The right not to know HIV-test results

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Summary

Large numbers of pregnant women in Africa have been invited to participate in studies on HIV infection. Study protocols adhere to guidelines on voluntary participation after pre-test and post-test counselling and informed consent; nevertheless, women may consent because they have been asked to do so without fully understanding the implications of being tested for HIV.

Our studies in Nairobi, Kenya, show that most women tested after giving informed consent did not actively request their results, less than one third informed their partner, and violence against women because of a positive HIV-antibody test was common. It is important to have carefully designed protocols weighing the benefits against the potential harms for women participating in a study.

Even after having consented to HIV testing, women should have the right not to be told their result.

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Introduction

The number of women of reproductive age in Africa infected with HIV is increasing rapidly, and for almost a decade, studies of perinatal HIV transmission have been undertaken. These studies are based on voluntary participation after informed consent and counselling before and after the test. The aims of counselling women with positive tests are to help them cope with the disease and prepare for the future, to reduce risk behaviour, and to enable women to make informed choices about reproductive health issues. However, little is known about the effectiveness of counselling pregnant women. We report here some effects on women of being told they are HIV positive in perinatal transmission studies in Kenya.

Patients and methods

As part of a study examining the effect of maternal HIV infection on pregnancy outcome in Nairobi, 7893 pregnant women from two ante-natal clinics were tested for HIV infection between January, 1989, and March, 1992, according to a protocol approved by the National AIDS Control Programme in Kenya. The methods and results of these studies have been described.[1–3] All pregnant women were invited to participate in the study after a group information session on HIV and other sexually transmitted diseases (STDs), which was given by a study nurse. Blood was obtained for HIV-1 and syphilis antibodies after individual counselling and informed consent, as recommended by the World Health Organization.[4,5] Counselling after a positive test was provided by a trained counsellor, and women were encouraged to visit the clinic at any time for further support. The effect of HIV infection on their own lives and the lives of their families was discussed. Emphasis was placed on information about heterosexual transmission, potential impact of future pregnancies on the woman's health, on the risk of perinatal transmission, and the high mortality of infected children. Women were advised to inform their partner of their HIV status, and to bring their partner to the clinic for further counselling. A free supply of condoms was offered as well as a choice of all family planning methods currently used in Kenya. The overall HIV-1 seroprevalence was 8·5% (672/7893).

Results

During the first two years of the study, 5274 women were tested for HIV and given an appointment one week later to collect their results. Over 90% of women returned to the clinic as instructed and were given their test result. 324 women were HIV positive and invited to participate in a study of HIV infection and pregnancy outcome. More than 25% dropped out immediately before counselling could be provided and never returned to the clinic. Out of 243 women invited to participate and counselled on at least two occasions, only 66 (27·2%) communicated the test result to their partner, of whom 21 showed up with their partner to be tested and counselled. 5 (23·8%) of these partners were HIV seronegative.

11 women were chased away from their house or replaced by another wife, 7 were beaten up, and 1 committed suicide. Most of these women (13 out of 19) had informed their partner as instructed by the research staff.

No (%)	Years of study	
	1989–91	1991–92
Tested	5274	2619
HIV positive	324 (6·1%)	311 (11·9%)
Counselled	243 (75·0%)	109 (35·0%)
Partners tested	21 (8·6%)	9 (8·3%)
Violence*	19/324 (5·9%)	6/311 (1·9%)

*No of women experiencing violence/no of women HIV positive.

Table: **Violence against women after HIV counselling**

Alarmed by the violence against women as a consequence of their being identified as HIV positive, we changed our policy on counselling. For the last year of the study we continued providing information on HIV and STDs to pregnant women waiting at the antenatal clinic, but after the blood test we did not give them an appointment for collection of results. Instead we told the patients they could come in at any time during the morning and ask for their results, or they could collect them at the next pre-natal visit.

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Only 109 out of 311 (35%) women with a positive test during the third year of the study ever called for the result or asked at subsequent pre-natal visits. Of the 9 partners who came to the clinic, 2 were seronegative. Violence related to the HIV testing was reported by 6 women (table). Throughout the study, the results of the blood test were requested at equal rates by HIV-seropositive and HIV-seronegative women, suggesting that this population did not consider themselves at special risk.

Discussion

These findings suggest that most women in this situation consent to testing if asked by someone they trust—in this case a medically trained person who is supposed to know what is best for them. Thus, if an appointment to return to the clinic was given, they kept it because they were told to; not necessarily because they wanted to know the test result. When free to inquire only if they wanted to, the majority of these women (202/311, 65%) did not. This attitude could be due to many reasons, including fear, ignorance, or reluctance to face additional burdens in life.

Our results also show that being enrolled in a study of perinatal HIV transmission is not always harmless for the women involved, who are often blamed for bringing AIDS or other diseases into the family. There is not much we can offer African women once we have told them the bad news: there is no zidovudine or any other medication available—neither for herself nor for preventing transmission to her child. The child is at high risk of being infected and there is no safe alternative to breastfeeding in most settings. Hence, the options for women who know they are HIV positive are either trying to cope with this extra burden silently or sharing the information with their partner at the risk of violence and/or divorce, and hence the breaking up of a family unit. The violence reported is probably an underestimate because we were not able to follow-up women in their communities and homes; our data only reflect spontaneous reports by women or their relatives.

Over 80% of our patients were married women in a stable relationship. Thus, the spread of the HIV epidemic may not be influenced by educating this group about the risks of transmission. Our findings are similar to those of previous studies in Nairobi in which 37% of HIV-infected pregnant women informed their partner,[6] and in Kinshasa where only 2% of women brought their partner for testing and counselling.[7] Also, knowledge of HIV-antibody status combined with an understanding of the risk of HIV transmission and possible adverse effects on health did not have a major impact on women's attitudes or subseqent childbearing.[6-9] This is not surprising given the strong pressure on women to bear children and the partner's lack of participation in HIV counselling.

Perinatal transmission and intervention studies should be carefully designed and women carefully selected after counselling. Even after agreeing to be tested, potential participants should be given the chance not to be informed on the test result and should have the right not to know. Before undertaking a new study, investigators should weigh the benefits of the study for women involved against possible risks such as increased violence and loss of security.

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