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Latin American Women Suffering from HIV/AIDS Battle Prejudice and Discrimination

by Louisa Reynolds

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Flora, a 50-year-old Guatemalan woman, knew that her husband was terminally ill. For three years, she had been aware that he was taking medication but never knew what his bottles of variously colored pills contained until two days before he died in hospital, when the doctors took her blood sample and she was diagnosed with HIV.

"I had never had intercourse with anyone else. He told me, 'I'm going to die, and you will too.' The doctors found out what was wrong long before I did," Flora says.

Flora was one of the 57 HIV-positive women interviewed as part of the study "Our Stories, our Words: The Situation Faced by Women Living with HIV in 14 Latin American Countries," published in May by the Movimiento Latinoamericano y del Caribe de Mujeres Positivas (MLCM+).

Researchers from MLCM+ talked to women from Argentina, Bolivia, Brazil, Chile, Colombia, Cuba, Ecuador, Guatemala, Mexico, Panama, Paraguay, Peru, Uruguay, and Venezuela, all between 20 and 79 years of age, using semi-structured interviews that included questions related to their social and ethnic background, how they discovered they were HIV positive, how they had managed their illness, its impact on their family life, relationships, and work, and other issues such as violence and discrimination.

Most interviewees fell within the 18 to 29, 30 to 39, and 40 to 49 age groups, and only nine of the 57 women interviewed lived in rural areas. Eleven were indigenous, six were mestizo, three were of Afro-Caribbean descent, and the rest did not identify themselves as part of a specific ethnic group.

To protect their right to confidentiality, their real names were not recorded. This is the first time that this kind of study has been carried out in Latin America.

More than 25% of the women interviewed, like Flora, found out they were HIV positive after their partner became ill or died of AIDS, which led to feelings of denial and disbelief. With the exception of three interviewees who attributed their illness to drug use and four women who were raped by strangers, all had become infected during heterosexual relationships with long-term partners.

**Discrimination at home and in workplace**

Many women interviewed spoke about how their illness had led them to feel stigmatized, as most people, including family members, the doctors treating them, colleagues at work, or teachers and parents at their children’s school, associated HIV with sex work or "promiscuity."

Marcela, 32, from Bolivia, worked as a kitchen assistant in a small restaurant. After one of her colleagues revealed the nature of her illness, Marcela was fired, even though she had never been late for work. Her bosses never explained the reason she had been made redundant, though she suspected it was because she was HIV positive.
"My older brother marked a set of kitchen utensils so that only I would use them, and my mother used to say that my illness was God’s way of punishing me for my bad behavior," said Carmen, 35, from Venezuela.

Most women interviewed said that they had suffered a loss of sexual desire because of feelings of guilt or shame, or from the weakening effects of antiretroviral drugs. Most had been told by health workers that they had to use condoms to avoid infecting sexual partners, but their partners often refused to have protected sex.

"I was afraid of having sex and infecting my partner because we are always made to believe that women are the source of the virus. The problem is that, when you tell a man to use a condom, he always asks why," said Clara, 42, from Bolivia.

Sixty seven percent of the women interviewed had suffered physical, psychological, or sexual violence during their lives, either during their childhood and adolescence or in their relationships, a situation that was worsened once their condition was revealed.

"My last partner used to insult and hit me. He called me an 'AIDS-infested nigger' and said that I ought to be grateful that he wanted to have sex with me," said Marta, 42, from Colombia.

Interviewees described misogynistic relationships in which their partners refused to have protected sex and decided when and how often intercourse would occur.

**Deficiencies in access to health care**

Many women said that they were often forced to travel for several hours to the nearest hospital to receive treatment and that transportation costs had exacerbated their poverty. Others, such as Cinthia, 25, from Bolivia, said that they had stopped receiving treatment because the hospitals had run out of antiretroviral drugs.

Other women abandoned their treatment because they felt unable to cope with lypodystrophy, a medical condition characterized by abnormal or degenerative conditions of the body’s adipose tissue, one of the most common side effects associated with antiretroviral drugs. Only Brazil has a specific government policy on treating this particular condition.

Most women interviewed had been subjected to prejudice from health workers. "One day I was crying, and the doctor said, 'Why are you crying? If you hadn’t slept with so many men you wouldn’t have this illness.' That was completely untrue, but I was too upset to answer back, and I just cried in silence," said Clara, 42, from Bolivia.

Many interviewees were tested for HIV/AIDS without their prior consent and very few of them received any counseling before they were informed of their condition.

Health workers often stigmatized them. "When they realized that I was HIV positive, they put on gloves and two white coats. 'What's wrong with me? What have I got?' I kept asking, but they said nothing. They pulled the bed covers off me and put them in a plastic bag as if I had the plague. I kept asking what was wrong with me, and a nurse burst into tears and hugged me and said, 'You're going to live, you’ll see.' The last thing that crossed my mind was that I could have AIDS. Then, I was taken out of the ward and left in the corridor, wrapped in a nylon sheet because they said that my illness was too contagious and that they didn’t know where to put me." This is how Clara described the stay in hospital during which she was diagnosed.
Many women reported that they were refused medical attention by gynecologists and dentists and that some doctors explained that because of their illness they were forced to wear two pairs of gloves as a precautionary measure.

Even though, if properly handled, HIV is no longer an obstacle for a normal and healthy birth, most interviewees were strongly advised against getting pregnant and some were forcibly sterilized.

The report’s final recommendations include the creation of gender-specific policies on the treatment of HIV/AIDS patients, the participation of HIV-positive women in public policy, information, and awareness-raising campaigns to fight stigma and prejudice, and the development of employment programs for HIV positive women.

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