Keeping AIDS at Bay in Cuba

Cuba boasts the lowest rates of HIV/AIDS in the Caribbean—if not the world. Should the credit go to the country's early, internationally condemned policies aimed at stemming the spread of the disease? And what's in store for this island nation now that its borders may reopen to Americans?

September 1, 2009 By Bill Strubbe and Karen Wald

Havana is at its finest in the morning, before the sweltering heat sets in, as the city revs into gear. Roosters crow from rooftops, children in red and white uniforms head to school, and a woman dressed in white tosses a Yemaya offering into the sea. After a hasty cup of café con leche and a roll, Maria Julia Fernández, clad in a T-shirt and capri pants that belie her 57 years, dons a helmet and mounts her motor scooter. Maneuvering along the pothole-strewn streets, she competes with jammed commuter buses, automobiles—many pre-1959 American classic models—and bicycles whose chimes resound off faded colonial and deco walls smoldering in the waxing sunlight.

Down Prado Boulevard, past the U.S.-style Capitolio building and a statue of the 19th century Cuban national hero José Marti, Maria Julia arrives at the shimmering sea. She turns west on the Malecon, the bustling waterfront promenade where, each evening, strollers seek respite from the heat. Reaching the Vedado neighborhood, she parks in front of a two-story colonial house where young men talk animatedly on the porch. Maria Julia waves hello, then walks into the entry hall of what was once an elegant home and is now papered with bold posters urging condom use. From the outside you wouldn't imagine that this building, indistinguishable from others on the block, houses the government-funded AIDS and STIs Information and Education Center (Centro Cubano de Información de Enfermedades de Transmisión Sexual, CCIETS-SIDA)—complete with a hotline, mobile medical unit, anonymous testing and peer support groups. Nor would you imagine that Maria Julia, energetic and healthy as she is, has been living with HIV for 23 years.

Three years before Maria Julia's HIV diagnosis in 1986, Cuba's former president Fidel Castro was first briefed by professor Gustavo Kouri at the country's Tropical Medicine Institute (Instituto Pedro Kouri de Medicina Tropical, IPK) about reports of AIDS cases throughout the world. After listening to Kouri, Castro reportedly said, "I think it should be your responsibility, and the institute's, to keep [the AIDS epidemic] from becoming a major health problem in Cuba."

By the late 1980s, when U.S. President Ronald Reagan had yet to deliver a speech on AIDS, Cuba's Ministry of Public Health (MINSAP) had developed an extensive program to prevent a full-scale AIDS epidemic there. With regular blood screening, medical care and economic support offered to everyone testing positive, it might easily have been a model envied around the world. All this,

however, was eclipsed by the government's highly controversial tactics: requiring at-risk communities (such as Cubans returning from abroad) to be tested for HIV; tracing the sexual partners of people who tested positive; and, from 1986, confining all those who tested positive to the Santiago de las Vegas Sanatorium, a hospice/health center on a former country estate called "Los Cocos."

Most of the world, including AIDS activists, condemned these measures as violations of individual human rights. The decision to place positive people in Los Cocos—widely dubbed a "concentration camp"—was particularly reviled.

But the inconvenient truth, born out by epidemiological data, is that Cuba is one of the few countries to succeed in stemming the spread of HIV during the early years of the epidemic. Today, Cuba has one of the lowest rates of HIV infection in the world, a prevalence of less than 0.1 percent among its sexually active population. That's six times less than the United States and a big exception in the Caribbean, the second most affected region in the world after sub-Saharan Africa, according to UNAIDS. Cuba also has the fewest deaths and highest percentage of known people with HIV/AIDS receiving treatment. While some international health experts credit the country's isolation (largely a result of a U.S.-led embargo on trade and travel to Cuba), the country's early HIV policies also deserve recognition for curbing the epidemic.

The Los Cocos sanatorium itself was part of an evolving strategy. The first step had been to sequester men who'd tested HIV positive after returning from African military duty; they were sent to Cuba's Naval Hospital. The assumption was that they would quickly become ill and die—a misperception based on the early pattern of the U.S. epidemic, where most AIDS cases were detected only when opportunistic diseases had already developed. But it soon became apparent that these men didn't match expectations. The "patients" were not only not sick, they were in fact healthy men—mostly heterosexual—just returned from long periods away and raring to get back into the swing of things.

That's what happened with Maria Julia's husband, Reynaldo Morales, when he returned from Angola in early 1986. "The joy of his return, after two years of separation, well you can imagine. Of course we made love," Maria Julia explains. "All the returning soldiers had taken blood tests—we thought they were just routine." But shortly afterward, Reynaldo was among those whisked into the Naval Hospital.

"We didn't know what was going on at first," recalls Maria Julia. "The men were stuck in the hospital, in pajamas, [with] no booze, no women. And they didn't know why. It was traumatic." Then she giggles, recalling how men tied bed sheets together to escape temporarily from the dreary routine. "Even though family and girlfriends could visit"—it was never a full quarantine—"they wanted what every red-blooded man returning from war wants." Once it became clear that these men were not dying anytime soon, they were moved from the Naval Hospital quarantine to the sanatorium at Los Cocos. "When the sanatorium was set up in April 1986, even with all its limitations," Maria Julia says, "it was a welcome relief from hospital confinement."

Maria Julia, then 34, soon tested positive as well and moved into Los Cocos with her husband. The surroundings were nicer than those at the hospital, but a military officer was in charge, and many patients remember those early years as bleak. Information was not always forthcoming, and many complained of the blunt manner in which untrained public health nurses informed them of their HIV status. One incident involved a young man summoned from studies abroad on the pretext of a serious family illness, only to learn the true reason when he was placed in the sanatorium. (Starting in 1989, it became routine policy for the newly diagnosed to be informed—and counseled—in a more caring manner by people who were themselves living with HIV/AIDS.)

Then, in July 1989, IPK medical director Jorge Pérez Avila, MD, became director of the AIDS Sanatorium. Pérez was AIDS-savvy, compassionate and dedicated to his patients. "You never have to knock twice at his door," one of Pérez's HIV-positive patients told POZ.

"He will bend over backward and spare no expense to make sure a patient is given every possible medication that might preserve his life," says Juan Carlos Raxach, MD, a gay man with HIV who lived in Los Cocos and now promotes AIDS education in Rio de Janeiro. "Once, a U.S. reporter interviewing Dr. Pérez questioned the financial logic of treating a patient with an end-stage disease with medication imported at enormous expense, since he would probably be dead in six months anyway," Raxach recalls. "Jorge was stunned by that question. 'And what if a cure is found in five months?' he shot back at her."

Historically, the socialist island nation of Cuba, which places the collective before the individual, has recognized that prevention is a better and cheaper approach to dealing with the virus than treatment. "Although thousands of [our] people travel to Africa and Latin America," Pérez says, "we prevent the introduction of malaria and other contagious diseases with international health checks when they enter Cuba. We vaccinate against hepatitis B so our children won't [later] acquire this disease through sexual relations." Recently, at the onset of the H1N1 (swine flu) scare, Cuba was the first country to ban temporarily flights to and from Mexico.

By 1989, 75 percent of Cubans 15 and older had been tested for HIV (the total population at the time was about 10.6 million); 434 people—315 men, 119 women—had HIV. Initially, most cases were among heterosexuals; it wasn't until the early 1990s that gay men began constituting the majority of positive male cases. This might have discredited the widespread assumption in America (where AIDS was branded "the gay plague") that Cuba's early isolation policies were linked to homophobia—if anyone outside the island nation had paid attention to the data.

Under Pérez's watch, daily life at the sanatorium improved. Along with access to specialized medical care—regular blood tests, physical checkups for opportunistic infections and supportive psychologists—residents received above average housing in a tropical setting, with air conditioning and color TV, a high-protein diet and recreational facilities. Coconut and mango trees shaded Reynaldo and Maria Julia's ample two-bedroom wood-frame bungalow. In this relatively stress-free environment, numerous patients, both gay and straight, fell in love and moved into one of these houses together. Raul Llanos, a gay economist who was finally able to live openly with his partner in the sanatorium, was upbeat about his life at Los Cocos. "You know, when you're first

told you have AIDS, all you think is, ‘Oh my God, I’m going to die.’ Here, you’re supported by others in the same situation. You have doctors and psychologists, and you know that everything is being done for you.”

But if Pérez made life in Los Cocos more pleasant, that didn’t erase the trauma of being separated from society at large and everything familiar. The sanatorium restricted residents’ freedom—galling to those who felt themselves capable of behaving responsibly. The Health Ministry faced an ethical dilemma: how to grant people with HIV/AIDS more freedom while simultaneously protecting the Cuban population from infection.

One of Pérez’s reforms was a stopgap measure offering greater freedom: Patients who passed an AIDS education program and a psychological evaluation could go home on Sundays with a chaperone. Patients deemed “responsible” were eventually allowed to leave on their own. One-day passes became weekend passes, and by the end of 1989, positive people could leave at will for family holidays or to care for a sick parent. Every weekend, Reynaldo and Maria Julia returned home to meet their teenage son, who arrived several hours later from the boarding school where he trained in judo—his sports school scholarship granted by the Ministry of Education when his parents contracted HIV.

Other changes occurred in increments. Also starting in 1989, patients were offered jobs within the sanatorium as office workers, doctors, nurses, lab technicians, accountants, mechanics, cooks and gardeners. Slowly, some began returning to jobs outside, or studying at the university.

While Cuba’s efforts were effectively stopping the spread of HIV, the epidemiological model of screening and isolation was having some decidedly negative affects among society at large. By 1989, Cuban AIDS experts noted that people avoided HIV testing for fear of being committed to the sanatorium. And many people didn’t use condoms because they didn’t feel at risk, thinking that everyone with HIV was already quarantined.

Through the efforts of Pérez and others, beginning in 1994, HIV-positive Cubans were no longer forced to live in the sanatorium. Yet few Los Cocos residents then chose to enroll in the out-patient programs. “We were surprised. We thought the sanatorium would empty,” says Rigoberto Lopez, MD, a Los Cocos epidemiologist. Maria Julia and Reynaldo were among the first of many to turn down the offer. “At Los Cocos, we have many friends, we feel useful, we keep busy,” Reynaldo explained in an interview back then. Known as a wiseguy and jokester, he was always ready to lend a hand to fix everything from cars to electric irons. Maria Julia, who had been an office worker at the Cuban newspaper *Granma*, was elected president of one of the neighborhood councils set up within the sanatorium.

Why didn’t they leave? Initially, Maria Julia didn’t feel secure enough to live outside and work. “We have our jobs waiting for us,” she said in an interview at the time, “but really, this thing [HIV] affects me psychologically, and I don’t think I could work. When I go back out on the street I want to be healthy.”

When Reynaldo became sick with neurotoxoplasmosis in 1995, Maria Julia and her son helped care for him until he died that August. Reynaldo's death was a hard blow, but it convinced Maria Julia to dedicate her life to AIDS prevention work. She returned to their apartment in central Havana and took part in international AIDS conferences. She helped organize Cuba's section of the AIDS Memorial Quilt and accompanied it to Washington, DC. She was trained as an AIDS educator and began working at CCIETS-SIDA, the AIDS Education and Prevention Center.

Today, 15 years after reentering society, she reconsiders her earlier quote and says, "I feel so useful today, knowing that every day I am helping others—especially unsuspecting wives and girlfriends—avoid contracting this disease. But it's been a long, slow process of educating the community, gaining acceptance and feeling enough self-confidence to go out in the world again. Back then, I don't think I could have done what I'm doing today."

"Leaving Los Cocos wasn't easy for the people living with HIV/AIDS," Pérez says. "Many worried about what would happen on the outside, if the services they'd been receiving would be available. It was necessary to first create ambulatory services and give them confidence that they could live on their own and manage their disease. This could only be done when we could guarantee that everything was in place for them to get the kind of attention they needed."

This meant making available 14 voluntary sanatoriums, or health clinics, one in each province, with ample stock of medicines and well-trained, sensitive staffs. Los Cocos now serves as one of these. Primary care physicians (family doctors) and personnel in neighborhood polyclinics and hospitals throughout Cuba were trained to recognize and treat HIV/AIDS-related symptoms.

Positive people themselves brought about other changes, speaking publicly about AIDS in their communities through Grupo Prevención SIDA (GPSIDA), the AIDS Prevention Group. Many Cubans had ignored attempts by the Health Ministry and the Centro Nacional de Educación Sexual (CENESEX) at AIDS education. But when "normal, everyday" people—women and men, homosexual and heterosexual, old and young—identified themselves as HIV positive at schools, dance clubs and on TV, the message began to sink in.

Today, a newly diagnosed person is referred to one of the sanatoriums for an eight-week, daily outpatient course on how to live with HIV/AIDS. People who might engage in risky behavior—those who are mentally imbalanced, exhibit addictive behavior or engage in prostitution—are still housed temporarily in a sanatorium until health workers feel certain of their safety and their ability to protect others. Only those who have committed crimes or knowingly infected or posed a danger to others may be sent to a closed-door facility.

When asked whether ending the sanatorium isolation policy has increased Cubans' willingness to test for HIV, Pérez says that many people still are afraid: "Despite all our education efforts, some people still fear that people will reject them. For various reasons that have nothing to do with the sanatorium, some people today wait too long to get tested or begin treatment; when they do, they're already sick."

The low rates of HIV on the island, Pérez maintains, result directly from the government's early measures. "The most important factor," he says, "was deciding to provide all the resources necessary—first, by buying AZT, the only drug then available. Then, in 1995, providing it to HIV-positive pregnant women to prevent maternal-fetal transmission; and now, using what modern medicine has put at our disposal."

The health ministry's decision in the early '80s to destroy all untested foreign-derived blood products strained the health care system mightily. But because of this move, Cuba is the only country in the world where HIV did not kill off an entire generation of people with hemophilia, who were wiped out in countries where clotting factor and transfusions transmitted HIV. Cuba still requires HIV testing for blood donors, army recruits, prison inmates, adults with sexually transmitted infections and all pregnant women. Routine testing allows Cuba to detect 80 percent of HIV cases, giving positive people a much better chance at a long, healthy life. In Brazil, by comparison, one third of adults have been tested, and only one in three of those testing positive is aware of the diagnosis.

Several additional socio-cultural reasons worked to Cuba's advantage: There's a low incidence of intravenous drug use; a 98 percent literacy rate results in HIV prevention messages reaching almost everyone; and Cuba's liberal, matter-of-fact approach to sex allows people to deal with pregnancy, HIV and STIs more openly than countries where organized religion exerts a powerful influence. Health care is considered a basic human right, and locally made generic antiretroviral drugs are available at greatly reduced cost. "We use HIV drugs produced in Cuba; we buy some from abroad, study them and develop treatment protocols," explains Pérez, who in early 2001 left the administration of the sanatorium to focus exclusively on his work at the IPK.

Veriano Terto Jr., who coordinates educational projects at the Brazilian Inter-disciplinary AIDS Association (ABIA) in Rio de Janeiro, has made several research trips to Cuba. "Despite the mistakes Cuba made at the beginning of the epidemic," Terto says, "I see how important a committed public health system can be to confront the epidemic." He praises the current practice of voluntary sanatoriums. "The situation of Cuban people with HIV/AIDS is much better than [that of] the majority of [positive] Latin Americans, because they have freedom of movement and access to food, housing, medical and psychological assistance."

Homophobia has eased in Cuba as elsewhere. In 1997, all vestiges of anti-gay laws were removed from the Cuban penal code. Under the leadership of Mariela Castro, MD, a trained sexologist and the daughter of current President Raúl Castro, CENESEX has promoted an inclusive approach to sexuality.

So, did Cuba's early elevation of public health concerns over individual rights help stem the epidemic there? The answer has more than historical significance: If Cuba's low HIV/AIDS prevalence is solely a result of the isolation imposed by international embargo, then the prospect of lifting that embargo threatens to explode the epidemic on the island. With a new U.S. president and polls showing that more than 60 percent of Americans favor lifting the ban on travel to Cuba, we may soon find out.

Pérez doesn’t expect more tourism to mean more HIV. After all, he points out, the increase in tourism in the early ’90s did not have this effect. “I don’t think tourism will greatly increase HIV cases if people are prepared and educated and know how to negotiate protected sex,” he says. “There will always be some cases in which people become infected. The greatest risk is for men who have sex with men—including many who don’t identify as homosexual. We have to work more to bring the AIDS prevention message to them.”

Back at the AIDS education center, Maria Julia is busy doing just that.

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