AIDS. The plan was touted as an attempt to breathe new life into the country's AIDS response, including effective strategies such as those outlined in the original National AIDS Plan. The National AIDS Directorate advertised the launch of the partnership as "10

Minutes to Save the Nation," and Mandela was scheduled to make a statement. Instead, the event was low key; Deputy President Mbeki stood in for Mandela, delivering a measured, unemotional speech and looking visibly uncomfortable as he touched the children with AIDS who surrounded him during the broadcast. Advocates noted that at least Mandela's presumed successor spoke more boldly about the epidemic than Mandela ever had. Mbeki pledged that the government would do everything in its power to support people with HIV, to improve their care and to end discrimination. "AIDS is real," he said. "It is spreading. We can only win against HIV if we join hands to save our nation.... For too long we have closed our eyes."

Zuma said that the partnership's purpose was to "ensure that the country's response to the epidemic involved all sectors of the community and that decisions were not taken from the top." She seemed to be harkening back to the collaboration that had produced the National AIDS Plan five years ago when she had called on the same groups for their support and commitment. "Each one of us has a role to play no matter how small the contribution," Zuma said. In support of the partnership, US$13.4 million was pledged for new media, information and prevention campaigns.

Since the partnership's launch, Mandela has made two important AIDS speeches. His 1998 World AIDS Day address contained his strongest words yet: "Our whole nation must take responsibility for turning the tide of this disease." But a true collaboration between public and private organizations has been less forthcoming. Many advocates, though, are supportive, such as HIV educator Petrus Ndaba, who works in public schools in the Free State province. "I think that we must give the partnership time -- it's easy to be skeptical and to judge it on what has gone before, but we need to be part of the partnership, encouraging and holding them to account," Ndaba says. "It does not help to always stay on the sidelines." But others, who have felt shut out for years, remain critical.

Important national HIV service providers like NAPWA, the AIDS Law Project and the AIDS Consortium are rarely consulted about government AIDS policy. And when they've taken their complaints to the media, officials have often dismissed their protests as "racist." It is, to say the least, a tricky dynamic: After decades of white-minority rule, most of the top leadership in the ANC government is black; the heads of many AIDS organizations in the country remain white.

These organizations, with NAPWA at the helm, recently launched the Treatment Action Campaign, an effort to get the government to provide drugs, such as AZT and 3TC, to people with HIV -- including a short course of AZT to all pregnant women. The group also plans to pressure pharmaceutical manufacturers to sell therapies to the government at cost. Mbeki has joined in the latter initiative, saying: "The problem lies not with the government. The problem lies with pharmaceutical companies' exorbitant prices on [the drugs], thus making it impossible for the government to make them available." Glaxo insists that it already offers AZT at a significantly reduced price.

At the end of April, two events threw into dramatic relief the continuing contradictions of the South African AIDS epidemic. On April 20, Supreme Court Judge Edwin Cameron, widely respected for his human rights activism, announced that he was "living with AIDS" during televised hearings for an

appointment to the country's highest court, the Constitutional Court (See "Judgment Day" below). In becoming overnight South Africa's best-known PWA, he emphasized: "The choice to speak is available to me for very particular reasons: because I have a job position that is secure; because I am surrounded by loved ones, friends and colleagues who support me, and because I have access to medical care and treatment that ensures that I remain strong, healthy and productive. For millions of South Africans living with HIV or AIDS, these conditions do not exist." Afterward, Mbeki announced his support.

Yet just three days earlier, Zuma had announced that she was taking steps, along with health ministers from Namibia and Zimbabwe, to make AIDS a notifiable disease. The new policy would compel doctors to disclose the positive test results of patients to their family and caregivers. "We want to know who is dying of AIDS, and relatives and partners must be notified," Zuma said. "It is time we treated AIDS as a public health issue like tuberculosis. We don't go about treating that with secrecy." It was a radical turnaround for the official who had begun her tenure with an outspoken defense of the rights of people with AIDS. NAPWA's Busse calls the decision, unveiled a mere four months after Gugu Dlamini's death, "outrageous"; Mark Heywood of the AIDS Law Project says the policy "is reinforcing oppression of women and undermining everything AIDS activists are trying to do."

As South Africans headed toward the election in June, the country had the fastest-growing epidemic in the world and a national policy that was largely still on paper. The hopes of 1994 have yet to be realized, but Mbeki's recent statements indicate that, unlike Mandela, he truly might make AIDS his issue. And without strong leadership and equally strong measures, South Africa's future will, like its neighbors' to the north, be wasted by AIDS.

Judgement Day

In April, Edwin Cameron, a South African judge nominated for the nation's highest court, shocked the public when he disclosed, during his judicial confirmation hearings, that he has HIV. POZ spoke to Cameron about coming out.

Many Americans say you are very courageous for disclosing so soon after a PWA was murdered. Is that true?

Cameron: It was easier for me than others here. The very paradox that my statement was designed to draw attention to is the fact that in the midst of this very dire reality, I am privileged in many ways. The four million South Africans with HIV are in a situation similar to that faced by PWAs in the U.S. in the early-to-mid-'80s: enormous prejudice and fear, and their own sense of a lack of remedy and support.

What is the remarkable outcome of your announcement?

Cameron: One is that my sexual orientation, race and gender have not been featured as debating points, even though I'm a gay white man with AIDS in an epidemic where the primary impact is borne by black heterosexual women. Those differences are subordinate to the fact that I'm

someone living with AIDS who has spoken out about it. That has been particularly moving to me. —Phill Wilson

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