

- *This article has been reprinted from the amfAR Global Link at www.amfar.org/GlobalLink*

Cuba Fights AIDS Its Own Way

Anne-christine d'Adesky

Article

January 2003 — Located a half's-hour drive from Havana, the sanatorium at Santiago de las Vegas is the biggest and oldest AIDS center of the 17 on the island. The main facility is hidden behind a walled entrance in an architectural hybrid of heavy Soviet-style institution and Alpine ski resort set in the humid tropics. Across the highway, smatterings of low Florida-style bungalows serve as laboratories and medical wards and house some 450 patients.

From 1986 to 1993, Santiago de las Vegas epitomized the country's much criticized quarantine that kept people with HIV apart from the general public. Forced quarantine ended in 1993, but the government retains an aggressive public health approach to controlling HIV. The sanatorium model reflects an emphasis on preventive care over acute care and on early diagnosis and quick treatment of infectious diseases like tuberculosis. Cuban officials take pride in the sanatoriums, crediting them with keeping HIV prevalence under 0.1% of adults between 15 and 49 years old. That is one of the lowest incidences in the world and ten to 60 fold below that of Cuba's Caribbean neighbors. By official count, Cuba has about 3,200 cases of HIV, almost entirely in gay and bisexual men.

Like TB, HIV is viewed by the state as a medical condition for which an individual bears social responsibility. Individuals who test positive for HIV are required to spend at least three months in an AIDS sanatorium where they take a training course in living with HIV and protecting others from exposure. As part of the sanatorium model's 1993 reform, they also have the option of attending the training on an outpatient basis. Today, 48% of Cuba's HIV population live in the sanatoriums. The rest live outside and receive care at a few specialty centers.

A key criterion for living outside the sanatoriums is disclosure of one's sexual partners and providing the health authorities with "confidence" that one is sexually responsible. The health authorities actively pursue contact tracing and HIV testing of sexual partners, strategies borrowed from the TB program. There is also mandatory HIV testing of pregnant women, soldiers and blood donors, but anonymous testing is available for the general public. Last year, over a million HIV tests were done in Cuba, out of a population of 11 million. Condom use has doubled in a few years. These are distributed in bars, clubs and pharmacies but are in limited supply.

Before 2001, some patients were getting dual therapy through foreign donors, and drug availability was problematic. Around 900 people now receive a triple generic cocktail of two nucleoside analogs and the protease inhibitor indinavir. Two new medicines in other classes will soon be attainable. The government has started training

the specialists who treat AIDS patients and other health professionals as well, but budget restrictions have hampered this effort.

"We have made a lot of progress, despite not having all the resources we need," said Dr. Jorge Perez, head of the national HIV treatment program and director of the Pedro Kouri Institute of Tropical Medicine (IPK) in Havana, an infectious disease hospital and the main center for AIDS research. The IPK serves as the central clearinghouse for all Cubans receiving anti-HIV drugs, which it distributes to their clinics.

"Free and Easy Access"

"One of the characteristics of the health system is that it is free and has easy access. Everyone is entitled to the same level of care," explained Dr. Perez. "Even though I am a specialist and in charge here, a patient from anywhere can decide to come and see me."

Like other health officials, Dr. Perez cited the U.S. trade blockade of Cuba as a critical factor that has affected the AIDS program and contributes to the chronic shortage of medicine, food and other necessities.

"It's true we are hurt by economic problems and our patients have suffered from a lack of medicine," said Perez. "The lack of money is a constant problem for everybody. But now that we are producing our own drugs, things have started to change."

The IPK is located outside the capital and is compared to the National Institutes of Health in the U.S. because it combines frontline clinical research with treatment. In reality it is a small, dimly lit place in need of a paint job. HIV patients praise the free medical care it provides, which includes both medicine and diagnostic tests. HIV patients have their CD4 counts assayed every three months, and those on treatment also get viral load tests. They return to IPK for monthly follow-up visits and are monitored at home by a family doctor.

Of the 900 people on anti-HIV therapy, 72% are men, and 28% women. One hundred thirty who have received drugs since 1996 require salvage therapy regimens. They rely mostly on donated drugs. Perez will not begin someone on a salvage regimen unless he has a guaranteed six months' supply of the drugs. Still there are gaps in the supply.

For the majority, anti-HIV drugs are seen as a godsend. After 18 months, Dr. Perez reported, "Most of the people on therapy are doing very well." His one-year follow-up data shows that almost all had undetectable viral levels, higher CD4 counts and improved weight gain. After three months of therapy, 74% who began with CD4 counts below 200 jumped to over 200, then climbed progressively to over 350 after a year. Those who began with CD4 counts around 350 went up to 500 within three months, "and very easily," the doctor added. As of December, 50 people were waiting to get their first anti-HIV medications but not because the drugs are lacking, Perez explained. It takes four to eight weeks to meet with referring doctors and complete the paperwork.

Cuba has a uniquely decentralized, family-centered healthcare

structure that relies on a local team of a family doctor, nurse, and social worker assigned to care for 120 people in a given community. Local health officials report up the ladder to regional and national authorities. "At each level, there are people invested in how the patient is doing," explained Dr. Perez. That includes the pharmacists at IPK who track every pill given out and the psychiatrist who evaluates how patients are coping.

Adherence to dosing schedules remains a daily challenge. Perez has had patients who stopped taking their medicine without telling anyone and even died. HIV treatment is supervised for those hospitalized at the IPK and at the sanatoriums but not for those living at home. The family doctor or social worker is supposed to follow up, but in reality, "many people don't like their families to know they have HIV. It's difficult to send a nurse in – it's an ethical issue," Perez said.

The biggest challenge is caring for patients with advanced AIDS. Treating their HIV does not help them much, Perez observed. In 2000, 141 people with AIDS died. In 2001, when triple therapy commenced, the number dropped to 116. The mortality rate is now 7%. Most new HIV cases are diagnosed early, within six months to a year of exposure, so AIDS itself should now be avoidable.

Life inside the Sanatoriums

Dr. Perez took over the reins at the Santiago de las Vegas sanatorium in 1989 and is lauded as the person responsible for opening up the system. "They have very good living conditions there," he related, adding that many living in the sanatoriums are poor, previously unemployed or lack family support to live as well outside. "They have a house, air conditioner, color TV, 100% of their salary and a diet very high in calories and rich in protein. No one else has so much," he noted, smiling.

That said, he was still shocked back in 1993, when only 10% of residents opted to leave the sanatorium when offered the chance. "It was not discrimination, it was fear," he explained. "Those were the years of the really bad 'Special Period' when people were hungry." Others point out that since most residents are gay or bisexual men, the sanatoriums provide a more tolerant social environment, allowing gay couples to live together, for example. Some residents have lived there since 1996.

According to sanatorium officials, residents can freely come and go and get daily visits from relatives and friends. It is a major change from 1989. "When there was no treatment, it was hard for the patients and for the persons caring for them to confront [the absence of medical options]," said a staff psychologist there. "This was a very difficult situation."

Of the 1,000-plus people who have passed through the sanatorium since it opened, 380 now live there. An extended medical and social support staff of over 300 attends to them. The facility includes a hospital ward and laboratory as well as specialized clinics to provide surgical, dental, gynecological, hematological and psychological services. It also offers legal and social aid, including peer support

groups. Between 1998 and 2000, there were 22 outpatient groups. Some members of the outpatient groups have become community educators who go into people's homes to talk about AIDS. They are part of the "Cara a Cara:" or "Face to Face" national initiative.

To an outside visitor, the sanatorium feels like an army base, set apart from civilian life in a self-sufficient world with a basketball court, a garden and other facilities. Residents live as couples or four to a small house, their rooms resembling college dorms with basic furniture, including the air conditioners Perez mentioned. At one house, four gay men gathered on a porch amidst the heat on a humid afternoon. They greeted a visitor politely but warily, aware that a staff psychiatrist was present. Yes, they replied, they receive superior medical care compared with outside hospitals, and they eat well. Yes, friends and family may visit them. All of them received a special stipend for working on the premises. Sanatorium residents are entitled to receive 100% of their former salary. Persons with HIV outside the system get 50%.

Many residents require treatment for their HIV, they confirmed. Two of the men were managing their drugs without much difficulty. One had experienced some initial side effects. A younger man was preparing to begin treatment. He was unsure of what medicine he would take or how it worked. All expressed a desire to know more about new developments in AIDS and to have more contact with HIV-positive persons outside Cuba.

How free were they to leave? They were free to go if they were healthy, had completed the HIV training course and were enrolled for social services, said the psychiatrist. "If they have health problems and they want to go, they can, but we don't recommend it," he added. "Or if they've started triple therapy, we suggest they stay a while to see if there are any adverse reactions."

What about the issue of "sexual responsibility" – the standard by which people are judged eligible to leave? "Here we view the idea of a person being responsible for the health of another as a very relative term," explained the psychiatrist. "We say that person has a right to a higher quality of life and social rights. But they must modify their behavior to care for themselves and others. If you meet someone who has psychological issues, who has no family to support them, or if they are a person who has infected several people because they have no conscience, then we have to make a plan for that person. For them, it can take longer." The program works, he argued. "Out of the thousand-odd people who have stayed here, or as outpatients, very few have infected others."

The Unofficial Story

That is the official story. Away from the eyes and ears of health officials, Cubans living outside the sanatoriums offer a different picture. "I have always disagreed with this decision by the state," Cheo (not his real name) remarked about the sanatorium system. Forty-one years old and bisexual, he was diagnosed with HIV in 1993, just as Perez was reforming the sanatorium system. An HIV test was done without his knowledge after he went to a hospital for what doctors thought was glandular cancer. "For me, it was obligatory to

be in the sanatorium; there was no other option. But I didn't want to go," he related. "For two years, they tried to pressure me, saying I had to go and learn to live with HIV, that there was good food, etc. But I said my parents supported me very well. I didn't want to be separated from them."

Cheo says he received regular visits from health officials and was threatened with arrest, as were his parents. He pleaded his case with higher officials and was allowed to take a training course in a Havana center. He has obtained treatment at the IPK. But for years, he said, "I had no support because I had no friends with HIV, and my family was ignorant about it. I thought I would die right away."

Cheo has survived two opportunistic infections. His virus overcame two previous HIV regimens, and he is currently waiting for salvage therapy. In his experience, new HIV patients have no problem accessing generic Cuban HIV medicines, but some people like himself are struggling due to their long treatment histories. IPK physicians are sympathetic, he said, and urged him to start his own mutual-aid group to seek foreign donations of the needed drugs.

In Cheo's view, life at the sanatoriums "is not a normal life, because it is very controlled. It is all about illness." People may get quality medical care, but they remain socially isolated." Though he knows that some longtimers living there have adjusted, Cheo believes, "If they could afford to, most would live outside. How can you call something a choice if you don't have another option?"

He isn't alone in complaining about the lack of privacy or consent for Cubans living with HIV. In interviews, several individuals complained of the paternalistic nature of the AIDS program, and of the prevailing stigma and isolation they suffer. "There is a lack of freedom here in Cuba, and when you have HIV, it's that much harder," explained Cheo. "You are seen as a threat to society by the authorities. These views are changing, but people still think that way."

As a sign of changing attitudes, health officials are funding an HIV prevention program aimed at gay men, called HSH – 'Hombres que tienen Sexo con Hombres (Men who have sex with men.) It is one of the projects of the Grupo Prevencion Sida, or GP-SIDA, a now-national group launched by longtime residents at the Sanitarium de las Vegas.

Still, the law makes it hard for people with HIV to organize or get support outside of state-run organizations, though independent self-help groups have been permitted to form since 1997. "We exist, but we aren't legalized," said Cheo, who added that informal groups cannot legally fundraise or apply for government funds. In Havana, around 60 people attend a support group at the Montserrat church, the largest of its kind. The church provides a safe haven, Cheo claimed, because "the government isn't allowed to enter that terrain."

Cheo is especially critical of the policy of contact tracing. "It's supposed to be a decision of the person to disclose, to take charge of their situation and inform the people they've had relationships with," he explained. "But the thing is, the authorities need to know and

there is a lot of pressure to tell them. If you don't say, and if they take you to the sanatorium, they won't release you because they won't have confidence in you."

Another critic, Manuel (again not his real name), said that gay people who test positive are asked to name their sexual partners of the previous five years. "Some people are afraid to name more than five persons because they will be labeled promiscuous," he noted, "but if you name too few, they'll say you are not disclosing."

Critics contend that there is a gap between official AIDS policy and discriminatory routine practices. "There is no privacy," said Manuel. "The minute you are diagnosed, everyone seems to know. The state can't protect you." Although a new labor law forbids the firing of HIV-positive individuals, both men have friends who've lost their jobs after being diagnosed. They know friends who have had unsafe sex with positive partners but won't get tested, out of fear of being sent to a sanatorium and losing their jobs. "A lot of people are in hiding or denial," added Cheo, who feels official HIV statistics are too low.

Despite their complaints, these critics don't hold AIDS officials accountable for the problems of the system. "Dr. Perez doesn't make the rules. Nor do the people who work at the sanatorium," said Manuel matter-of-factly. "They can't speak out any more than we can. If they did, they'd be risking their jobs. A lot of people are doing what they can to help us. We appreciate that."

By highlighting Cuba's AIDS successes and struggles, officials hope foreign donors will respond. By speaking out, their critics are looking to HIV-positive groups for support. The Cubans urgently need more medicine (especially NNRTIs and OI drugs) as well as food and other basic necessities. Doctors and patients who lack access to the Internet seek the latest AIDS information. In a rare note of agreement, critics and officials alike feel that a change of U.S. policy toward Cuba and an end to the trade embargo would dramatically alter the economic and medical picture.