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REPRODUCTIVE RIGHTS VIOLATIONS REPORTED BY MEXICAN WOMEN WITH HIV

Tamil Kendall

ABSTRACT

Demand for reproductive health services by people with HIV is increasing, as is the urgency of protecting and promoting their reproductive rights. The reproductive rights of Mexicans with HIV are formally protected by the constitution and by health and anti-discrimination legislation, as well as by international conventions. However, the reproductive rights of women with HIV continue to be violated in public clinics and hospitals. This paper discusses three violations identified as priority problems by Mexican women with HIV, illustrating these problems with cases identified during a participatory skills building workshop. The violations cover the following rights: the right to non-discrimination, the right to adequate information and informed consent to medical procedures, and the right to choose the number and spacing of children. Physicians can either violate or promote reproductive rights. Unfortunately, in many instances Mexican physicians continue to perpetrate reproductive rights abuses against women with HIV. Collaborations between women with HIV, civil society, government, and international organizations are needed to educate and sanction health care providers and to support women with HIV in their pursuit of reproductive rights. Demanding accountability from health care practitioners and the State to guarantee reproductive rights in countries where these rights are formally protected will improve the quality of life of people with HIV and can demonstrate that rights-based approaches are compatible with and, indeed, crucial for public health.

INTRODUCTION

There are about 33 million people living with HIV around the world. Half are women, and the vast majority are of reproductive age. Indeed, one of the outstanding tendencies of the HIV pandemic is that it increasingly affects young people, with 45% of new infections occurring among people 15 to 24 years of age. In Mexico, there are approximately 180,000 people with HIV, of which 50,000 are women of reproductive age.¹ Numbers alone make the reproductive health and rights of men and women with HIV an important global and domestic health and rights issue. Yet perhaps just as urgent, at a time when lawmakers are developing and promulgating laws that criminalize HIV transmission and exposure in the name of public health, is the need to defend the reproductive rights of people with HIV in response to the epidemics of stigma and discrimination.² Governments and health care systems must improve their responsiveness to the reproductive needs of people with HIV to meet their national and international commitments to reproductive rights and to promote the health of their populations.

Reproduction is widely regarded as a key element of transition into adulthood, with its related gender expectations, in cultures around the world, including Mexican culture.³ Unsurprisingly, studies from high-income countries conducted since the advent of highly active antiretroviral therapy (HAART) have found that men and women of reproductive age with HIV express the same desires for children as the general popula-

tion.⁴ Research in some African countries has found the fertility of women with HIV to be broadly similar to that of the general population, both in the pre-HAART era and with the greater availability of antiretroviral treatment.⁵

Studies in low-, middle-, and high-income countries associate the desire for children among HIV-positive people with subjective perceptions of good health, younger age, being in a stable heterosexual relationship of shorter duration (two to five years depending on the country), and having fewer children (not having attained lifetime fertility goals).⁶ Around the world, people with HIV say they want children to fulfill a culturally valued and socially validated role: parenthood.⁷ Antiretroviral treatment and knowledge of and access to interventions to prevent vertical (mother-to-child) HIV transmission are perceived as important supports for pursuing reproductive life goals.⁸ Although quantitative research on reproductive intentions or behavior of people with HIV in Mexico is not available, qualitative research suggests that some Mexican men and women with HIV desire children, particularly if they are childless.⁹

Reproductive rights and the prohibition of discrimination due to health status are explicit in Mexican legislative frameworks and in various international conventions signed by Mexico. The Mexican Constitution specifically forbids discrimination based on health status.¹⁰ The Mexican General Health Law states that family planning services are “a means for every person to exercise their right to make free, responsible and informed decisions about the number and spacing of their children, with full respect for their dignity.”¹¹

Moreover, the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW), a binding treaty ratified by Mexico in 1981, guarantees women’s rights to “decide freely and responsibly on the number and spacing of their children and to have access to the information, education and means to enable them to exercise these rights.”¹²

Mexico has a longstanding and successful national family planning policy and offers extensive access to a number of reproductive health care services. In 2005, 91% of pregnant women attended prenatal care, and 93.4% of women were attended by a physician during labor and birth.¹³ However, challenges related to timely access to a comprehensive contin-

uum of care, the poor technical quality of diagnosis and intervention, and failure to respect women’s right to self-determination in making reproductive choices persist.¹⁴ Reproductive rights violations by health care providers have been identified in the delivery of Mexican public health services. These violations include misinforming and coercing women to adopt birth control methods preferred by providers and verbal abuse toward women who do not conform to providers’ preferences about the number of children or the “right” way to behave during labor.¹⁵ Clearly, it is not only Mexican women with HIV who experience reproductive rights violations in the context of Mexican public health care; however, the abuses discussed below occurred after the HIV diagnosis, were perpetrated by physicians working in public hospitals who knew the woman’s diagnosis, and were perceived by the women as HIV-related discrimination.

Most international human rights instruments predate the HIV epidemic and do not specifically address the reproductive rights of people with HIV.¹⁶ Interestingly, Mexico pioneered recognition of the sexual rights of people with HIV. In 1992, in collaboration with three nongovernmental organizations (Mexicans Against AIDS, GIS-SIDA, and the Fund for Community Health), the National AIDS Programme published a declaration that recognized that HIV and AIDS should not be an impediment to exercising one’s sexuality.¹⁷ However, despite recognizing the sexual rights of people with HIV and reproductive rights generally, recognition of the reproductive rights of people with HIV by Mexican policy makers has ranged from circumspect to ambivalent. The 2002 revision of the Declaration of Human Rights of People with HIV published by Mexico’s National Human Rights Council mentions the “right to a family” rather than the more specific and concrete right to choose the number and spacing of children.¹⁸ The 2007 guidelines for delivering antiretroviral treatment at public health institutions, which warn health care providers that violation of the rights listed contravenes national and international agreements and norms, truncates reproductive rights by deleting the right to “a family” and only mentioning legal guardianship with reference to parenthood by people with HIV.¹⁹ As the number of people living with HIV in Mexico has increased, so too have the absolute number and proportion of women infected.²⁰ Consequences of this increase include a growing demand for reproductive health services among women with HIV and the urgent need to protect

reproductive rights. In this paper, I argue that despite formal protections for reproductive rights in the legal ideals expressed from the theoretical “firmament” of the Mexican Constitution and international conventions, down in the “trenches” of front-line health care delivery, many physicians are overtly hostile to HIV-positive women’s reproductive rights.

METHODS

This paper is based on 1) the experiences shared by women with HIV during a training session on sexual and reproductive rights that was held in February 2007, 2) the declaration presented at the press conference that concluded this training, and 3) the previously unpublished conclusions of the Women’s Roundtable from the 2007 National Citizen’s Forum on HIV and AIDS. This forum was hosted by Mexico’s National AIDS Program (CENSIDA) in Guadalajara Jalisco in November 2007 to generate a consensus on priorities for HIV prevention and care as input for the 2007–2012 National Action Plan on HIV and AIDS. The Women’s Roundtable brought together 25 activists (mostly women with HIV), health care providers from public institutions, and representatives of international organizations. During both meetings, rapporteurs took notes, and participants generated conclusions that were presented publicly at the events’ conclusions. The author participated in both events and analyzed these written documents for this paper. The specific cases of rights violations discussed here illustrate common problems that were identified during both meetings.

The cases were documented during the three-day training workshop to increase the capacity of women with HIV to act as reproductive rights advocates. The training was sponsored by the United Nations Population Fund (Mexico Office) and was facilitated by the Mexican nongovernmental organization Colectivo Sol in February 2007. Sixteen HIV-positive women from northern Mexico (Nuevo Leon, Aguascalientes, Sinaloa, Tamaulipas, and Nayarit), central Mexico (Guanajuato, San Luis Potosi, Mexico State, and Mexico City), and southern Mexico (Chiapas and Yucatan) participated. The women were invited to participate because of their leadership and advocacy activities on behalf of women with HIV.

The workshop included lectures by sexual and reproductive rights experts, participatory exercises to define and exemplify basic concepts in sexual and

reproductive health and to identify issues specific to women with HIV, and skill-building exercises in peer counseling and documenting human rights violations. To practice documenting human rights violations, the women with HIV used a standardized form to describe in writing instances when their human rights had been violated; women with limited literacy skills dictated their experiences of rights violations to their peers or the workshop facilitators. It has been recognized that documenting rights violations in this way provides peer support, which can increase comfort with disclosing sensitive information and allows women to immediately check the account, ensuring the validity of the representation of the event from her perspective.²¹ Yet relying on written accounts is also a limitation, in that the author was unable to elicit additional details from the reporting individuals about the rights violations and the contexts in which they occurred.

During the workshop, after the women had shared with the large group instances of rights violations, the author requested permission to analyze and publish these cases of reproductive rights violations, using pseudonyms and omitting identifying information to ensure confidentiality. The women’s accounts of reproductive rights violations were then translated by the author from Spanish to English. Admittedly, there is a selection bias in these accounts because the women with HIV who shared the accounts received specific information about their reproductive rights, and consequently identified these violations, while many other Mexican women, both those living with HIV and those who are not, can suffer reproductive rights violations without identifying them as such and may even naturalize or normalize reproductive rights abuses.²²

FINDINGS AND DISCUSSION

The reports suggest that the ability of women with HIV to exercise their reproductive rights was severely constrained by the attitudes and actions of health care providers. The specific reproductive rights violations discussed below include 1) the right to non-discrimination in health services, 2) the right to adequate information and informed decision making, and 3) the right to choose the number and spacing of one’s children.

The right to non-discrimination in health services

The Mexican Constitution prohibits discrimination on the basis of health status, and the 2003 Federal Law to Prevent and Eliminate Discrimination dic-

tates measures to guarantee access to medical care and social security, including both negative and positive guarantees of access to reproductive health care.²³ National guidelines for HIV prevention and care emphasize that health care providers cannot discriminate against people with HIV.²⁴ Yet the reported experiences of Griselda and Carmen illustrate how these women were constructed as posing a threat to the health of others by their physicians because of their HIV-positive status and were required to meet special and discriminatory conditions in order to receive medical services.

When Griselda, a 29-year-old woman with a stable partner also living with HIV, requested a pregnancy test because her menstruation was late, her physician responded with insults and threats:

The doctor said: How can you even think about getting pregnant knowing that you will kill your child because you're positive?!!! He threatened not to see me again if I got pregnant. He told me that I was "irresponsible," a bad mother, and that I was certainly running around infecting other people (public hospital, 2006).²⁵

Griselda's physician's opposition to her becoming pregnant and his blatantly discriminatory comments about her ability as a mother and her sexual behavior reveal an underlying belief that as an HIV-positive person, she poses a threat to others. His statement that she would "kill" her child should she become pregnant is medically incorrect — HAART is provided free of cost in Mexico independent of whether or not the person with HIV has health insurance, and the national guidelines for providing antiretroviral treatment mean that if a woman knows her HIV diagnosis before becoming pregnant or receives a positive diagnosis during pregnancy, the probability of mother-to-child transmission is minimal, in practice less than 2% among Mexican women who receive the medical interventions recommended by the national guidelines.²⁶ Potential harm to the child is an ethical issue to be considered by women with a range of health conditions that may have an impact on pregnancy outcomes and child health, including HIV. Health care providers may play a valuable role in supporting women, as they enable women to address the issue of possible harm by providing accurate information about potential risks. Nevertheless, the rights

to exercise autonomy over family size and to live free from discrimination based on health status are fundamental rights recognized in national and international legislation. In addition to violating Griselda's rights to non-discriminatory health services and to choose the number and spacing of her children, the physician's attitude and threat to withdraw medical services obstructed her right to benefit from accurate information and scientific advances. The actions of this physician are also a barrier to implementing optimal medical interventions that would prevent vertical HIV transmission and would promote Griselda's health and that of any future children.

Carmen faced similar discrimination from her physician when she sought treatment for cervical dysplasia, a precursor of cervical cancer:

After examining me, the doctor said the dysplasia hadn't responded to medicine or surgery. I said that it must be because of "what I have." He asked: "what do you mean what you have?" [I replied,] "HIV." He got angry: "How dare you not tell me your diagnosis? Don't you know that we use the same instruments for all the patients? We only wash it with bleach and bleach doesn't kill all bacteria." That day, they cancelled all the appointments after mine. The doctor said that when I returned for treatment, I had to tell him that I live with HIV and bring a disposable speculum. Even when I arrive early and bring the disposable speculum, they leave me until last. Since then, there is a barrier between me and that doctor. I went to the appointments, he came in very serious, and the first thing I said is "I have HIV." So, I stopped going, they weren't treating the dysplasia, and now I don't know how I am (public hospital, 2005).

The physician's misdirected anger at Carmen for not disclosing her HIV status because they "only wash [instruments] with bleach" is apparently based on an erroneous belief that bleach is ineffective in preventing HIV transmission; while not ideal, washing with bleach is an effective method to kill the virus and eliminates the possibility of HIV transmission. However, the physician's comment serves to highlight how ignorance among health care providers and insuf-

ficient supplies to implement universal precautions, such as latex gloves and sterilizing equipment, can contribute to a vicious cycle in which social stigma and lack of institutional protocols and infrastructure reinforce each other. Shalini Bharat and Vaishali Sharma Mahendra rightly argue that to improve respect for the reproductive rights of people with HIV, a rights-based agenda needs to be extended to providers as well by providing adequate training and access to the materials and equipment needed for them to protect themselves and their patients from HIV infection.²⁷ Mexican primary health care providers often lack gloves and masks, while in secondary and tertiary hospitals, the needed materials are generally available but the high number of patients and rapid rhythm of work incite providers to ignore universal precautions, unless they know that the patient is living with HIV.²⁸ Increased awareness about the need for universal precautions and insistence on creating the conditions for their implementation by health care providers will reduce transmission of a wide range of diseases in addition to diminishing HIV-related discrimination that stems from differential treatment of people with a known HIV diagnosis. It is important to foster an institutional culture of universal precautions. Yet, in Carmen's case, it is notable that in the end it was not material factors (bringing her own speculum) but social mistreatment (being seen last, facing the humiliating ritual of declaring her HIV status to the physician at every visit, and the perceived "barrier" to communication after disclosing her HIV status) that resulted in her abandoning treatment.

Both the Citizen's Roundtable and the Declaration that arose out of the sexual and reproductive rights training generated a consensus on the need to eradicate discrimination by gynecologists toward women with HIV and that this take place through training and through monitoring and evaluation by committees that include HIV-positive women. In addition, both the Roundtable and the Declaration concurred on the need to prioritize the diagnosis and treatment of sexually transmitted infections in women with HIV.

The right to information

National and international conventions and legislation emphasize the importance of education and information as the foundations for effective exercise of reproductive rights. Hilda's experience illustrates how physicians' autocratic communication and decision-making styles and deficient medical knowledge,

or outright negligence, threaten women's reproductive rights:

She [the physician] prescribed Truvada. I had heard that there were medications that caused harm, so before I took them, I asked. I went to the civil society association, and they told me that Truvada could harm me and my baby. At the association, they called the laboratory that makes it [Truvada] and they confirmed that a pregnant woman should never take Truvada because it causes [congenital] malformations in the baby and harm or even death in the mother. I went back to the hospital to tell the doctor so that she could change the medication. I even brought her printed information. But she got really angry. She told me that all of the doctors from the State met to decide how to care for me and that they had agreed that the best option for me and my baby was to give me Truvada, and that I should take the medication that she had given me. She didn't want to change the medication at that time. After that, the laboratory called the hospital. The hospital called me and told me not to take the medication that they had given me, and to come in [for an appointment]. I went, but the doctor didn't see me. Instead, her assistant gave me a different regimen (public hospital, 2005).²⁹

Dialogue is a precondition for informed decision-making. Hilda's experience demonstrates how highly stratified social relations between physicians and patients can violate a patient's right to information and prevent patient-physician communication when people with HIV know more than their doctors and when the physician's response results in violations of the right to health. Hilda's story also indicates steps that can promote respect for reproductive rights such as education of people with HIV and the creation of multisectoral support networks. Hilda's knowledge, gleaned through contact with a nongovernmental organization, meant she knew about the danger posed by some antiretrovirals during pregnancy. She received support from civil society and a pharmaceutical company in her quest to get her antiretroviral regimen changed.

The right to choose the number and spacing of children

The right to choose the number and spacing of children is clearly and concretely articulated in Mexican legislation and in binding international conventions to which the nation is party. Nonetheless, a survey of Mexican health care providers conducted in 2003 found that 59% of respondents felt that women with HIV should be prohibited from having children.³⁰ The effects of such discriminatory attitudes on women with HIV are highlighted in Maria's story:

I was 24 years old, and I wanted to get pregnant. A month after conceiving, I went to the gynecologist. The doctor criticized me, he said I was irresponsible. They examined me, and then the doctor told me that there was a problem, that [the pregnancy] wasn't possible and that they had to perform an abortion right away. They gave me a paper to sign. I was really sad and confused. I kept on thinking about getting pregnant, but it didn't happen. So after a year, I asked a different doctor why I hadn't gotten pregnant. He looked at my medical file and said: "How are you going to get pregnant? You're sterilized, you can't have children" (public hospital, 2005).

Maria was denied her right to choose the number and spacing of her children. Sterilization is obviously an inappropriate contraceptive method for a 24-year-old woman with a stated desire to have children. Maria's case highlights that complying with bureaucratic formalities is not sufficient to ensure informed consent. It is probable that Maria consented to both the abortion and the tubal ligation by signing the piece of paper presented to her when she was told she needed to have an abortion, *but she did not know that she was doing so*. Without access to Maria's medical records, it is impossible to determine whether or not there was a medical reason for terminating the pregnancy. However, the physician's discriminatory assessment of Maria as "irresponsible" for wanting a child despite living with HIV and his unilateral decision to remove her reproductive capacity suggest that he was motivated by his own stigmatizing beliefs and paternalistic attitudes. Shamefully, Maria's experience of coercive abortion and sterilization without true informed con-

sent is echoed in the international literature by the experiences of other HIV-positive women.³¹ Faced with these realities, women with HIV in Mexico have demanded training for health care providers so that they "understand the true meaning of informed consent, and don't reduce it to a signature, without the person understanding the type of intervention or treatment and its consequences."³²

CONCLUSIONS AND RECOMMENDATIONS

Mexico's formal adherence to domestic and international legislative frameworks and conventions that guarantee respect for reproductive rights and non-discrimination against people with HIV did not protect Griselda, Carmen, Hilda, or Maria. Their experiences emphasize that physicians and other front-line health care workers are fundamental actors in either violating or promoting reproductive rights. In the case of these women, discrimination by Mexican health care providers was enacted on three levels: misinformation and verbal abuse, differential and discriminatory treatment, and medical interventions that either violated reproductive rights through omission (that is, refusing to change a treatment regimen) or commission (sterilization without informed consent). The violations documented here are echoed in the international literature and suggest a common conclusion: health care providers' negative attitudes toward HIV-positive women's reproduction and the providers' consequent discrimination prevent women with HIV from benefiting from scientific advances to promote their reproductive health.³³ The negative attitudes and discriminatory practices of health care providers are a barrier to the effective exercise of reproductive rights.

In Mexico, the reproductive rights of people with HIV are already enshrined in national and international legislation, but health policy makers and decision makers must make those reproductive rights explicit in official documents and treatment guidelines. Civil society and international organizations need to continue to advocate for recognition of reproductive rights with federal- and state-level policy makers and must create alliances to bring forward cases of human rights abuses under existing legislation. For such strategies to work, people with HIV must be informed about their sexual and reproductive rights and must develop skills to advocate for these rights. Poignantly, in their

declaration at the end of the training during which the cases of reproductive rights abuses shared in this paper were documented, the participating Mexican women with HIV stated:

Human rights belong to everyone, but we don't know about them. There is a lack of adequate and accessible information to learn about them, and therefore it is necessary that institutions carry out intensive dissemination about the rights of people with HIV and sexual and reproductive rights.³⁴

The context of the cases shared here suggests an obvious methodological limitation to how one interprets the data from these reports. That is, the women who identified priorities for improving the sexual and reproductive health of women with HIV in Mexico during the 2007 Citizen's Roundtable on HIV were activists, and the cases selected to illustrate reproductive rights violations were identified by women with HIV who had received specific information about sexual and reproductive rights. The cases shared here cannot tell us about the frequency of reproductive rights violations among women with HIV or if women with HIV without access to information perceive reproductive rights violations as a priority. On the other hand, the identification of reproductive rights violations and the demand for the dissemination of information about human rights by participating women with HIV suggest that replicating and scaling up training on reproductive rights for women with HIV and for health care providers, like the training on reproductive rights that is documented here and others like it that have been developed collaboratively with the International Community of Women Living with HIV and AIDS, is an important first step toward the effective exercise of reproductive rights.³⁵ However, as Hilda's case demonstrated, unless a woman has allies (whether they be in civil society, government, or the private sector), wide-ranging discrimination against people with HIV frequently blocks avenues to pursue redress of reproductive rights violations. These alliances are not only important for providing moral support and relevant information but also for providing access to necessary material resources for defending rights, such as a local or long-distance telephone call or money for transportation to the clinic

to return yet again to change the prescription. In the Mexican context, training the functionaries of the National Human Rights Commission and the State Human Rights Commissions in reproductive and sexual rights and enlisting their support under the aegis of national and state level anti-discrimination legislation is a promising strategy.

These experiences of Mexican women with HIV suggest either that Mexican physicians have deficient information about HIV and reproduction (for example, the probabilities of mother-to-child HIV transmission and appropriate drug regimens) or that stigma and discrimination cause them to dispense with scientific objectivity and the health of women with HIV and their children. In either case, the knowledge of physicians and allied health professionals working in HIV must be improved. As public sector employees, health care workers must be held responsible for the human rights and health provision standards laid out in Mexican legislation and guidelines and must be sanctioned for discrimination and medical negligence whether perpetrated through omission or commission. Women with HIV have demanded to be included in such monitoring boards. Engaging people with HIV as experts about their disease and as partners in outcomes of monitoring and decision making can contribute to a more productive dialogue about reproductive options at the individual level and can increase overall respect for HIV-positive men and women at the society level, contributing to reduced rights violations.

Further, insisting on respect for the reproductive rights of people with HIV can have a positive spillover, creating institutional cultures that respect the rights of all. There is some evidence that promoting the reproductive health and rights of women with HIV can improve overall health care quality and respect for women's reproductive rights. A study from Côte-d'Ivoire found increased communication between women and health care providers and greater respect for the confidentiality of all women after the implementation of a program to prevent perinatal HIV transmission.³⁶ The Mexican literature on reproductive rights violations among presumably HIV-negative women and the experiences and priorities documented above suggest that the implementation of universal precautions for the protection of

health care providers and health care users (independent of knowing the users' HIV status), the provision of accurate information about reproductive options by health care providers, respect for women's right to choose, and ensuring substantive rather than administrative informed consent are priorities for improving the effective exercise of reproductive rights of Mexican women who are living with HIV, as well as those who are not.

We find ourselves in a perilous era for sexual and reproductive rights. Criminalization of HIV transmission, including mother-to-child transmission, is a global tendency.³⁷ Human rights activists and people with HIV must close ranks to defend the gains made over the past 25 years in the recognition of reproductive rights for everyone. We must ensure that people with HIV are included in this universal access. In countries such as Mexico, where the reproductive rights of people with HIV are formally protected, achieving the effective exercise of these rights can promote the well-being of people with HIV and can demonstrate that rights-based approaches are compatible with, and indeed necessary for, public health.

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25. The parenthesis following each illustrative case of rights violations includes where (the type of institution) and when (the year) the abuse occurred.

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