

HOW HIV STATUS IMPACTS CHILD-BEARING DECISIONS: RESULTS FROM A QUALITATIVE STUDY IN KAMPALA, UGANDA

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Introduction

Women who become infected with HIV during their fertile years confront a difficult set of issues related to childbearing. While advances in anti-retroviral (ARV) prophylaxis help HIV-positive women reduce the risk of mother-to-child transmission (PMTCT), availability of ARV remains limited in developing countries. In making fertility decisions, these women are weighing the risk of infection of the newborn, the effect that the pregnancy may have on their health, their estimated life span after having the child and the value they and possibly their partners place on having a child. In addition to these personal issues, social stigma may be exercised upon a pregnant woman whose HIV-positive status is known.

Several studies in developing countries suggest that testing positive does not generally change reproductive behavior and that counseling about contraception does not significantly change pregnancy outcomes among HIV-positive women. Moreover, little is known about how health professionals address the issues surrounding HIV, unwanted pregnancy and abortion and how they treat the abortion complications of women who are known to be infected. An understanding of these factors and how they are interrelated is crucial. It is for this reason that the Guttmacher Institute, in collaboration with Ugandan partners, undertook a study of HIV-positive women's fertility experiences since being diagnosed HIV-positive as well as their fertility expectations in Kampala, Uganda. The study also interviewed health care providers (HCPs) who provide health care to HIV-positive patients specifically around contraceptive use and childbirth.

Background on HIV and pregnancy in Uganda

In Uganda the prevalence of HIV sero-positivity among pregnant women remains unacceptably high despite the fact that the trend over the past decade has been downward (29.5% in 1992 to 11.3% in 2000) (UNAIDS Report 2002). In the perinatal mother-to-child transmission programs (PMTCT), the reported prevalence among pregnant mothers ranges between 8% and 12% (Quarterly Report Mulago PMTCT Programme).

Uganda has a very high fertility rate and a low contraceptive prevalence rate. According to the Demographic Health Survey of 2000, the total fertility rate is 6.9 children per woman and 23% of married women and 44% of sexually active unmarried women use a method of family planning. In addition, about 40% of married women who use contraception are using traditional methods, and about 14% of unmarried users are doing so. Moreover, 51% of married women and 10% of

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unmarried do not want a child soon, or do not want any at all, though are not using an effective method of contraception. Unintended births are very high in Uganda. Around half of all births were reported to be unintended: 30% of them were wanted later and 18% were not wanted at all.

In a country with a low rate of contraceptive use and high HIV prevalence, the question is, what does fertility behaviour look like among HIV-positive women who know their sero-status? What are HIV-positive women's concerns, fears and options when they become pregnant again? In addition, it is not well known how health professionals address issues surrounding HIV-sero-positive women with unwanted pregnancy or with abortion and how they treat abortion complications of women known to be infected. We set out to document the concerns, preferences, communication with partners and others, decisions and practices of HIV-positive women when they become pregnant; to document attitudes, preferences and practices faced by the health professionals when managing HIV-positive women of reproductive age, and to describe HIV-positive women and health professionals' perception of public opinion and stigma associated with HIV-positive women bearing children.

Methods

Study sites:

The study was carried out in two settings: The AIDS Support Organization (TASO) at Mulago Hospital and at the Mulago Hospital PMTCT (Prevention of Mother to Child Transmission of HIV) program, settings that provide specific services for HIV people.

The **Mulago Hospital PMTCT** program started in April, 2000. Mulago Hospital is a national referral and teaching hospital in Uganda and the PMTCT program is run under the directive of the Mulago PMTCT Task Force which includes representatives from all relevant hospital units. They conduct health education, pre- and post-test counselling, provision of Nevirapine tablets for pregnant women and infants, ongoing counselling before and after birth, determination of status for infants at 18 months, and sensitization of the community regarding PMTCT. To date, over 80,000 women attending Mulago ANC¹ have received HIV test results and more than 5,000 sero positive women have received Nevirapine to prevent MTCT.

TASO is a local non-governmental organisation founded in 1987, which has since grown into one of the biggest organised national responses to the HIV/AIDS epidemic. Operating through seven sites and one affiliate site, TASO provides counselling regarding HIV testing, HIV prevention, family and couple relationships, bereavement, and spiritual matters. Program activities also include provision of medical care, institutional and community capacity building, community education, social support, advocacy, and community mobilization.

Study Design:

¹ ANC: Antenatal Clinic

The process of recruiting the respondents was carried out by counsellors from TASO and the Mulago PMCTC program who were viewed as the most trustworthy people by HIV positive women. They discussed the study with potential respondents to find out if they are willing to participate and if the potential respondent was willing, the counsellor established a suitable time/place for the interview. Two interviewers who have the experience with handling the topic conducted all the interviews. Informed consent was obtained from each respondent before the interview commenced.

The semi-structured in-depth interviews were conducted with 40 HIV-positive women 18-49 years old who have tested positive for HIV and who know their HIV status, whether or not they have children who are enrolled in TASO's or Mulago Hospital's programs and 15 health care professionals with different areas of specialization who have HIV-positive female patients. The interviews took place between February and April, 2005.

The HIV-positive respondents were selected using a convenience sample of clients from the two recruitment locations. The health care providers were selected from the study sites, ***TASO and the Mulago PMCTC Program*** as well as from other facilities where care is provided to HIV-positive women of reproductive age.

In-depth interviews with women focused on awareness of women's HIV status and its consequences, women's concerns toward pregnancy and HIV, and decisions on preventing pregnancy. If the respondent experienced a pregnancy while being HIV-positive, either if she found out she was HIV-positive while pregnant or whether she got pregnant after she was aware of her HIV status, a full pregnancy narrative of her most recent pregnancy was captured. In-depth interviews with providers focused on their attitudes, preferences and practices regarding treatment of pregnant HIV-positive women.

Preliminary Results

The analysis which follows draws on data from approximately half of the women IDI respondents. No analysis has been done on the health care provider interviews yet. We have no reason to suspect that the sample of women IDI respondents analyzed to date and therefore included in this write-up is in any different than the remainder of the sample that has not yet been analyzed. Therefore, while the total number of respondents who are being drawn on for this analysis is small, we expect trends emerging at this stage to be reflective of the themes that will emerge in the remainder of the transcripts yet to be analyzed.

How respondents learned of their HIV status

A little over half of the respondents found out they were HIV-positive during a pregnancy. Of the women who found out their HIV-status during a pregnancy, seven respondents described how they had accepted voluntary counselling and testing (VCT) during prenatal care. Two of these respondents suspected they were HIV-positive before they took the test: one respondent said that her husband's former partner died of AIDS, another said that her husband had been ill.

Of the respondents who were tested at other times, two got tested because they had strange medical symptoms, one was tested because she had wanted to study abroad and the test was a

prerequisite; one was tested at school, one got tested because her husband was sick, and one got tested because her husband's girlfriend died.

Just under half of the respondents said that they had been infected with HIV through sexual intercourse with their husbands. Two of these women said that their husbands had had extra-marital relations that they knew about. One said that she had been infected by her parents but was unsure how it happened and two were unsure about how they became infected. The remainder who provided data on this were infected by other partners or were unsure if it was their husbands who infected them.

The most common advice that the respondents received when they were diagnosed HIV-positive was to eat well, not to have unprotected sex and not to worry. Three respondents were told to not have any more children. One was told not to have "too much sex" because the "virus will gain momentum" and one was told to get her child tested. One respondent said she received no information at diagnosis.

Reactions to pregnancy

Except for the two nulliparous respondents, all of the respondents had given birth at least once since finding out they were HIV-positive. Approximately one-fourth of the sample had had no additional pregnancies after they found out that they were HIV-positive, another one-fourth had one more pregnancy after finding out they were HIV-positive, two had two more pregnancies after testing HIV-positive, and two had three more pregnancies after testing HIV-positive.

Among these respondents who knew their HIV status at the time they became pregnant with their most recent pregnancy, over half of these reacted negatively to the discovery that they were pregnant. This sample included respondents from each parity division. Two respondents specifically said that they were concerned that they could die as a result of the physical toll the pregnancy would take, one was scared upon learning she was pregnant but felt better after she received counselling, and another said that she was scared because her child could be born positive. One of the 5+ parity respondents said that it was not good to be pregnant, but that she had no choice: Her partner wanted a child.

When asked whether she had considered abortion, two of the respondents who felt negatively about being pregnant said that they did not think about abortion. Two-thirds of the respondents who felt negatively about being pregnant said that they had thought about abortion. Two were counselled against it, one decided against abortion because she thought about how she could die and one decided against it in the hope of having an HIV-negative child.

Of the two respondents who felt positively when they found out they were pregnant, both of them had intended to get pregnant. The nulliparous respondent said that she wanted to have a baby since she hadn't fallen sick and the 2-4 parity respondent said that she wanted to have that child.

All of the respondents' partners reacted either encouragingly or positively to the news of the pregnancy. One of the respondents who was happy about her pregnancy related that her partner

was also happy and that he did not know of her HIV status. The other respondent who was happy about her pregnancy related that her partner had been sceptical that she would be able to give birth. Among all the other respondents who felt negatively about their pregnancies, the partners were positive and encouraging: One partner encouraged the respondent to receive antenatal care and one expressed hope at having a second boy. One of the respondents in this group also related that her partner did not know about her status. In all, approximately a third of the respondents' partners did not know that the respondent was HIV-positive.

Among the sample who found out they were HIV-positive while they were pregnant with their last pregnancy, two-thirds of the respondents—across the parity divisions—reacted negatively to the news, but for different reasons. A nulliparous respondent said that she was devastated, explaining further that she had already separated from her partner, another said that the health worker whom she spoke to told her the pregnancy was bad because it reduced her life span. Another type of negative reaction to the pregnancy upon finding out she was HIV-positive was worry about the pregnancy experience. One respondent said she was worried because she was scared she would not be able to push out the baby and another worried that being HIV-positive, she would not be able to sustain the pregnancy. Only one respondent who found out that she was HIV-positive during the pregnancy said that she felt positively about the pregnancy and that she was not worried and that she wanted the child. Only two of the 7 pregnancies captured here were intended—one being the pregnancy by the previous respondent who was not worried and another being the pregnancy by the respondent who was scared she would not be able to push the baby out.

Among these respondents who found out their HIV status during their last pregnancy, 3 thought about abortion. Each of these three had reacted negatively to the pregnancy and one had specified that the pregnancy was unintended. They were all parity 2-4. Of the two who provided greater detail about their thoughts regarding abortion, both said that they had decided against it because they feared that they could die during the procedure. One of these two said that she held one never knows if the baby will be born HIV-positive or HIV-negative. The other said that she had been told that having an abortion was more dangerous than having the child and doctors had told her that “Doctors don’t kill,” meaning that she could not get an abortion from him/her.

Four respondents described how their partners reacted positively to the news of the pregnancy—that the partner wanted more children, that he liked the baby, and that they both hoped that the child could be HIV-negative. Yet among this sample, in comparison to the sample described above whose partners who unanimously supportive, two respondents in this sample related that their partners reacted negatively. Both of these were respondents who had considered abortion. One respondent related that she and her partner decided together not to have an abortion. The other related that her partner wanted her to have an abortion but she refused and he stopped talking to her until she gave birth.

Future childbearing preferences

Among the women with parity 0 or 1, all of them were able to clearly enunciate what their fertility preference had been prior to being diagnosed HIV-positive and were able to clearly define their new preference for half or fewer children than they had hoped to have prior to their

diagnosis. Of the two nulliparous respondents, only one still intended to have children. The other did not intend to have any children. Both of the parity=1 respondents hoped to have one or two more children. The reasons the respondents presented for revising their total desired fertility were that her, the mother's, life would be further compromised and that it degraded her morale to have children.

The respondents of parity=2-4 were less able to vocalize how their childbearing preferences may have definitively altered based on their HIV-status. While a few specified that they had revised their fertility preferences down because of their HIV status, this appeared to be less of a conscious decision for these respondents because some of them had already had their intended number of children: Four respondents said that they want no more children. One respondent specified that her HIV status did not influence her desire to have children. The reasons given by these respondents for how their HIV status influenced their attitudes towards having children were that pregnancies put her life further at risk and because she has responsibilities to take care of her existing children. While one respondent said that she originally wanted to have "all the children that God determined," she stated that she was now committed to not having any more (she had three). Two respondents spoke of the role that counsellors played in helping them determine their fertility preferences.

The respondents of parity=5+ were even more likely to say that they wanted "no more" children than the other two parity groups. Concomitantly, their reasons as to why they wanted no more children were less well-defined than the other two parity groups. One respondent with eight children said that she simply lost interest in having children but it was unclear if this was related to her HIV status or not. This group did have two cases of reported child mortality of the last child.

When asked if they wanted another child, approximately half of the respondents said that they did want another child. Their reasons were that because with Nevirapine it is possible to have an HIV-negative child. A woman with one child said that her one child would feel lonely without a sibling. The large minority of respondents who said that they did not want to have a child gave as their reasons that they don't have a partner and their HIV status (this reason was given by a parity=0 respondent).

When asked how they would react if they were to get pregnant now, approximately half said that it would be a bad thing if they got pregnant right now—distributed across all the parity groups. One woman said that it would be so sad because her health would be compromised, another said that if the man responsible for the pregnancy were not positive and he found out she was, he'd abandon her. The majority of other respondents said that they would greet the news of a pregnancy by talking to a counsellor and getting early, specialized pre-natal care. Only one woman with parity=1 said that she would feel positively if she got pregnant.

No woman said that she would have an abortion, although one parity=5+ respondent said that she would explore the possibility and go talk to health workers for a consultation. The reasons they gave for not having an abortion was because after an abortion, women can end up with complications such as an injured uterus or bladder and possibly even die; an abortion would

compromise her health more than a delivery; it is illegal; it is against the teachings of the bible; and if you follow the correct procedures, the baby can be healthy. One woman said that she can't imagine having an abortion and another said that she would never have an abortion.

Conclusion

Most women believed they had been infected by their husbands. The most common advice they received at the time of diagnosis as to eat well, not to have unprotected sex and not to worry. It was not clear whether the admonition not to have unprotected sex was meant to protect the woman and her partner from spreading the virus, to contracept, or both. Only just over one in ten respondents were told not to have any more children.

Among the respondents who found out they were HIV-positive while they were pregnancy, two-thirds reacted negatively to the news, compared to over half of the respondents who knew they were HIV-positive when they became pregnant with their last pregnancy. While two-thirds of the respondents who knew they were HIV-positive when they became pregnant thought about abortion, less than half of the respondents who found out they were HIV-positive during their last pregnancy thought about abortion. Therefore, the women that knew that they were HIV-positive at the time of conception more commonly thought about abortion than women who found out during the pregnancy that they were HIV-positive. Yet the reasons why both groups of women decided against abortion were similar—that they feared death and that they hoped they could have an HIV-negative child.

In spite of this inner turmoil that the respondents were experiencing, almost all of their partners reacted positively to the news of the pregnancy. Only two partners of women who found out they were HIV-positive during the last pregnancy did not react positively to the pregnancy and in both situations, the couple discussed the possibility of abortion. Partners' positive reactions can be understood in part by the fact that approximately a third of the respondents' partners did not know that the respondent was HIV-positive. Men's almost unanimous support of the respondent's last pregnancy may be a reason why none of the women had an abortion.

As would be expected, the respondents with the lowest parity were most likely to have revised their desired fertility downward, usually by half, based on their HIV diagnosis. The primary reason for revising this number downward was that women said that future pregnancies would further compromise her life. Higher parity women were less able to enunciate specific changes to their desired fertility based on their HIV status. Nevertheless, approximately half of the respondents still wanted at least one more child. Many of these women said that they wanted this child because with Nevirapine, it is possible to have an HIV-negative child. Yet when asked how they would react if they were to get pregnant now, approximately half said that it would be a bad thing if they got pregnant right now—distributed across all the parity groups. Therefore, there might be a difference between wanting more children—in the abstract—versus being pregnant now. The latter might be more influenced by the woman's present circumstances including her health. This possible contradiction might shed light onto why the majority of respondents want more children but most reacted negatively upon finding out they were pregnant with their last pregnancy.

While abortion was rejected by the vast majority of respondents even when the pregnancy was unwanted, the most common reason given for rejecting the possibility of having an abortion was because of its physical dangers since abortion is illegal in Uganda. Only three respondents expressed moral reasons against having an abortion.

Many of these women experienced unwanted fertility after being diagnosed HIV-positive. More children born to HIV-positive women increases the health burden on HIV-positive women and will most likely lead to early family disintegration due to the mother's premature death, thus increasing the burden of AIDS orphans in countries already strapped of resources, in part, because of their efforts to provide medical care to their HIV-positive population. Women's fears and concerns about having children as well as contraceptive counselling and stigma experienced by HIV-positive women in addition to health care providers' experiences and attitudes towards HIV-positive pregnant patients remain to be explored in this extremely rich data set.