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Poor HIV/AIDS Monitoring

by LADB Staff

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[The author is a staff writer for Inforpress Centroamericana/Central American Report, published in Guatemala.]

A 2000 law requires the Instituto Guatemalteco de Seguro Social (IGSS) to provide anti-retroviral drugs to its members. However, IGSS only covers about 17% of the Guatemalan population and, with a rising number of AIDS cases, IGSS is depleting its infectious-disease budget by buying high-cost, brand-name medications. People with AIDS not covered by IGSS must pay for the medicines out of pocket an impossibility for most Guatemalans or rely on extremely limited medicines purchased by the government or donated by nonprofit organizations.

At the Clinica Familiar Luis Angel Garcia, one of the two major AIDS clinics in Guatemala City, patients are mostly treated for opportunistic infections that come from a weakened immune system. The AIDS-specific medicines that are provided are small donations from a US-based recycling program for unused AIDS medicines. The average income of AIDS patients at the clinic is US\$100 per month, about one tenth the monthly cost of anti-retroviral treatment.

Official statistics are unreliable

Most experts said that government AIDS statistics were dramatically understated and that HIV incidence is one of the highest in Latin America. Official statistics show 4,400 reported AIDS cases in Guatemala since 1984.

"We are now where Africa was ten years ago," said Dory Lucas Alecio, director of the Ministry of Health's Programa Nacional de Enfermedades Transmitidas Sexualmente VIH y SIDA. Lucas said that not all cases are reported. The Programa Nacional estimates about twice as many cases. Other experts insist the real figures are much higher and say there are significant holes in the reporting system.

A Guatemalan epidemiologist said official figures could be problematic. "The system here is passive, not active," said the doctor. "If a departmental hospital does not send in a report each month, AIDS cases are not reported. There's no follow-up. With other diseases, like cholera, [the Ministry of Public Health] actively gathers data and sends it by fax." Lucas says the program does follow up, but calls to some regional hospitals revealed that the Programa Nacional's cumulative March 2002 statistics were consistently lower than the data regional hospitals reported, sometimes by as much as 40%. IGSS, which covers less than one in five Guatemalans, reported 356 new AIDS cases in 2001.

Using conservative estimates, this caseload extrapolates to 2000 new cases in the last year, or more than four times the national system's reported total of 439. This is not a true epidemiological calculation, but it suggests the inadequacies of the national reporting system. Data provided by

individual hospitals suggest that even data they do send to national officials sometimes are excluded from official statistics. The San Juan de Dios Hospital reported 281 new AIDS cases in 2001. Added to IGSS's 356 new cases, this results in 637 new AIDS cases in 2002. Thus, in just the IGSS system and one additional urban hospital, the number of new cases exceeds the Programa Nacional's official total for the entire country by 45%.

In response, the Programa Nacional said IGSS failed to report their 2001 cases. Inclusion of the IGSS figures, which the Program Nacional says is forthcoming, would increase the 2001 totals for new AIDS cases by 81%. Taken together, data suggest the Programa Nacional's claim of a 50% underestimation of AIDS cases is itself an underestimation. IGSS data show a rapid growth of new patients. From 1986 to 1999, there was a total of 462 AIDS cases in the system, an average of 33 new cases yearly.

In 2000, that grew to 296 new cases, and in 2001 to 356. In Central America, only Honduras has reported more AIDS cases. Similarly, doctors at the national hospital in San Marcos, a rural department in western Guatemala, say they have seen an explosion in cases in the last two years and estimate they have at least one new HIV-positive patient per week.

No systematic tracking of HIV

Perhaps the most serious problem is a lack of data on the incidence of HIV, the virus that causes AIDS. Although the Ministry of Public Health keeps records of AIDS cases, it does not track HIV. After infection with the virus, disease progression can take from four to ten years. This means the number of AIDS cases reflects the dynamics of the epidemic years ago. Experts say HIV statistics are vital to understanding the current state of the epidemic.

How many HIV-infected individuals are there in Guatemala? Estimates made in collaboration with epidemiologists and the UN AIDS program (UNAIDS) suggest that 1.4% of the Guatemalan adult population, ages 15-49, was infected with HIV at the end of 1999. This is one of the highest rates in Latin America, though not as high as in some Caribbean countries or in Africa. These figures conflict with those of the Guatemalan government. While UNAIDS projected about 70,000 HIV-positive people at the end of 1999, the Ministry of Public Health estimates 40,000 HIV cases, or 0.4% of the population.

Lucas said the HIV/AIDS epidemic is still a "low-level epidemic." But again, these calculations are partly based on underreported national figures. The discrepancy comes partly from a lack of reliable data. There is no systematic monitoring of HIV at any one place from year to year. Instead, the Programa Nacional has relied on a small number of sentinel studies that measure infection rates in small samples. Lucas says a collaboration with the US Center for Disease Control (CDC) will work to develop a better surveillance system, but it will not be ready until mid-2003.

"What bothers me the most," said Blanca Samayoa, professor of Epidemiology at the University of San Carlos, "is not having data on HIV." So, is underreporting causing authorities to take the epidemic less seriously than they should? Though Lucas compares Guatemala today to Africa ten years ago, the statement is less a doomsday forecast than the recognition of an opportunity to

combat the epidemic. The debate seems to be on whether HIV is restricted to isolated, high-risk groups (gay and bisexual men and sex workers) or is beginning to spread to the general population.

A UNAIDS report states that, in Central America and the Caribbean, HIV "is mainly heterosexually transmitted, with unsafe sex and frequent partner exchange" as forces in the spread of the disease. Samayoa said this observation is reflected in the changing composition of patients the Clinica Familiar Luis Angel Garcia sees. The first patients were mostly male, but the clinic now serves more women than men, suggesting that any restriction to the gay community has been outpaced by HIV's spread throughout the population at large.

Lucas and gay-rights organizations argue that, although women now comprise a growing percentage of cases, bisexual partners may have infected them. Lucas said it is hard to categorize means of transmission "because there is not a culture [in Guatemala] of appropriating homosexuality as an identity."

Dr. Ruben Mayorga, executive director of the Guatemalan HIV/AIDS organization OASIS, says he believes HIV in Guatemala is concentrated in high-risk groups and prevention strategies should focus on those groups. "In no Latin American country, except Brazil, Chile, and Mexico, has more than 5% of the total prevention budget been spent on targeting high-risk groups," said Mayorga. "The prevention campaign I have seen is signs that say 'have you talked with your family about AIDS?' And one doesn't know what follows. You can talk with your family and reproduce all the prejudices and not advance AIDS prevention."

Despite differences about the focus of prevention efforts, an unusual alliance has sprung up between activist organizations and Programa Nacional personnel in interpreting Guatemalan HIV statistics. Both groups tend to use lower estimates than do the UNAIDS program and doctors in local clinics. Activist organizations worry that exaggerated numbers of AIDS cases will keep government officials from assigning budgets for combating the disease, said Richard Stern, director of Agua Buena, a Costa Rican human rights group doing AIDS-advocacy work. If the problem is portrayed as too large, governments will consider it hopeless and not spend money to address it.

Lucas says the Guatemalan AIDS program "has to be very careful strategically." She said Guatemalans do not understand spending a large amount of money on a disease stigmatized and viewed as the fault of those infected. Whatever the truth behind the numbers debate, even the lowest estimates of HIV infection will press the limits of the health care system in the coming years, as HIV-infected individuals develop AIDS.

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