Sexuality, reproduction, and HIV in women: the impact of antiretroviral therapy in elective pregnancies in Cuba

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Objective: Since HIV was first diagnosed in Cuba in 1985 to the end of 2006, 246 HIV-positive women have given birth to 266 children; of these, more than half were born after 2001, when antiretroviral therapy (ART) became widely available in Cuba. The objective of the study was to explore how the provision of ART free at point of delivery to all clinically indicated patients might be related to the rapid increase in pregnancies in HIV-positive women.

Design: A qualitative instrument was designed to assess how reproductive and sexual histories were affected by a diagnosis of HIV and by the availability of ART.

Methods: Data were collected from 55 women, representing 26% of HIV-positive women who are known to have given birth in Cuba. A structured interview was used to collect qualitative information on women's reproductive and sexual histories.

Results: Sixty-four per cent of women interviewed reported becoming pregnant aware of their HIV status or that of their partner; of these, all except one became pregnant after ART became widely available in Cuba. The majority said their worries about transmitting HIV subsided after talking to doctors, obtaining information on mother-to-child transmission, learning they could receive ART and deliver by Cesarean section to reduce the risk of vertical transmission significantly, and meeting HIV-positive women who had HIV-negative children.

Conclusion: The introduction of effective therapy for HIV, by transforming the social and clinical course of HIV/AIDS and allowing the possibility of having HIV-negative children, contributes to decrease HIV/AIDS-related fear and stigma and reshape reproduction.

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Introduction

At the age of 13 years, Yeyslis* rebelled by dropping out of school. She did not have any stable work. When she was diagnosed with HIV in 1990 after dating her second boyfriend, she was unaware of the severity of her diagnosis. At the time, because quarantine was, and until 1993 remained, mandatory in Cuba for all people living with HIV, Yeyslis was transferred to the sanatorium Santiago de las Vegas, outside Havana. While in the sanatorium, Yeyslis had four unplanned pregnancies, all of which ended in induced abortions, like many HIV-positive women who also lived there. It had been hard for her to take care of her new boyfriend's ailing son; the boy died of AIDS before reaching adolescence. In 1998, thanks to medicines donated to Cuba, Yeyslis became one

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* Her name and those of other women mentioned in this article have been changed to maintain confidentiality. The names used here, however, have attempted to keep either the creativeness embedded in the first names of a large portion of the Cuban population born in the past 40 years or the frequent use and adaptation of foreign-language names.

of the first Cuban patients to be enrolled in the antiretroviral therapy (ART) programme. Those diagnosed after 2001 would be able to look ahead to a greater life expectancy, as Cuba started to produce and distribute generic antiretroviral drugs for all people diagnosed with AIDS. In 2003, when she returned home to Santa Clara from the sanatorium, pregnant for the fifth time, Yeyslis did not want to have another abortion. She knew that ART would dramatically reduce the chances that her child would be born with HIV, and that her own mother would take care of the child if necessary. In Santa Clara, a city in central Cuba, only a handful of women had HIV, and the notion of carrying a pregnancy to term was still unusual, as it was believed that all newborns of HIV-positive mothers would acquire the virus. Even Yeyslis's doctors tried to convince her to have an abortion, which only reinforced her motivation to carry her pregnancy to term. Yeyslis gave birth by Cesarean section, and did not get 'her tubes tied' because she considers herself young and is hoping for a cure. Since her child was born, Yeyslis has known of other women with HIV who have also given birth, although she still expressed concern that her son would be rejected once he started attending preschool.

Since HIV was first diagnosed in Cuba at the end of 1985 [1,2], the birth rate among HIV-positive women has increased from 0.12 children per woman in 1985–1996 to 0.21 in 2002–2006 (see Fig. 1) [3,4]. A total of 246 HIV-positive women have given birth to 266 children, the majority of whom were born after 2001. Of all these children, 29 were infected during pregnancy, labor, or breastfeeding, nine of whom have died as of June 2007 [5]. As a result, UNAIDS has termed Cuba's prevention of mother-to-child transmission (MTCT) of HIV programme as 'among the most effective in the world' [6]. Many reasons have been cited to explain this relative success: the existence of a solid and accessible maternal and child health programme before the HIV epidemic; routine testing of HIV during the first trimester of pregnancy; easy access to voluntary pregnancy interruption during the first 12 weeks; and the availability of prophylactic measures such as the provision of zidovudine starting at the 14th week of pregnancy (unless the woman is already on ART); surgical birth; and the distribution of evaporated milk to help avoid breastfeeding; all of which are fully publicly subsidized and provided free of charge to all Cuban nationals [1,7,8]. The estimated prevalence of HIV in Cuba is 0.1 for the total population [9] and 0.01 for pregnant women [10]. An estimated 99.4% of infections are through sexual contact [11]. Of the total 8087 Cubans who had been diagnosed with HIV by the end of December 2006 [3], 1562 (19.4%) were women.

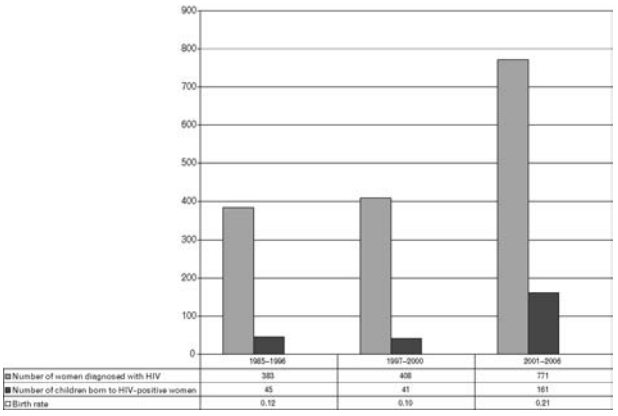

Fig. 1. Number of women diagnosed with HIV, number of children born to HIV-positive women, and fertility rate (number of children per woman) in three time periods. Cuba, 1986–2006.

Although it is well documented around the world that AIDS-related mortality has significantly dropped since the introduction of ART in 1996 [12], little is known about the impact of ART on the experience and quality of life of people living with HIV in poor countries, partly because effective therapy was only introduced in these settings in very recent years. In Cuba, ART started to be provided in June 2001 through the public health network to those who met the clinical criteria for AIDS [1,8]. Before the advent of ART, anthropologists had suggested that the introduction of effective therapy might profoundly alter the social interpretations of disease [13,14]. Other social scientists have shown that stigma is aggravated by an undefined aetiology and the lack of an effective treatment [15]. Exposure to a new disease generates new cultural models of the aetiology and expected course of disease [16–18]. These models change with time because diseases have a social course, that is, pathology is embedded in social experience [13]. Some studies have shown how the social experience of HIV/AIDS, including stigma and discrimination, is affected profoundly by the advent of effective therapy [19,20]. On the basis of this framework, the research described here explores the relationship between the introduction of ART in 2001 and the subsequent increase in births among HIV-positive women in Cuba.

Methods

The study was approved by the Ethical Review Committee of the Institute of Tropical Medicine Pedro Kourí in Havana. To explore the relationship between the provision of ART to all clinically indicated patients and the rapid increase in pregnancies in HIV-positive women, we invited all women who brought their children from throughout Cuba to the biweekly pediatric HIV clinic at the Hospital of the Institute of Tropical Medicine during a 10-week period between the end of September and early December 2005 to participate in the study. All the women invited agreed to participate in the study.

The sample consisted of 55 women drawn from the population of 213 HIV-positive or HIV-serodiscordant women who had given birth in Cuba since the first woman was diagnosed in 1986 until December 2005, 26% of the total population of HIV-positive women who have given birth to a total of 229 children. Participants agreed to be interviewed about their life with HIV and their reproductive and sexual histories. The purpose of this structured, open-ended life history interview was to identify what factors contributed to the women's decisions concerning their pregnancies. All the interviews were conducted at the Hospital of the Institute of Tropical Medicine Pedro Kourí, where a pediatrician (González-Núñez) follows all children born to an HIV-positive parent in Cuba until the child's negative HIV diagnosis is confirmed. As of June 2007, of the 20 children diagnosed with HIV who were still alive, 18 were receiving ART and two were asymptomatic.

On the basis of our interest in exploring how the experience of people diagnosed with HIV was shaped by whether effective therapy existed and was available, we stratified the sample into four categories based on the time of diagnosis. The first group included women who were diagnosed before the end of June 1996, when no effective therapy for AIDS was known. The second group included women who were diagnosed between July 1996 and May 2001, when ART was known to be effective but was unavailable in Cuba except through donated medications; zidovudine, however, had already been introduced in 1997 to prevent MTCT of HIV. The third group included women who were diagnosed after June 2001, when ART was made readily available in Cuba free of charge to all patients who met the clinical criteria for AIDS. HIV-negative women who had an HIV-positive partner comprised the fourth group in this study. We subsequently stratified each diagnosis group by time period of the onset of pregnancy. The temporal sequencing of the HIV diagnosis allows the examination of the association between the provision of ART and the rapid increase in pregnancies carried to term among HIV-positive women.

Results

Of the 55 women interviewed, 35 (64%) were aware of their HIV-positive status or that of their partner before the onset of their most recent pregnancy, all of which resulted in the birth of a child. All of them but one became pregnant after June 2001, when ART became widely available in Cuba. The great majority of these women had had serial abortions until their experience living with HIV, along with the lives of those around them, was transformed by the introduction of ART. Among women who had had at least one abortion after having been diagnosed with HIV, the main reason stated was that at the time there was no available treatment for HIV disease. Figure 2 illustrates the smaller percentage of induced abortions in women in our sample who were diagnosed with HIV in recent years.

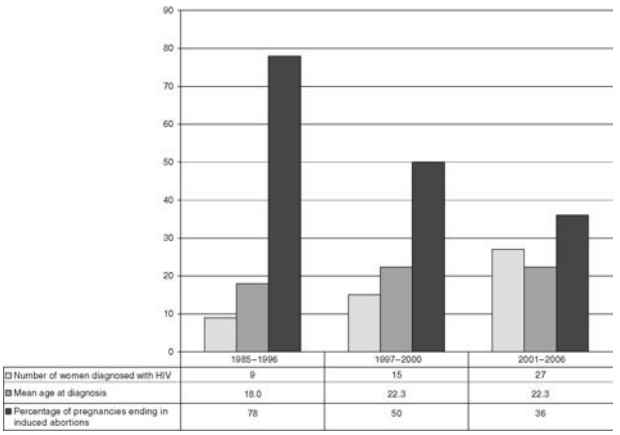

Fig. 2. Distribution of the 55 women in the sample by time of HIV diagnosis with information on mean age at HIV diagnosis and percentage of induced abortions out of their total pregnancies. Cuba, 2005.

Yibaleitis, for example, had been diagnosed with HIV in 1993 at the age of 18 years. She had already had one abortion at that point. Later, after the diagnosis, she had six more because it was out of the question that she would have a child, she did not want to. Yibaleitis subsequently changed her mind, however, and tried to become pregnant. At the sanatorium, where she had lived for several years, 'all the children born (to HIV-positive women) were healthy, so I thought that mine would be healthy too', she said. Her family supported her decision, except for her mother-in-law, who insisted that she should have an abortion because the child would be born with the disease. 'But I was going to have that child, because I own my body', Yibaleitis resolved. It was during the beginning of her pregnancy, when her viral load increased and her CD4 cell count decreased, that she started ART. 'Since he was born, my life has completely changed. I'm another person, I'm different. Despite the fact that my child has it (HIV), I'm so glad that I had him. I'm happier, everything has changed.'

It had been different for Kitiuska, however, who was diagnosed with HIV several years later, in 2003, at the age of 18 years, during the last weeks of high school. She went to get tested when she heard the rumor around her neighborhood that a former boyfriend had AIDS. Upon learning her diagnosis, she took her final exams, graduated, and moved to the sanatorium, where she met her current partner, who had been diagnosed with HIV 2 years earlier. At the sanatorium they met other couples who were also living with HIV and who had had healthy children. 'We always wanted to have a child, but

we asked around to know more', and sought the advice from the clinical team, who explained that with the recommended prophylactic measures they could go ahead with their plans and that they should not wait, arguing that it was better to become pregnant while she was in the early stages of HIV disease. Kitiuska had had an abortion when she was 15 years old because she did not want to interrupt her education. Five years later, a child came as a gift: 'If I wasn't already thinking too much about HIV, now much less so. He distracts me from the world around me. I only think about him, I am happy as I am. What I wanted, I got it.' Kitiuska, who for now does not need ART, plans to attend nursing school when her child is a year old.

Twenty-eight women (51%), 26 of whom became pregnant after 2001, said their worries about transmitting HIV to their child subsided after discussing their pregnancy with doctors, seeking information on MTCT of HIV, learning that they could deliver by Cesarean section, learning that ART was available, and meeting HIV-positive women who had had HIV-negative children. When Dorelis, for example, was diagnosed with HIV at the age of 17 years, in 2002, she moved to the sanatorium in her province. Three years later, she became pregnant with an HIV-positive man who also lived at the sanatorium and who did not accede to her requests to use condoms. She had had an abortion at the age of 13 years, and this time decided to have the child. Although at first she was concerned that she could transmit HIV, Dorelis stopped worrying when she initiated zidovudine prophylaxis at 13 weeks of pregnancy. Having also met and interacted with HIV-negative children born to other women living in the sanatorium with her and being able to talk with her doctors about how to prevent HIV transmission also helped ease her worries.

On the basis of our interviews, in the years since ART became available, family members (such as a partner or mother) and health professionals have been more inclined to support women in their decision to carry their pregnancies to term. Only three women stated feeling pressured by their doctors or family to seek an abortion. Vanessa was diagnosed with HIV in 2000 at the age of 25 years after having had a healthy child. After the diagnosis, however, she had three induced abortions. At the sanatorium in Pinar del Río, she planned a pregnancy with her partner after they were told that there was a 70% chance that her child would be born HIV negative. Her family tried to convince her to have an abortion, but she felt reassured by the availability of ART and by the extensive array of support provided to people living with HIV in Cuba. The birth of her daughter in 2005 radically changed her life to a positive experience; her plans are 'to keep going, to keep living'. Before the introduction of ART in Cuba, however, it was common for doctors to recommend abortions strongly and even to exert a lot of pressure, based on what women reported in the interviews.

The reasons to plan a pregnancy or to accept an unplanned pregnancy were similar for women with no indication for ART and for those on ART. Twenty-four women chose to become pregnant because of their own desire to have a child or to 'give their partner a child', either because he was childless or had not had any children with her at that time, or because health professionals or other women reassured them that the risk of MTCT was low. Twenty-six women did not plan their pregnancy but chose to carry it to term because they were reassured by health professionals or other women about the low risk of transmitting HIV. Five women stated they had wished to interrupt their pregnancy but were not able to do so either because it was too late in their pregnancy or because it entailed additional health risks.

Several women indicated that they have felt discriminated against at some point in their lives as a result of HIV: 'No matter where I go, there's always someone who will reject me', 'It's hard to live with a red ribbon stuck on my forehead, to always feel highlighted', or 'I felt like something bad, like the pest'. Some of them, however, stated that they experienced a process of greater social inclusion in recent years, oftentimes enhanced by their giving birth to a child. Some women mentioned that since they had their last child, more women they know who live with HIV have sought to become pregnant.

Discussion

Between 1986 and 1993, all people diagnosed with HIV in Cuba were quarantined in the AIDS sanatorium closest to their home [1]. At the time, HIV crossinfection was not known to pose health problems, and unprotected sex among people living in the sanatoria, all of whom had HIV, occurred frequently. For many Cuban women, abortion was the preferred method of fertility regulation. The rate of abortion (surgical and menstrual regulation) reached its peak in 1990, with 72.9 per 1000 women of childbearing age and decreased to 56.9 per 1000 women of childbearing age in 2004 [21]; approximately a third were (and continue to be) performed on women younger than 20 years of age [22,23]. There are no published statistics on abortion rates among women living with HIV in Cuba.

Until 1993, most pregnancies among HIV-positive Cuban women were terminated; the few who carried their pregnancies to term gave birth by Cesarean section and were advised against breastfeeding. After 1993, when ambulatory care for people living with HIV was introduced, there was an increase in the absolute number of pregnancies carried to term. This was most likely as a

result of an increase in the total number of women of childbearing age with HIV who were diagnosed late in their pregnancies. During the first 2 years after the introduction of zidovudine in 1997 to prevent MTCT of HIV, most pregnant women living with HIV either continued to have abortions or refused to take zidovudine. Since 1999, there has been an increase in the number of pregnancies carried to term and an increase in the uptake of zidovudine among pregnant women and their newborn children [4]. More than 50% of all births to an HIV-positive parent occurred after ART became widely available in June 2001.

The few studies published that examine the frequency of pregnancies after the introduction of ART have been conducted in the United States [24,25] and Europe [26,27]. Those studies have shown that, as in our sample in Cuba, voluntary abortion has decreased among HIV-positive women. In one of the studies conducted in the United States, the authors suggest that, given that conception rates among women who are HIV positive have remained stable even after the introduction of ART, 'seropositive women who conceived were more likely to continue their pregnancies after HAART rather than that HAART led women to conceive who would not otherwise have done so' [28]. Our study indicates that both situations occur. Some women, after having had multiple abortions because no treatment was available for HIV, sought to become pregnant after the introduction of ART in Cuba. Most women in our study who had not planned their pregnancies decided to carry them to term because they were reassured by the availability of ART. The decision to carry an unplanned pregnancy to term occurred in women at different clinical stages of their HIV disease, including those who were receiving ART and those who were not.

Our study suggests that by transforming the social and clinical course of HIV/AIDS in Cuba and by allowing for the possibility of giving birth to HIV-negative children, ART can profoundly reduce HIV/AIDS-related stigma and discrimination directed towards women living with HIV who decide to give birth. ART lessens the pressure to have abortions exerted by family members and health professionals upon HIV-positive pregnant women. Moreover, our study indicates that in a setting where access to ART is universal, such as in Cuba, ART availability goes beyond improving the quality of life of those who are receiving treatment. By transforming HIV/AIDS-related fear and stigma, it allows HIV-positive women to regain control over their reproductive lives, and to be seen by society as 'worthy' of nurturing a child [29]. In the era of ART, HIV-positive women contest, through pregnancy, years of disease and rejection.

The availability of ART has the potential to reshape the experience of reproduction, decision-making, and the behavior of women who live with HIV, their family members, their health professionals, and their communities. In its ability to help overcome HIV/AIDS-related stigma, the successful provision of ART demonstrates a capacity to treat not only physical disease but the often far more damaging social disease aspects of HIV/AIDS.

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Conflicts of interest: None.

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