

# “It’s Not Good to Be Sick and Have the Child”: Perspectives on Pregnancy After HIV-Positive Diagnosis Among Women in Western Jamaica

Courtney Andrews <sup>1</sup>, Tina Kempin Reuter <sup>1</sup>, Valeria Londono <sup>2</sup>, Lea Claye <sup>3</sup>, Maung Aung<sup>4</sup>,  
Pauline Jolly<sup>3</sup>

<sup>1</sup>Institute for Human Rights, University of Alabama at Birmingham, Birmingham, Alabama, USA, Birmingham, AL, USA; <sup>2</sup>Minority Health Research Training, University of Alabama at Birmingham, Birmingham, AL, USA; <sup>3</sup>Department of Epidemiology, University of Alabama at Birmingham, Birmingham, AL, USA; <sup>4</sup>Epidemiology and Research Unit, Western Regional Health Authority, Ministry of Health, Montego Bay, Jamaica

Correspondence: Courtney Andrews, Institute for Human Rights, University of Alabama at Birmingham, HHB 551, 1720 2<sup>nd</sup> Avenue South, Birmingham, AL, 35294-1152, USA, Tel +1 205 975 6492, Email [cjandrews@uab.edu](mailto:cjandrews@uab.edu)

**Purpose:** To identify factors associated with reproductive decision-making for women living with HIV in Western Jamaica, to assess their confidence in anti-retroviral therapy to reduce the chances of mother to child transmission of HIV, and to better understand the experience of stigmatization surrounding becoming pregnant after HIV diagnosis.

**Participants and Methods:** Two focus groups were conducted among women living with HIV in the four parishes of Western Jamaica in 2011. A trained moderator conducted the focus groups along with two student notetakers. Qualitative coding and content analysis were used to identify common themes and exemplary quotations characterizing those themes.

**Results:** Participants agree that adherence to antiretroviral therapy as prescribed by a physician facilitates better health and longevity; however, they were conflicted on the efficacy of the therapy to prevent mother to child transmission of the virus. Participants report that becoming pregnant after HIV diagnosis continues to be highly stigmatized. Among participants, fear of MTCT and concern that their children will be mistreated are the primary drivers of reproductive decision-making.

**Conclusion:** Despite advances in HIV treatment and assisted technologies to prevent MTCT, participants show skepticism that ARV medication is effective at preventing MTCT. Stigma and discriminatory behavior by community members and health-care professionals continue to shape reproductive decision-making for the women who participated in this study. More informed counseling that includes education on recent advancements in HIV treatment and its efficacy at preventing MTCT should be more widely available to pregnant women. To reduce stigma and discriminatory behavior, this education should extend to the larger community.

**Keywords:** HIV, reproduction, mother to child transmission, stigma

## Introduction

Approximately 38 million people throughout the world are living with HIV, and 53% of these are women and girls.<sup>1</sup> Regionally, the Caribbean has the highest HIV prevalence in the Americas and the second highest globally, following sub-Saharan Africa.<sup>2</sup> It is estimated that 74% of people living with HIV (PLHIV) in the Caribbean are in their reproductive years, and half of these are women.<sup>3</sup> Recent advances in antiretroviral (ARV) therapy allow for PLHIV to live longer and healthier lives, and assisted reproduction technologies provide safer conception and birthing options.<sup>4</sup> According to a UNAIDS 2020 report, 64% of pregnant persons living with HIV in Jamaica are accessing ARV medication to prevent mother-to-child transmission (PMTCT) of the virus, and the rate of new HIV infections averted due to PMTCT is near 100%.<sup>5</sup> This means that becoming pregnant and having children after being diagnosed with HIV is relatively safe for both mother and child if the mother is receiving ARV therapy. This is important in part because fertility is a marker of status and is culturally regarded as an important aspect of womanhood in Jamaica.<sup>4</sup> For women living with HIV, the ability to get pregnant and have children facilitates a greater sense of normalcy and cultural success.

While advances in HIV treatment and the reduction of MTCT have changed the reality of living with HIV in significant ways, stigma and misinformation about HIV remain pervasive and continue to shape the lived experience and reproductive decision-making processes for Jamaican women who are diagnosed with HIV. The study described here sought to better understand the fertility desires and reproductive needs among women living with HIV in the four parishes of western Jamaica. In 2015, around the time the study was conducted, the rate of HIV infection among pregnant women in the urban parish of St. James was 2.9%, compared to the national average of 1.4%.<sup>7</sup> Focus group discussions were conducted to identify what kinds of considerations women living with HIV make in formulating and achieving their reproductive goals, including their level of confidence in ARV therapy to prevent MTCT. We also explore the extent to which the attitudes and behaviors of health-care workers and the broader community remain steeped in outdated information that perpetuates stigma and discriminatory behavior toward women living with HIV and their children. Studying the culturally specific reproductive needs, desires and motives of PLHIV is necessary for implementing more suitable and rights-driven guidelines for health care, HIV education, and social policies.

## Background

Among women of reproductive age living with HIV, the frequency of both intended and unintended pregnancies has progressively increased.<sup>9,10</sup> Proper management is fundamental to prevent perinatal spread of HIV from mother to child. In establishing the Prevention of Mother to Child Transmission Initiative, the World Health Organization (WHO) developed a comprehensive approach to making antiretroviral therapy widely available to pregnant women with an HIV-positive diagnosis. As many women are unaware of having HIV until they seek prenatal care, this included testing pregnant women for HIV and offering both ARV therapy and pre-exposure prophylaxis (PrEP) during antepartum, intrapartum, and postpartum care to women who test positive.

While advances in treatment constitute a net positive for women living with HIV and their offspring, it is important to consider how social and cultural factors shape knowledge, attitudes, and behaviors about HIV and reproduction. Further, structural factors limit access to quality care and other forms of necessary support for many women, especially in impoverished areas like western Jamaica. Misinformation about HIV drives stigma, including self-stigma, which affects the health-related behaviors of individuals as well as how they are treated in clinical and social settings. Discriminatory behavior toward persons with HIV contributes to the unwillingness of women to disclose their HIV status, which limits their ability to seek and receive critical medical care. This also impedes the implementation of supportive programs and initiatives for women in this situation and serves to exacerbate spread of the virus. Studies among pregnant women living with HIV in Kenya have found that high rates of testing refusal are associated with fear of stigma and discrimination from male partners, friends, family, and the wider community.<sup>10,12</sup> A study among women living with HIV in Nigeria found that fear of stigma as well as lack of social and financial support and poor patient–provider interaction at health-care facilities served as barriers to PMTCT uptake.<sup>13</sup>

For women and men living with HIV in their reproductive years, studies have shown that HIV status does not attenuate the desire to have children.<sup>4,14</sup> However, while the right to have children is recognized and generally perceived of as safe, health-care providers seldom ask about fertility desires or provide reproductive and conception counseling to PLHIV.<sup>11</sup> This serves to perpetuate misinformation, stigma, and fear among people living with HIV who may want to become pregnant.

## Materials and Methods

The data for this research paper come from a cross-sectional study conducted among women living with HIV and receiving care at clinics in the four parishes of western Jamaica (St. James, Westmoreland, Hanover, and Trelawny) under the Western Regional Health Authority (WRHA). With tourist-based economies, these four parishes are among those with the highest cumulative number of HIV cases, including among pregnant persons.<sup>7</sup> The quantitative component of the study used a questionnaire to collect information on sociodemographic factors and health-seeking, reproductive, and sexual risk behaviors among women living with HIV who either had or had not become pregnant since diagnosis.<sup>8</sup> Because the focus was on reproductive decision-making, participation was limited to adult women in their reproductive years. The survey results showed that women diagnosed more recently (within 5 years prior) were less likely to become

pregnant and that those with a CD4 count of less than 350 were six times more likely to become pregnant than those with a CD4 count above 350. The aim of the qualitative portion of the study (described here) was to further explore questions around reproductive decision-making for women living with HIV and to allow participants to speak to their own experiences and the challenges they face. Women with a diagnosis of HIV who were 18–54 years of age and were living in one of the four parishes under the WRHA from January to December of 2011 were eligible to participate in the study. Eligibility criteria was the same for all participants, and participants were divided into two separate focus groups depending on whether or not they had become pregnant since being diagnosed with HIV.

## Participant Recruitment and Data Collection

Participants were identified from the Prevention of Mother to Child Transmission (PMTCT) register kept at Cornwall Hospital. All participants had been previously diagnosed with HIV and were receiving clinical care at Cornwall. Women who had been diagnosed prior to becoming pregnant and those diagnosed during pregnancy were instructed to visit the clinic for prenatal care at least once before delivery. Number and frequency of postpartum appointments were dependent on viral suppression and other health issues. Follow-up care typically lasted around six months after giving birth. In addition to their clinical care, all were followed up by social workers and adherence counselors at the clinics. The names listed in the PMTCT register were reviewed by the social workers and adherence counselors in each parish to determine if the women were alive, still living in the region, and still receiving follow-up care. The social workers and adherence counselors approached women who were eligible for this study when they visited the clinic and asked them if they would be willing to participate. Women who indicated willingness to participate were then introduced to the research staff, and arrangements were made to meet them at the clinics or hospitals where they were receiving care. The research staff presented the informed consent form to interested participants, encouraging them to ask for any needed clarifications about what was expected of them. After all the information was presented, the women were asked if they consented to participating in the study. Of those approached, 23 women declined to participate in the focus groups, citing fear of their status being disclosed, cost, and time associated with traveling to the hospital for the focus group. Forty two percent of those who agreed to participate had been diagnosed within the previous four years, while 58% had received a positive diagnosis more than five years prior. At enrollment, participants were asked for the number of pregnancies they had since they were diagnosed with HIV. Based on availability, a convenience sample of 17 women was selected, and these were divided into two groups based on whether or not they had gotten pregnant since receiving an HIV-positive diagnosis. In addition to the signed informed consent form, participants were asked to sign the Audiotape Release form signifying their willingness to participate in the focus group sessions, which were tape recorded. The recordings were transcribed, and participants were assigned numbers so that names were not included in the transcripts. Participants received J\$200 for their participation in the focus groups.

The focus groups were structured according to methodology described by Kitzinger.<sup>15</sup> After getting an initial picture of predictors of pregnancy after HIV diagnosis from the survey results, focus groups were used to further develop our understanding of reproductive decision-making processes and challenges in the context of women living with HIV in western Jamaica. These provided a safe space for participants to talk through their ideas and experiences beyond what was covered in the survey. Both focus groups were facilitated by a trained moderator and assisted by two note takers. Each session lasted approximately 2 hours and was audio recorded. The format of the sessions was as follows: 1) welcome and introductions; 2) introduction of the project and purpose of the focus group; 3) establishment of ground rules; 4) questions and answers regarding focus group process; 5) posing of six to eight specific questions; 6) summary of focus group content; 7) eliciting of final thoughts; and 8) closing.

## Analysis

Two independent coders read and analyzed the focus group transcripts and worked together to develop an open coding scheme. Two primary coders subsequently used NVivo software (QRS International) to conduct “focused coding,” which included a detailed analysis of themes identified during open coding. Any discrepancies were resolved by a third coder. The process was repeated until thematic saturation was reached. Overarching themes pertaining to HIV treatment, factors

relevant to reproductive decision-making, and HIV stigma were identified, exemplary quotes characterizing themes were highlighted, and investigator insights relevant to the decision-making process were noted in memo format.

## Ethical Approval

The study protocol was reviewed and approved by the Institutional Review Board of the University of Alabama at Birmingham, USA, and the Western Regional Health Authority, Ministry of Health, Montego Bay, Jamaica, prior to its implementation. All aspects of the study procedures comply with the Declaration of Helsinki. All participants consented to participating in the study and to publication of their anonymized responses.

## Results

This study was primarily concerned with the ideas women living with HIV in Western Jamaica have about HIV and mother to child transmission (MTCT) of the virus and how they weigh various factors in making decisions about reproduction post HIV-positive diagnosis. The predominant themes discussed in the focus groups were the level of confidence participants had in antiretroviral therapy to prevent MTCT and allow PLHIV to enjoy long, healthy lives, concerns about the mistreatment of their children due to the stigma around the disease, support (or lack thereof) from health-care providers, family members, and the larger community, and HIV education in Jamaica. Each of these themes is discussed in turn. We prioritize the use of direct quotations from participants and make every effort to represent their perspectives and experiences accurately.

### Concerns About Mother-to-Child Transmission of HIV

The first focus group was comprised of women that had become pregnant since being diagnosed with HIV. In this group, three participants said they did not choose to become pregnant, but – as one of these women explained – “it just happened, so ...” The participants were then asked if they were thinking of becoming pregnant now, and everyone that answered the question said no. One woman cited her reason as “it’s not good to be sick and have the child, having to worry about yourself and the child.” Others expressed concern that the child would be born with HIV. One woman affirmed this concern by relating that even though she took the medication as prescribed by the doctor during her pregnancy, her child was born with the virus. Another participant challenged this concern by saying, “But it is not 100% that the child will be born with it.” In response, several participants lamented that even if the child is not born with HIV, others will assume the child has it and treat them poorly. Only one participant said she intentionally became pregnant after being diagnosed with HIV, her reason being that she had two boys and she really wanted a girl. She said she got a lot of pushback from people in the community and felt judged for her decision.

In the second focus group, participants were asked if they were considering becoming pregnant. One woman said, “Pregnant no, I do not want to have any more children, that is a danger to the children.” Another said that she did want to have another child and that in order to ensure the child would not be born with HIV, she planned to get pregnant by artificial insemination and birth the child by C-section. She explained, “You know if it is a vaginal birth then the chances are like 100, when like with the C-section the risk is much lower.” Several participants seconded the fear that the child would be born with HIV. In response, three other participants said that with the medications available these days, the risk of MTCT was very low. One participant who works at an HIV clinic explained,

I work with women and the chance of these babies contracting the virus is like 0.1, the chances are getting lower and lower every day, the medications are getting better and as long as the persons take the medication properly, on time, every day, attend all your doctor’s appointments chances are very low ... we are hoping that one day a mother will be able to have children and there will be no chances of passing on the virus.

Participants in both groups were asked if they would choose to terminate the pregnancy if they found out they were pregnant now. One woman said she wanted to do that and tried but was unable to find anyone to perform the abortion as the practice is illegal in Jamaica. Another said she would not end the pregnancy, but she reiterated the concern that the child would be born with the virus. Others simply responded that they would avoid getting pregnant altogether.

## HIV Medication

Despite some disagreement among participants over whether or not ARV therapy is effective at preventing MTCT, participants did agree that taking HIV medications as prescribed is vitally important (“a hundred percent important,” “extremely important”) to maintaining good health. One woman said she stopped taking her medicine out of curiosity to see what would happen, and her health immediately started to decline. She said that when she is taking the medicine, she does not feel like she is sick at all. Another said that when she was not taking her medicine, she contracted pneumonia and became very ill. In summarizing this experience, she said, “So people say AIDS is horrible, it really is not as long as you take your medications as should.” Another said that taking the medication allows her to live a normal life, one in which no one around her is aware of her positive status. She explained, “For now I take my medication and look good, nobody has to know that I am sick.” Some participants did mention adverse side effects to taking the medication. These include chest pain, vomiting, fever, swelling, and skin problems. The social worker reminded the women that typically side effects subside after a short time taking the medication consistently, and several women attested that this was their experience.

Participants mentioned that another benefit to taking HIV medication and seeing the doctor regularly is that other aspects of one’s health can be tended to during this process. As one participant explained,

Without HIV other things can happen to you, other complications, women who have HIV and go in for regular checkups have a chance to detect other illness at an early stage and might even live longer because every six months you do general test. The liver the lungs etc.

## Concern for Children

As mentioned, some participants expressed concern that a child born to a mother with HIV will be assumed to have the virus and will be treated poorly because of this. One woman insisted that it is not right for women living with HIV to get pregnant because even if the child does not have HIV, “they [are] going to say once the mother has it the child have it.” Participants agreed that many people still believe that the chances of the mother passing HIV to her infant are very high and that this will create problems for the child even if they are not born with the virus. When another woman contradicted her by saying that she has had two children since her diagnosis and neither of them are HIV positive, one woman retorted, “You are not listening to what I am saying, even if they don’t, they will say the children have it and will treat them bad.” Another agreed, saying, “The children don’t understand what they going through and people will treat them worse.” One woman described the dilemma in this way: “Yea them a go say the mother and father have it so the child has it. And what I can step over the child can’t step over.”

A few women expressed concern that having HIV would shorten their time with their children. They were asked if they worried about who would take care of their children should something prevent them from being able to do so. One participant said she did not know. Another said she supposed her family would do it, but she did not want that for her children. As one participant explained, “Right now me just want to live to see my daughter grow up.” Most of the women did not have plans in place regarding care for the children should they become severely ill or pass away.

## Stigma and Discrimination

Participants were asked if they felt like people in the community discourage women living with HIV from having children. Several responded that yes, this is a widespread problem in the community. One woman said community members called her “wicked” for having a baby after her diagnosis. Another explained, “They don’t really understand it, so they are really against it, because they are not educated about it, they are against it.” When asked if health-care workers discourage women living with HIV from getting pregnant, one participant responded, “everyday, everyday.” Another said, “not all of them but some of them.”

Several participants lamented that stigma leads to isolation and failure to seek treatment. “It always feel as if someone is watching you,” said one participant, meaning she felt her actions were overly scrutinized because of her HIV diagnosis. Another woman explained,

The problem is that a lot of people out there have it and they don't want to feel left out or discriminated against so they have unprotected sex and just keep living.

Several women said they knew people that were living with HIV but not seeking treatment because they were ashamed. Others said that because the medication is so effective, they could lead relatively normal, healthy lives if it were not for the stigma and discrimination they face on a regular basis – both in the community and in the healthcare system. One participant said,

It's embarrassing, I feel ashamed to have to tell [the social worker] of this. Not even my mother know. So it's best if you know that you sick and keep it to yourself.

## HIV Education

When asked where they learned about HIV, one participant said high school while others said church or religious education classes. One woman expressed being so devastated upon learning of her diagnosis because “based on what I heard about the virus before, when I found out I had it, I thought I would have been dead in like three days.” Several participants agreed that they were under the impression that HIV was an immediate death sentence. On the prevalence of HIV in Jamaica, one woman said, “It is everywhere, like three in every five persons.” According to participants, common misconceptions like these continue to be passed around, even in clinical settings. “It is just medical things everybody mix up, nobody knows nothing,” one woman said. Another responded, “That need to stop. This education level to the Jamaican on HIV is too low.”

When asked what they wish more people in the community understood, one participant said, “that you can live as long as you want to with HIV, that you are not going to die instantly.” Another said that people need to be encouraged to use condoms. One woman reminded everyone that even in situations where both partners have HIV, condom use is encouraged, to avoid infecting the other person with a different strain of the virus. This exposure to different strains, she said, makes the medication less effective. This is another misconception, as the medication is effective against both strains and would prevent the individuals from getting the other strain.

## Need for Support

One thing participants agree on is that PLHIV, especially pregnant women, need more support – from doctors, social workers, family, and community members. This includes emotional support in dealing with the trauma, reminders to take the medication, and financial support to get to the pharmacy and to the clinic. “You need a good support system, especially when the side effects kick in, someone to tell you not to give up,” one participant explained. One woman said her family abandoned her after her diagnosis. “In this situation you need your family to stand by you ... Family? Them disappear first.”

Participants had mixed feelings about HIV support groups – some found them helpful while others considered them destructive and a waste of time. One participant described her support group as “a tear down group.” When asked how social workers can be more supportive, several participants said they could do better about helping them find employment and financial assistance. Others mentioned feeling disrespected by doctors and hospital staff. One woman said the doctor or nurse will call her to ask if she has taken her medication but will not ask how she is feeling or if she is in any pain. Another woman expressed concern that hospital staff talk about her and tell people in the community of her status. She explained,

Worse if you come from a community where nobody don't know and you come into the health system come see people who you know. And them just chat everything that them see.

## Discussion

Among focus group participants in this study, reproductive decision-making primarily centers around fear that the child will be born with the virus and concern that the child will face stigma and discrimination even if they are not born with

HIV. This seems to be because many community members continue to believe that MTCT is more common than it is and that HIV medication is not effective at preventing MTCT. Participants report that even health-care providers and social workers discourage women from becoming pregnant after HIV diagnosis. Misconceptions and advice that is medically wrong or outdated seem to be the rule rather than the exception in both the general population, and more concerning, among medical providers. Health-care providers who subscribe to the notion that women living with HIV should not become pregnant often lack the knowledge to counsel patients on their fertility options and are ill-equipped to provide patients with quality reproductive health-care services.<sup>10</sup> Additionally, mothers are all too aware of the fact that their diagnosis will have repercussions for their children, and they do not want to subject their children to mistreatment. For these reasons, some participants spoke of becoming pregnant after HIV-positive diagnosis as a moral failure, and many expressed not wanting to become pregnant, not because they did not want children but due to the concerns presented here.

It is important to note that several focus group participants did not choose to become pregnant. None of the participants specifically mentioned rape or forced sexual contact; however, some participants alluded to their pregnancies as the result of non-consensual sexual activity. When women do become pregnant after such an experience, there is little recourse for them to end the pregnancy safely because abortion is illegal in Jamaica.

For those who do become pregnant, the stigma around HIV and AIDS often leads to isolation and neglect. This stigma is rooted in misinformation that continues to plague HIV education and prevention efforts in the community. This was evident in our study as some participants overestimated the number of people living with HIV in Jamaica, while others exaggerated the risk of MTCT. Participants were apt to throw out a statistic as if it were fact, despite there being no evidence to support it. Prior to diagnosis, many of these participants believed that persons living with HIV were constantly sick and on the verge of death.

Participants did agree that taking HIV medications as prescribed is vitally important to their state of health, quality of life, and longevity. They expressed that if not for the stigma and discriminatory behavior they often experience, they could lead relatively normal lives managing HIV. As the title quote reflects, living with HIV, even if one is taking medication and able to live a healthy and normal life, is experienced as “being sick.” For people living with HIV, there is both internal and external pressure to assume the sick role despite being in good health. Thus, poor health (physical, mental, emotional) may be more a function of internalized stigma than a consequence of the virus itself. For women in their reproductive years, this social pressure forces the question of whether or not to become pregnant while “sick,” even if the person is not actually sick.

Most of the women that participated in the focus groups did not have plans in place to ensure care for their children in the event that they became severely ill or died. This seemed to be partially a matter of not feeling terribly urgent because they had some confidence in the medication to allow them to live long lives but also because they did not have anyone to reach out to for assistance. Having better support – financially, emotionally, and therapeutically (reminders to take medication and assistance with daily activities when experiencing side effects) – is something for which nearly all the participants expressed a strong desire.

## Limitations

This study has several limitations. This data was collected in 2011 and may not seem pertinent today. However, while Jamaica has made great strides in ending the HIV epidemic in the past three decades, it appears that little has changed since the early 2000s.<sup>16</sup> HIV prevalence in Jamaica remains around 1.5%, and stigma and discriminatory behavior continue to pose challenges for PLHIV.<sup>16</sup> While Jamaica achieved the vertical elimination target of two percent or less rate of MTCT in 2015 and 2016, this was not achieved in 2017, when the rate of MTCT grew to six percent.<sup>17</sup> The target has since been reached a new, though this should not be ignored as an anomaly. That is to say, the situation remains precarious, and our data can shed light on the long-term trajectory of Jamaica’s goal to eliminate MTCT of HIV.

With regard to the focus groups, we note that not every participant in the focus groups answered every question, and in one of the transcripts, participants are not numbered, so it is impossible to know who is speaking, and there is no way to quantify the responses. Further, while the moderators loosely followed the interview guide, not all of the same questions were posed to both groups, and the two conversations went in slightly different directions. Participants treated the focus group discussion like

a support group – they asked each other questions and asked the moderator questions about the virus and employment opportunities and how to receive financial assistance for HIV medication. While we gleaned valuable information through these kinds of conversations, they sometimes veered from the initial focus on reproductive decisions. Throughout both focus groups, the moderator often felt compelled to offer corrections to misinformation that was presented by the participants and to answer their questions about the current state of the HIV epidemic in Jamaica, and a few participants tended to dominate the conversation and often argued with what others were saying. It is unclear the extent to which this may have influenced the level of comfort certain participants had in providing their opinions.

## Conclusions

Participants in our study acknowledge the importance of seeking treatment for HIV and adhering to a prescribed medication regimen. They are less convinced that the medication will prevent MTCT should they become pregnant. They report that this concern is widespread in the community and among health-care workers, and it serves to perpetuate stigma and discriminatory behavior toward women living with HIV and their children. Based on our focus groups, it seems that outdated educational initiatives and prevention efforts result in isolation and neglect for many women living with HIV as well as for their children. This may serve as an antidote to the recent advances in HIV treatment that allow PLHIV to live longer and healthier lives because it often leads to fear of disclosure and refusal to seek treatment, which makes management of the disease unnecessarily difficult and facilitates transmission of the virus. Efforts to update people in the region on advances in HIV treatment to prevent MTCT and allow individuals with HIV to lead long and healthy lives are needed in western Jamaica. PLHIV who are considering becoming pregnant or are pregnant need access to informed reproductive counseling. This will put women living with HIV in a better position to make more informed decisions about their reproductive goals and to seek safe fertility options.

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## Disclosure

The authors report no conflicts of interest in this work.

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