Plenty of Nothing

No drugs, no care, no support for Nicaragua's PWAs

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The trip from San José, Costa Rica, to Managua, the Nicaraguan capital, takes only an hour by plane, but crossing the border is like traveling back in time. Decrepit taxi cabs, at least two decades old, creak along rutted roads. Thousands of squatters from the countryside live in abandoned houses with crumbling walls and huge rats. There is very little activity even in the downtown area compared with cities in more vibrant Central American countries such as Panama.

One of the world's most troubled nations, Nicaragua has been struggling for years to overcome the devastating effects of a series of natural disasters, including a massive earthquake that leveled Managua in 1970, not to mention more than two decades of political strife marked by covert U.S. military intervention against the former socialist Sandinista government. Although the Sandinistas lost power in 1990 and the United States withdrew from the scene, two successive governments have been largely ineffectual and the country remains poor and isolated.

Life here, especially for people with HIV, is, as Thomas Hobbes once said about pre-industrial England 300 years ago, nasty, brutish and short. It is abundantly clear that the treatment revolution that has restored the health of many U.S. PWAs has touched Nicaragua not at all. With little hope of receiving therapy for opportunistic infections (OIs), let alone antiretroviral medications, people with HIV have no alternative but to live with the virus as best they can for as long as they can.

In Nicaragua it's even hard to come by accurate basic information about the epidemic—number of AIDS cases, HIV infections, transmission rates. According to government statistics, there have been only 170 diagnosed cases of AIDS. But nearly every independent observer agrees that hundreds, if not thousands, more go unreported. Health care officials estimate that a minimum of 5,000 Nicaraguans have the virus, although it is impossible to know for sure because no testing procedures exist. Many Nicaraguans leave the country to find work elsewhere in Central America, where the per capita rates of infection are often higher, and some return with HIV. In the two nations bordering Nicaragua—Honduras and Costa Rica—reported AIDS cases total more than 10,000 and 1,400, respectively.

Dr. Roberto Pao, the coordinator of the government's AIDS Control Department, acknowledges that for PWAs prospects are bleak. In fact, AIDS tops a list of conditions—-including some forms of

cancer—-that are entirely excluded from both public and private medical attention. Pao points out that neither the government-run health care system, which has scarce funding, nor the private insurers that provide coverage to many of the country's employed, are required to help people with HIV. Hospitals routinely refer PWAs to nongovernmental organizations (NGOs) for assistance. There is no hospice in the country for men who have AIDS; a small church-funded program for women, which houses all of four, recently opened.

But need breeds ingenuity. It is common practice for a PWA seeking medical attention for, say, Pneumocystis carinii pneumonia (PCP), tuberculosis or some other OI to hide his or her HIV status from health officials. This is easier in Nicaragua than in many countries because hospitals and clinics do not routinely test patients for HIV (donated blood is screened). CD4-cell counts and viral load tests are unheard-of, so the HIV positive have no way of calculating disease progression other than by gauging how they feel from day to day. One PWA, 28-year-old Sergio, offers this despairing confirmation: "I feel completely hopeless. I can't get the tests I need to find out how advanced my AIDS is and I can't get the medications I need or will need, and I make $130 a month."

The burden of providing medical care falls to the few functioning NGOs. One, the Xochiquetzal foundation, serves a variety of disadvantaged populations. Its budget is provided largely by the Dutch government, and its program mandates focus on trying to improve the overall human rights conditions of women and sexual minorities, as well as for PWAs. Xochiquetzal, which is named after the Aztec god of love, operates Managua's sole AIDS support group, but only about a dozen people attend regularly.

Xochiquetzal's director, Hazel Fonseca, says that her chronically underfunded organization is often unable to provide even the most basic services for PWAs. It tries to buy medicines to combat OIs, using fees from the few patients who pay a nominal sum. But in all of 1997, just $7,000 was collected for this program. The agency does not even attempt to buy antiretrovirals, which are unavailable.

Despite such appalling conditions, there has been scant sympathy in Nicaraguan society for people with HIV, most of whom are already marginalized because they're poor, gay men, women or IV drug users. Nicaragua remains a conservative country, dominated by the Roman Catholic Church and characterized by a "macho" culture. Women have few rights, and homosexuality is against the law, thus further stigmatizing those with HIV and stymieing prevention efforts.

The public message transmitted to PWAs is distinctly disempowering. AIDS is viewed as an inevitably fatal disease that must be accepted passively by those whose activities—illicit sex or drug use—led to infection. In church, school, hospital and home, PWAs are constantly reminded, "Be a 'good victim' in order to receive what mercy we will bestow upon you."

Oddly, the Nicaraguan legislature passed a seemingly progressive law in December 1996 meant to codify the rights of Nicaraguans with HIV. Drafted and lobbied for by the local human rights NGO Nimehuatzin ("stand up for a noble cause"), the law guarantees access to adequate medical

attention and counseling, and it prohibits discrimination in employment and education. But Rita Arauz, Nimehuatzin's director, says that the law exists only on paper and discrimination remains rampant.

The 1996 election of President Arnoldo Alemán Lacayo initially promised improvements for Nicaraguan PWAs, as the AIDS anti-discrimination law indicated. But, as the law's ineffectiveness proves, the president has shown little interest in AIDS issues. Instead, he is focused on stimulating economic growth by privatizing government agencies, including the national health care system. While such developments may prove disastrous to the nation's already-precarious health care, they are likely to be of little consequence to PWAs, who by now are used to the government ignoring them.

One of the most disturbing aspects of this situation is the lack of any movement by PWAs on their own behalf. The PWAs in Xochiquetzal's support group—who would only speak anonymously—show no willingness to organize to obtain better medical care, even though self-empowerment movements are growing in other Central American nations. Few Nicaraguan PWAs even know about protease-based combination therapy. Most do not speak out because they fear being ostracized by their families, friends and employers.

Nothing better exemplifies the skewed priorities surrounding AIDS in Nicaragua than a 1995 seminar sponsored by the World Health Organization and the Panamanian Health Organization. The two groups spent $159,000 for the conference, held at a luxury oceanside resort in Montelimar. The seminar reportedly was dominated by religious groups whose leaders only support HIV prevention measures based on abstinence and monogamy. The shoestring-budget NGOs were able to secure neither money nor commitment to establish better systems of care, treatment or prevention. Nimehuatzin's Arauz sadly and angrily predicts that in the face of such conservative intransigence, Nicaragua faces an explosion of HIV cases for many years to come.

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