It Can’t Happen Here

The horror of facing AIDS in a land of denial

December 1, 1994 By Joseph Downton

It’s five o’clock on a Friday afternoon and I’m sitting in the shabby second-floor waiting room of PROSA (*Programa de Soporte a la Autoayuda de Personas Seropositivas*), the office of the only HIV social services group in Lima, Peru. The city seems light-years away from my home in Brooklyn. Seated next to me, nervously twisting his T-shirt into tiny knots, is my one-time lover and dearest friend Eduardo; we are here to see if he can connect with a local support network and, with luck, find a credible doctor.

Several weeks have already passed since Eduardo first called to inform me, voice shaking, that he had returned from the government hospital with his worst nightmare realized: his HIV test had come back positive. I’ve had other friends call with the same news, and it is never easy to accept, but this one was different. This time it was a call from someone with whom I had shared my most intimate thoughts, swam naked in the ocean, slept together, wept together, listened to bad music together and all the other things that lovers do together happily and without careful thought. This is someone I promised to always love and nurture -- no matter what.

One single phone call and the world temporarily lost its relevance, I became overwhelmed with my own sense of powerlessness. If he had been in the same neighborhood or city or state or even the same country, I would have been able to put my life aside and run to Eduardo to hold him, calm him and soothe his tortured breathing. But Lima is half a world away. He was crying hard, harder than I had ever heard or known, and I could barely understand the semi-incoherent words, half in Spanish, stumbling from the telephone receiver. One plea did come through clearly: "Please come and help me. It’s so bad here that I can’t get *any* medical care."

From the comfort of my apartment it was difficult to conceptualize the medical difficulties that lay ahead for Eduardo, a citizen of a country where proper health care for seropositive people is largely unavailable. HIV testing alone can be an epic ordeal, much less gaining access to a doctor or a laboratory for basic blood work. According to Eduardo, in the entire country of Peru there exists but a single, organized overworked center for HIV support groups, a direct result of the largesse of activists from Norway. I initially dismiss his contention as another of his famous exaggerations; surely there had to exist some services in a city the size of Lima, with medical schools as well as research hospitals at major universities. I had to come and see for myself, to experience this city in person.

On the flight down from New York City, I reflect on the consistent frequency with which I have heard New Yorkers complain about the difficulties involved in visiting their doctors. My *God*, the indignity and inconvenience of having to make appointments several *weeks* in advance for blood labs, only to have the receptionist call to *reschedule* -- what is this world coming to, if I may ask?

If it's not the inconveniences of life with HIV, then American kvetching invariably centers around the perceived attitude exhibited by the staff of a certain local services group or the exorbitant price of AZT or the lack of sufficient health insurance or the doctor's cavalier attitude toward the aches, pains and fears of a body in limbo.

The complaints, it occurs to me, seem increasingly irrelevant. In the United States, despite its shortcomings, we at least enjoy the luxury of multiple options in fighting HIV -- even in the remotest of cities. In Lima, there is simply no choice: your options are a basic, coldly analog "take it or leave it."

Through the open windows of the spartan office housing the support services organization, I can hear the distant cries of the fruit and vegetable vendors from the street market below. The room, illuminated by a single, naked lightbulb hanging from a dangerously frayed cord, is furnished with a few broken-down plastic chairs. No stacks of the latest gay magazines or *Architectural Digest* can be found; reading materials consist only of a handful of safer sex brochures and a few dog-eared copies of Norwegian magazines. The others waiting in the room with us seem nervous and ill at ease, almost embarrassed to be seen in an AIDS support office. Whenever the front door opens, heads snap upwards in unison, catch a furtive glimpse of the newcomer and lower once again in silence.

While we wait for an appointment to consult with a volunteer, I request an opportunity to speak with Julio Cruz, the group's director. Cruz comes out of his office to greet us and takes me into a tiny room that doubles as both his office and a meeting space for one of the center's support groups. With a little linguistic help from my friends, I learn that I am the first American Cruz has had a chance to talk with about the desperate situation his country is now facing. He is eager to inform the United States -- anyone in the United States who might be able to help -- about the situation in Peru.

According to Cruz, the AIDS epidemic in Peru has reached a point where government officials are now downplaying its magnitude for fear of a full-scale panic. As a result, Peruvian health officials have refused to release anything more than an unrealistic and severely diluted estimate of the severity of the problem. This blatant disregard for the well-being of ordinary citizens makes it impossible to even estimate the exact number of AIDS cases in Peru, especially given the Peruvian government's insistence that only 130 deaths have been caused by HIV since 1982. Cruz personally estimates the number of infected persons nationwide to be closer to 100,000 and adds that at any given time PROSA's sparse three-person staff juggles a caseload that numbers into the hundreds.

"The scariest thing that has happened here is the way the debate over quarantining HIV positive

individuals went unnoticed by the local press," he says. "Julio Castro, a member of Peru's Congress, managed to get a law passed that points to quarantine centers as the next step. He actually managed to have a law passed which decreed that all citizens must be tested for HIV."

When I ask how Castro intends to accomplish such a monumental task, Cruz laughs and says, "It would be just impossible. No one is going to show up at a hospital on their own. This is a nation that has a deeply ingrained disgust for authority and rules. If they don't obey something as simple as a traffic light, they certainly aren't going to have their blood tested by the government for a life threatening illness without being strong-armed to do so."

Cruz's assistant brings me a copy of the law; as Eduardo translates the legalese for me, it becomes apparent that the government first tried to use scare tactics to coerce the public into accepting the idea of mandatory testing and quarantining as necessary steps to halt the spread of the disease. They suggested that the first people to be tested would be the city's legion of male and female prostitutes. Next up would be any individual who had come into contact with these sex workers or any group who the government deemed to be probable carriers of the virus -- an obvious code for homosexuals.

When no one seemed to heed the official government quarantine bill, the government decided that they would copy a page out of Fidel Castro's Cuba and couch the quarantine as a paternalistic measure to assist the sick.

"At least the quarantine centers in Cuba are staffed by actual doctors," sniffs Cruz as we look over the document. "Here they will have to force doctors at gunpoint to go work in such a hospice."

"We are the only social services group for HIV positive individuals in the city. They won't give us any money for educational materials; everything we have is by donation from a group in Norway. We are lucky to have a few friends in the medical community here in Lima that slip us a few sample cases of medication and vitamins when they can, but it is never enough."

He adds that nearly 75 percent of PROSA's caseload is now heterosexual, with an increasing number of female cases. "Gay men just are afraid to be seen coming in here. Someone might tell their families. They just don't want to risk it. They would rather forgo treatment and just get sick. I am fighting centuries of cultural bias against open homosexuality and it's so frustrating."

When I ask him what the ratio of doctors to patients is in the city he merely laughs and tells me that there are only seven doctors currently treating HIV. I am dumbfounded by this pronouncement; imagine a city the size of Dallas, Texas with only seven doctors treating a caseload of nearly 100,000 patients. When Cruz takes notice of my shocked expression, he suggests that I might want to trot across town and speak with the director of the only AIDS clinic in town.

Twenty minutes later I have entered the foyer of the *Via Libre* clinic, which is housed in a crumbling government building located in the city's oldest quarter. We literally have to beg the

receptionist for a precious moment of the doctor's time. The battery of questions I have to answer, plus a demand to view my passport, leads me to suspect that visitors are viewed with deep suspicion, and in particular anyone associated with the media. While we wait patiently for the good doctor, an elderly woman begins to scream for help for a boy whom I take to be her teenage grandson. Before the staff is able to lead the gaunt young man to the bathroom, he begins to vomit blood onto the marble floor and faints in the arms of a nurse, who carries him onto a gurney and rushes him into an adjoining room.

After thirty minutes, the director of the clinic emerges and introduces himself as Dr. Luis Cuellar. He looks over at the wailing grandmother and says to me in English, "He is only 15, so sad."

Dr. Cuellar explains that, like PROSA, all of the funding for his clinic comes from a foreign country, which in this case happens to be the Netherlands. He is one of seven doctors on staff who volunteer their time each night after they have completed their rounds at the nearby government hospital.

"Please tell your people in America," he says. "We each see twenty or more patients each night. That might sound like many, but those are only the ones who are able to gather the courage to come here. It is nowhere near the number of people who are sick that we couldn't even begin to help."

I ask him where they get their medication, and he informs me that it is all purchased with money the doctors donate from their own meager salaries.

"You can get AZT at pharmacies here with no prescription, but everyone is afraid to take it. You see, there is a severe nutrition problem in Peru. Most people can't tolerate the drug, even in the smallest of dosages. In addition, tuberculosis (TB) is rampant in our city. We are constantly being exposed to TB. Since our digestive systems can't handle AZT, most people prefer not to risk the chance of the drug making their systems weaker. Most AIDS cases in Peru list the cause of death as TB, not *Pneumocystis* or KS. Roughly 40 percent of all my cases are here because of TB. We are just overwhelmed, and I go home every night feeling hopeless."

As we get ready to leave, he slips me his card and asks me to tell my friends in the U.S. to send money, clothing, vitamins, anything that they can spare. "We have so little that we have less than nothing."

The lobby is now jammed with people: Young, old, male and female. Open places to sit are at a premium. The receptionist makes a valiant attempt to maintain some semblance of order. Outside of the clinic, I have to push past a line several persons deep just to make my way to the curb. I have never seen such a large crowd at any AIDS clinic in the United States, not even in New York City or San Francisco, and I am deeply depressed by the sight of so many people clamoring for help. As we make our way back to Eduardo's car, he turns to me and says plaintively, "It's worse than I told you, isn't it."

It is a statement, not a question, and he is right. It is worse than I ever imagined. And it is with an enormous amount of frustration that I realize I have no idea where or how to start helping him. There are many kinds of privilege in this world, including the privilege of wealth, of status, and of sanctimony. I have the privilege of escape. Sooner or later -- too soon in any case -- I will return to a land of clean state-of-the-art hospitals, well-funded and organized support groups and prescriptions filled on demand in 24-hour-a-day drug stores. I will hear complaints of slow medical service, of callous bureaucrats, and of exorbitant pharmaceutical prices. And my sympathies will lie elsewhere because I will be reminded of Eduardo, waiting in endless lines for a few precious moments with an overwhelmed physician in a shabby clinic lit by the glow of a single bulb.

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