

Women's reasons for not participating in follow up visits before starting short course antiretroviral prophylaxis for prevention of mother to child transmission of HIV: qualitative interview study

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Abstract

Objective To find out why pregnant women who receive HIV-1 positive test results and are offered short course antiretroviral prophylaxis to prevent transmission of HIV from mother to child do not participate in necessary follow up visits before starting prophylaxis.

Design Qualitative interview study.

Setting A programme aiming to prevent transmission of HIV from mother to child at a public antenatal clinic in Abidjan, Côte d'Ivoire.

Participants Purposive sample of 27 women who had received HIV-1 positive test results and were invited to return for monthly follow up visits before starting prophylaxis with zidovudine at 36 weeks' gestation, but who had either refused or discontinued the visits. None of the women started prophylaxis.

Results Most of the women explained their non-participation in follow up visits by referring to negative experiences that they had had while interacting with programme staff or to their views about the programme. Additional reasons concerned their disbelief of HIV positive test results and personal factors.

Conclusions Difficulties experienced by women during their contacts with staff working on the prevention programme and negative views that they have about the programme can contribute to their non-participation in prophylaxis. Training and supervision of programme staff may increase the likelihood of positive interactions between staff and clients, thereby facilitating women's participation in preventing transmission of HIV from mother to child. Outreach and mobilisation in communities that are served by prevention programmes may complement these measures at programme level by contributing to increased social support for women's efforts to prevent transmission of HIV from mother to child.

Introduction

Treatment for the prevention of transmission of HIV from mother to child has become increasingly available in Africa, but many women do not participate (see also bmj.com). Refusal to be tested for HIV and non-receipt of HIV test results have been studied as barriers to participation,¹⁻³ but no studies have examined why fewer than one third of pregnant women who receive HIV-1 positive test results eventually start taking antiretroviral prophylaxis.⁴⁻⁵ This problem affected a programme aiming to prevent transmission of HIV from mother to child in Abidjan, Côte d'Ivoire, where the seroprevalence of HIV-1 in

pregnant women is 12%.⁶⁻⁷ At the time of our study, the programme included group counselling before HIV testing, conducted by trained social workers, followed by private sessions with social workers during which individual women accepted or refused HIV testing, and HIV testing; counselling two weeks after the test by trained social workers or programme doctors; and, for women whose test results were positive for HIV-1, monthly follow up visits with a programme midwife before starting free prophylaxis with a short course of zidovudine at 36 weeks' gestation; and zidovudine before and during labour.⁶ Programme staff informed women about the risks of HIV transmission through breast feeding but did not advise against it. During the programme's first 15 months of operations, from February 1998 to the end of May 1999, 72% of 9657 pregnant women who were offered HIV testing accepted the test. Of the 884 women who tested positive for HIV-1, 395 received their test results. Only 118 (35%) of the 333 women who tested as positive for HIV, who received their test results, and who were invited to return for follow up visits during this period eventually started taking zidovudine. Of the 215 women who did not start taking zidovudine, 181 had refused to return or discontinued follow up visits. Another 34 were lost to follow up or removed from the programme because they were ineligible (unpublished data).⁶ We studied women's non-participation in follow up visits before starting prophylaxis.

Methods

We conducted our qualitative, cross sectional study from October 1998 to the end of May 1999. We present interview data from women who had received test results that were positive for HIV-1 and had been invited by programme staff to return for monthly follow up visits, but who had either refused or discontinued the visits. None of them had started taking zidovudine.

The women of interest to our study were sampled purposively. They had no further contacts with programme staff, but a programme doctor on our team was able to locate and contact these women because they continued to see other staff at the clinic for consultations before and after giving birth, to have their babies vaccinated and weighed (see bmj.com).

Data collection and analysis

Female sociology students from the Université de Cocody (Abidjan) interviewed individual women in

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French or Dioula, asking open ended questions about their reasons for refusing or discontinuing follow up visits.

Sociodemographic characteristics

The median age of the women was 24. Eighteen had been born in Côte d'Ivoire; 14 were nationals of nearby West African countries. They had limited education (zero median years of completed schooling, range 0-9 years); 17 were non-literate in French. The median number of living children per woman was 1 (range 0-5); they reported 23 instances of miscarriages (3), stillbirths or infant deaths (13), or abortions (7). The median length of time since the women's latest HIV test was four months.

Results

Twenty four of the 27 women described their interactions with programme staff or their views about the programme when explaining their refusal or discontinuation of follow up visits; 14 did not believe their HIV positive test results; four described personal factors.

Experiences at the programme

Interactions with programme staff

Some women were dissatisfied with how HIV testing had been explained—for example, "If [the social worker] had talked about AIDS from the start, I would not have taken the test because I am afraid to know that I'll die from such a horrible disease"; others were unhappy with counselling after the test—"The social worker told me I was negative and then she said that my blood was not clean. How can you be negative and have dirty blood? It is nonsense."

Some women were afraid of the staff—"I did not want to continue the pregnancy [but she then changed her mind]. I was afraid to come back when I finally decided to keep the infant. I thought the doctors would chase me away; would yell at me." "I came for the appointment, but unfortunately I went to see a clinic midwife who had been seeing me. She told me that I did not have an appointment, so I did not know which midwife to see. I didn't know whom to ask, and I was afraid of being yelled at in front of the other pregnant women. So I went home, and I did not do anything else because I was discouraged."

Four of the 13 women who had discontinued follow up visits could not find programme staff when they returned for their follow up appointments—"I waited for more than one hour, but I did not find anyone. I continued my visits to [other clinic departments]. I did not have the courage to return." "I thought it was impossible to continue if I missed [sic] an appointment. I was afraid of the midwife's reaction. I was afraid to come back."

These responses indicate the importance of positive demeanour of the staff and clear explanations of the programme's procedures—for example, women who cannot complete follow up visits need to know that they will be welcomed, not scolded, for returning again. When women return, staff members must be available to meet them. Training for programme staff may be necessary in interaction skills, punctuality, etc. Additionally, periodic supervision and occasional

interviews with women after their staff contacts may be useful for gauging the extent to which staff use their skills appropriately. The results of supervision and exit interviews need to be reviewed with staff promptly, and recurring issues need to be dealt with in subsequent training and supervision.

Views about the programme

Some of the women did not believe that prophylaxis was effective—"We are told that the virus passes in the blood and my infant shares my blood. The contamination between me and my infant had already happened, so [there is] no hope of saving it. We have always been told that you can't cure AIDS, so the medications that I heard about are nothing but an illusion for me." The handling of blood specimens caused concerns: "The doctors can make mistakes with the blood during the test," as did fears that participation would lead to serostatus disclosure: "I wanted to think about it before deciding because I wanted to see how I could come back here without having someone I know learn about it. My husband might see me with the medicines, and he will want to know what they are for. That way he will find out about my [HIV positive test] result. Even the location bothers me, because everyone who comes to the clinic knows what goes on [at the programme]. As soon as a pregnant woman is seen coming here, it's known right away that she is seropositive." Costs also created barriers: "I was not able to complete any appointments, because of [not having] money for the ultrasound examination. If I don't have it, I won't be followed up by the midwife."

Programme staff need to ensure that their clients have up to date information on the interventions that are proposed to them. When, as is the case at the Abidjan facility, services for the prevention of transmission from mother to child are separate from other perinatal services, changes in the physical layout of service delivery may reduce the likelihood of unwanted visibility that can be associated with participating in interventions. Integrating prevention services for transmission from mother to child with other services for mothers and children may be helpful. Finally, programme policies could be modified to reduce or eliminate fees that impede participation.

Disbelief of test results

Fourteen of the women did not believe their HIV positive test results—"I do not touch sharp objects that belong to other people; I have known only two men in my life, and I think they are not positive." "I was negative on my first test, and I have not had any changes in behaviour or partners." All three women who had discontinued the follow up visits for this reason added that they had had no intention of returning again—"I'm sure that I am negative and my baby is fine; it's not sick. If I were positive like they say, I would not be in such good shape! I told the midwife that I would participate because I wanted to get away from her."

Programme staff need to explain that circumstances such as those described in the responses above, and which women may interpret as contributing to, or as being indicative of, a reduced risk or no risk of HIV infection, do not necessarily do either. Women must have accurate information about the circumstances of risk and effective prevention measures.

Personal reasons

These reasons included highly personalised reactions—"I was ashamed of myself, to realise that I was infected by AIDS"—and descriptions of disruptions in women's lives: "I did not see the midwife because the social worker told me to come back another day. But I could not return because my house burned down and I had to move to Marcory [another neighbourhood]. This was a long distance for me, and I didn't have enough money to come here several times."

Although programmes cannot deal with unexpected events that affect women's lives, these examples show the importance of staff demeanour that is supportive of women's feelings and programme policies that are responsive to circumstances that may impede their participation—for example, the costs of transport to the programme could be covered.

Discussion

Factors associated with the functioning of a programme aiming to prevent transmission of HIV from mother to child created barriers to the participation of pregnant women who knew that they were HIV-1 positive in follow up visits that were necessary before starting zidovudine prophylaxis. For many of the women in the study, these barriers consisted of negative experiences that they had had or expected to have during their interactions with staff working at the programme.

Outreach and mobilisation

Many of the women were concerned about their problematic contacts with programme staff, but some of their responses—for example, with regard to fears about disclosure of their serostatus, their understandings, beliefs, and views about HIV risk, transmission of HIV from mother to child, its prevention, and about the programme itself—indicate that efforts may also be needed in the communities where women live. Involving women's partners in the prevention of mother to child transmission of HIV is widely recognised to be desirable, but this rarely occurs.⁸ Outreach to couples in Zambia has increased participation by women's partners in HIV counselling and testing⁹; this approach may lend itself to adaptation by programmes that aim to prevent transmission of HIV from mother to child. In addition to media based approaches for disseminating prevention information, outreach focused on couples can provide women and their partners with opportunities outside antenatal settings—where men are rarely seen—to discuss and clarify their understanding of transmission of HIV from mother to child and options for prevention. Outreach to couples and community mobilisation may complement the measures at programme level that are suggested above by contributing to greater social support for women's prevention efforts, thereby increasing their sense of self efficacy and making it easier for them to protect their infants.^{10–12}

Generalisability of findings

We used purposive recruitment to interview women who were difficult to reach; therefore our findings may not be generalisable to other women in similar circumstances. However, they provide insights

What is already known about this topic

Women's refusal of HIV testing and their non-receipt of HIV test results have been studied as barriers to the prevention of HIV transmission from mother to child in Africa

No studies have examined why pregnant women who receive HIV positive test results do not begin prophylaxis after it is offered to them

What this study adds

Difficulties experienced by women during their contacts with staff of a programme aiming to prevent transmission of HIV from mother to child, and negative views they have about the programme, can contribute to their non-participation in prophylaxis

Programme related barriers to women's participation need to be understood better and dealt with to facilitate the prevention of HIV transmission from mother to child

concerning factors that can affect women's actions once they learn that they are HIV positive and that prophylaxis is available. Although this kind of study presents ethical as well as methodological challenges, our recruitment strategy aimed to protect women's confidentiality. Our team's programme doctor was as discreet as possible when contacting women about interviews. Both he and the interviewers emphasised that participation in interviews was voluntary and anonymous; all the women who were contacted could refuse either at the time of their initial contact or when they met interviewers. Most of the women spoke freely about their experiences; it is therefore possible that these structured conversations created opportunities for them to discuss topics that were difficult to discuss with other people, including, on a routine basis, programme staff. Focused dialogues of this kind offer the potential for increasing the capacity of programmes to prevent mother to child transmission of HIV to understand the circumstances of the women they serve better and to serve them more effectively.

Conclusion

Barriers of the kind described in this paper may contribute to persistently low levels of participation in prophylaxis elsewhere in Africa by pregnant women after receipt of HIV-1 positive test results, but research on these factors has been limited. Greater efforts are needed by qualitative researchers and by management and staff of programmes for the prevention of transmission of HIV from mother to child, to clarify and address programme related barriers to protecting African infants from HIV infection.

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- 1 Cartoux M, Meda N, Van de Perre P, Newell ML, de Vincenzi I, Dabis F. Acceptability of voluntary HIV testing by pregnant women in developing countries: an international survey. *AIDS* 1998;12:2489-93.
- 2 Kiarié J, Nduati R, Koigi K, Musia J, John G. HIV-1 testing in pregnancy: acceptability and correlates of return for test results. *AIDS* 2000;14:1468-70.
- 3 Ladner J, Leroy V, Msellati P, Nyiraziraje M, De Clercq A, Van de Perre P, et al. A cohort study of factors associated with failure to return for HIV

- post-test counseling in pregnant women: Kigali, Rwanda, 1992-1993. *AIDS* 1996;10:69-75.
- 4 Ekouevi DK, Rouet F, Becquet R, Inwoley A, Vihoo I, Tonwe-Gold B, et al. Immune status and uptake of antiretroviral interventions to prevent mother-to-child transmission of HIV-1 in Africa. *J Acquir Immune Defic Syndr* 2004;36:755-7.
- 5 Malonza IM, Richardson BA, Kreiss JK, Bwayo JJ, Stewart GC. The effect of rapid HIV-1 testing on uptake of perinatal HIV-1 interventions: a randomized clinical trial. *AIDS* 2003;17:113-8.
- 6 Wiktor SZ, Ekpini E, Karon JM, Nkengasong J, Maurice C, Severin ST, et al. Short-course oral zidovudine for prevention of mother-to-child transmission of HIV-1 in Abidjan, Côte d'Ivoire: a randomized trial. *Lancet* 1999;353:781-85.
- 7 Ezoua J, Sassin-Morokro M, Ekra A, Sidibé K, Maurice C, Nolan M, et al. Trends in HIV prevalence among pregnant women attending urban antenatal clinics in Côte d'Ivoire, 1997-2000. Abstract presented at the XIIIth International Conference on AIDS and STD in Africa, Ouagadougou, Burkina Faso, 9-13 December 2001. [Abstract 12PT5-416.]
- 8 Nebié Y, Meda N, Leroy V, Mandelbrot L, Yaro S, Sombié I, et al. Sexual and reproductive life of women informed of their HIV seropositivity: a prospective cohort study in Burkina Faso. *J Acquir Immune Defic Syndr* 2001;28:367-72.
- 9 Mckenna SL, Muyinda GK, Roth D, Mwali M, Ng'andu N, Myrick A, et al. Rapid HIV testing and counseling for voluntary testing centers in Africa. *AIDS* 1997;11:S103-110.
- 10 Painter TM. Voluntary counseling and testing for couples: A high-leverage intervention for HIV/AIDS prevention in sub-Saharan Africa. *Soc Sci Med* 2001;53:1397-411.
- 11 Allen SA, Karita E, N'Gandu N, Tichacek A. The evolution of voluntary testing and counseling as an HIV prevention strategy. In: Gibney L, DiClemente RJ, Vermund SH, eds. *Preventing HIV in developing countries: biomedical and behavioral approaches*. New York: Plenum Press, 1999:87-108.
- 12 Farquhar C, Mbori Ngacha D, Bosire R, Nduati R, Kreiss J, John G. Prevalence and correlates of partner notification regarding HIV-1 in an antenatal setting in Nairobi, Kenya. Abstract presented at the XIII International AIDS Conference, Durban, South Africa, 9-15 July 2000. [Abstract TuOrC307.] (Accepted 6 July 2004)

Relation between online “hit counts” and subsequent citations: prospective study of research papers in the *BMJ*

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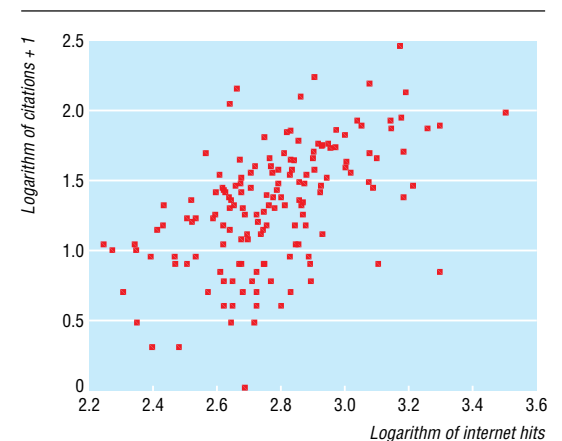
Evaluation of published medical research remains a challenge. Two classic yardsticks are the citation count (the number of times a given paper is cited by others)^{1,2} and the impact factor of the journal that published the paper (which reflects the average number of citations per article).^{2,3} However, the citation count can be assessed only several years after publication, and the impact factor is not paper specific and is thus virtually meaningless in assessing any given paper.³ Another measure, which can be obtained rapidly and is paper specific, is the “hit count” (the number of times a paper is accessed online). Whether this count predicts citations is unknown. I examined this issue prospectively in a cohort of papers published in the *BMJ*.

Methods and results

The study used articles published in volume 318 of the *BMJ* (1999) in sections titled Papers, General Practice, and Information in Practice. The hit counts (full text articles, HTML version) for the main body of each article within a week of publication were provided by a *BMJ* staff member because the “hit parade” posted on the journal website was found to be unreliable for 1999. I obtained the number of citations on 24 May 2004 from the ISI Web of Science, an internet service

to which the local medical library has a subscription.¹ I also recorded for each paper the study design and the number of pages.

Nine papers were excluded because they did not report research (but reported discussions of, for example, NHS management and statistics methods). The remaining 153 papers comprised 29 randomised trials,



Relation between citations and internet hits for 153 papers in volume 318 of the *BMJ* (1999)