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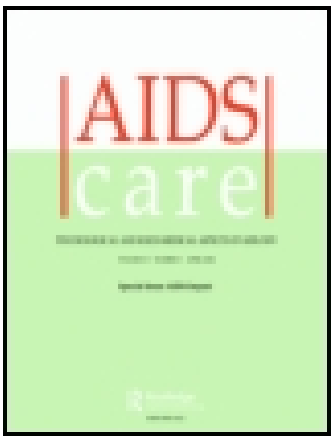

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Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda

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Attitudes to voluntary counselling and testing for HIV among pregnant women in rural south-west Uganda

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Abstract *This paper describes the results of a study exploring the attitudes of women attending maternity clinics to voluntary counselling and testing during pregnancy in rural areas in south-west Uganda. It was a qualitative study using focus group discussions (FGDs). Twenty-four FGDs were carried out with 208 women attending maternity clinics in three sites in rural south-west Uganda. The FGDs were all recorded and transcribed, and analysed using standard computer-based qualitative techniques. Almost all women were willing in principle to take an HIV test in the event of pregnancy, and to reveal their HIV status to maternity staff. They were anxious, however, about confidentiality, and there was a widespread fear that maternity staff might refuse to assist them when the time came to deliver if their status were known. This applied more to traditional birth attendants than to biomedical health staff. There were also rumours about medical staff intentionally killing HIV-positive patients in order to stem the spread of the epidemic. Women were concerned that if their husbands found out they were HIV-positive they would be blamed and separation or domestic violence might result. In conclusion: although VCT during pregnancy is acceptable in principle, much will need to be done to ensure confidentiality and allay women's fears of stigmatisation and discrimination during delivery. Community sensitisation will be necessary and male partners will have to be involved if interventions are to be acceptable.*

Introduction

Vertical transmission rates of HIV in Africa are 21–43%, and most infants acquire infection during the peripartum period. Interventions to reduce the risk of mother-to-child transmission of HIV in areas where antenatal testing programmes are not in place will require a large degree of preparation to ensure that infected women are appropriately identified and understand the benefits of treatment.

Studies have shown that treatment with zidovudine (AZT) can significantly reduce the rate of vertical transmission of HIV. A trial in France and the USA (ACTG 076) showed a 67% reduction in transmission with a regimen involving oral AZT treatment of pregnant women from 24 weeks, intravenous infusions in labour and treatment of the infant after delivery for six weeks (Connor *et al.*, 1994). This regimen is, however, too costly (about $300 per woman) and too technically demanding to be useful in developing countries. Encourag-

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ingly, a subsequent trial in Thailand has shown a 50% reduction in vertical transmission can be achieved using AZT in pregnant women from 36 weeks and three-hourly during labour (Shaffer *et al.*, 1999). In this study there was no post-delivery treatment and women did not breastfeed. This regimen is more practical and less expensive (about $75 per woman), but still may not be appropriate in the rural African setting where there is little alternative to breastfeeding.

Two studies of short course AZT in breastfeeding populations in Africa have been published recently. These studies showed a 37–38% reduction in transmission at three and six months (Dabis *et al.*, 1999; Witkor *et al.*, 1999). A third African study has also been reported recently (Saba *et al.*, 1999). This found that treatment with AZT and 3TC reduced transmission by 50% when the drugs were given from 36 weeks gestation, intrapartum and postnatally for one week, and by 37% when treatment is given intrapartum and postnatally. The cost of the two regimens was $150 and $25, respectively.

More recently, a study has been reported from Uganda where just two doses of nevirapine (200 mg at the onset of labour and 2mg/kg to the neonate within three days of birth) reduced vertical transmission by 48% compared to AZT (600 mg at the onset of labour and 300mg doses every three hours during labour, followed by 4mg/kg given to the neonate twice daily for one week). Transmission rates were assessed at 14–16 weeks after delivery. The cost of this regimen is $4 per woman (Guay *et al.*, 1999, Marseille *et al.*, 1999).

This latter regimen is more appropriate to the African situation, being more affordable and technically feasible, but it still cannot be adopted wholesale. Although provision of nevirapine to all pregnant women might be potentially cost effective, ideally HIV-positive pregnant women should be targeted in poor resource countries. This requires voluntary counselling and testing (VCT). However, women might not wish to come forward for treatment because of the stigma of openly acknowledging their HIV status. Clearly, if they do not come forward for treatment then the intervention will not achieve its public health potential. The acceptability of VCT to women is therefore important to the success of such interventions. A comparison of 13 studies in urban areas, mainly in Africa, showed that VCT is acceptable to pregnant women who want to reduce the risk of transmitting HIV to their children (Cartoux *et al.*, 1998). However, as the authors point out, in many developing countries women may be reluctant to be tested for fear of discrimination or domestic violence (Temmerman *et al.*, 1995; Van der Straten *et al.*, 1995) In this paper we report the results of a study of the attitudes to voluntary counselling and testing of women attending maternity clinics in three rural areas in south-west Uganda.

There is no routine counselling and testing of pregnant women (or indeed anyone else) for HIV in rural Uganda. VCT is available in hospitals and other centres in the urban areas, and The AIDS Support Organisation (TASO) has eight regional centres that provide VCT and basic medical care to people living with HIV and AIDS. Although they do also operate in the rural areas surrounding the towns in which they are situated (in a radius of about 35 km), these services are not specifically targeted to pregnant women.

Methods

The study was carried out in Masaka District in south-west Uganda by the Medical Research Council Programme on AIDS, which has been collecting community-based data on various topics relating to HIV since 1988. The prevalence of HIV among the general adult population in Uganda is estimated at between 4% in some rural areas and about 25% in some urban centres. The prevalence in Masaka District is about 8% of the adult population in the

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study area (Nunn *et al.*, 1997). The HIV prevalence in pregnant women is estimated at just over 10% (Carpenter *et al.*, 1999). Masaka District has a largely rural population that is dependent on subsistence agriculture.

Twenty-four focus group discussions (FGDs) were carried out with 208 women attending seven maternity clinics in three rural areas. After discussing the project with the health workers, the researchers were introduced to women attending the maternity clinics. The fieldworkers told the women that we were interested in discussing various issues relating to counselling and testing for HIV during pregnancy. The researchers then asked the women whether they would be willing to participate in the discussions. A time and place were arranged and all the women who turned up were included in the FGDs. Most of the women turned up, though we are not sure of exactly how many did not and their reasons for not coming. Of the 208 participants, approximately 30% were pregnant at the time of the study, the remaining 70% were breastfeeding. As they came from the same community many of these women would have known each other.

In focus group discussions, which are currently one of the most widely used methods for collecting qualitative data in the social sciences, the idea is that the participants discuss the relevant topics among themselves with the facilitator keeping the discussion moving and on track (Morgan, 1993; Stewart & Shamdasani, 1990). The FGDs in this study had between six and ten participants each. An expert facilitator supervised them while an assistant took notes recording body language and impressions, and operated the tape recorder. The same facilitator managed all FGDs. Topics that were presented to the participants for discussion included:

- Can a woman pass on HIV to her infant through breastfeeding?
- Can unborn babies of HIV-positive women be HIV-negative? If so, can they become infected during delivery?
- If it were possible to reduce the chance of HIV-positive women passing on HIV to their infants during delivery by giving them treatment that required them to be counselled and tested and to reveal their HIV status to maternity staff in order to get the treatment, would women be willing to be counselled and tested? Would you be willing to be counselled and tested?
- Would you inform maternity staff if your result was positive? What would be the reasons for testing or not testing, informing or not informing?

An attempt was made to recruit women who already had at least one child, so most of the participants had personal experience of delivery and breastfeeding.

All FGDs (which lasted for an average of 90 minutes) were transcribed verbatim in the vernacular (Luganda) and translated into English. These texts, together with the assistant facilitator's notes, were entered into Atlas-ti (Scientific Software Development, Berlin), a software program based on the grounded theory approach and designed to assist in the coding and analysis of large amounts of textual data. Analysis made use of what have become standard qualitative techniques: texts and observations are coded using inductively generated codes to label important themes and topics, and coded segments are then compared both within and between FGDs, thus generating higher order generalisations (Fielding & Lee, 1998; Miles & Huberman, 1994; Strauss & Corbin, 1998).

The presentation below closely follows the sequence in which the various topics were discussed in the FGDs. Following the sequence of the topics as they were discussed reflects the natural flow of the FGDs.

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Results

Study population

The median age of the respondents was 23 (range = 14–38 years), the median number of children was three (range = 0–9). They were all housewives or peasant farmers.

Awareness of vertical transmission

Although most women were not aware that HIV could be transmitted through breast milk, they were aware that the baby could be infected during delivery because of blood contact:

> Facilitator: Can a baby of an infected mother get HIV through her mother's breasts? Can the baby be infected through breastfeeding?
>
> Nabiteeko[1]: Personally, I hear that the baby gets infected at birth, when cutting the umbilical cord.
>
> Nabbumba: AIDS does not pass on to the baby through breastfeeding,[2] perhaps when the baby is being delivered and the infected mother's blood mixes with the baby's blood, that is when the child can get AIDS.
>
> Nalubega: We were told by medical workers that it is not easy for the baby to be infected through breastfeeding, and they said that in most cases the baby is infected during birth, when the mother's blood is transmitted to the baby through the umbilical cord.

Testing and counselling

We did not make any attempt to find out the women's current HIV status or whether they knew their status. Some women were, in principle, willing to take an HIV test and be counselled in the event of pregnancy. Others were unwilling because of the possible consequences and stigma attached to obtaining a positive HIV result. The women were aware that treatment would not benefit them, only their infant (the facilitator had explained this):

> Facilitator: Would you be willing to have a blood test [for HIV] and have counselling if this might reduce the chance that your child would be born HIV-positive?
>
> Nakiganda: I would take the blood test to save my baby.
>
> Nakamya: Yes, so would I.
>
> Nabwami. If I find out that I am infected then I prefer not to conceive anymore. My baby will suffer anyway when I die. So maybe I wouldn't take the test.
>
> Facilitator: What do you say about it?
>
> Aisha: It is very difficult. It is to bring your grave nearer.
>
> Polly: I would like to know my status if this will prevent my baby from getting infected, but on the other hand I fear knowing that I am among the dead and I am to experience much suffering of AIDS, so I would not want to know my HIV status for fear of those deep thoughts.
>
> Gertrude: It would be better for me to know my HIV status because mothers infect

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their children with aids through breastfeeding, as the breast milk itself does contain some blood.

Namanda: If you are infected I don't think this testing will help to prevent your baby from getting the virus because the blood of the mother is infected, so the child too has to be already infected as they share the same blood.

These discussions were hypothetical and it is difficult to know how women would really react if they were actually confronted with the possibility of testing and treatment. It is also difficult to estimate proportions of women who are for and against testing, because in the discussions individual women are often ambivalent: on the one hand they would like to be tested if this would improve the chances of their infant surviving, on the other hand they do not want to 'be brought nearer the grave' or 'counted among the dead' by the knowledge; they want to be tested, but are scared of the possible outcome.

They also expressed some uncertainty about the reliability of test results:

Joyce: You can go for test but not be sure of the results.

Facilitator: You doubt the results?

Joyce: Yes, they can give you the results, but you don't have any symptoms.

Facilitator: You know, you can be infected and not have symptoms.

Prossy: They can even say you are negative, but you know from your symptoms that you are infected. You may doubt the results of the machine that tests blood [laughter].

Informing maternity staff

There was also much ambivalence regarding whether or not they would be willing to inform maternity staff of their status once tested. On the one hand, the welfare of the unborn child was central for almost all women:

Grace: I would inform the midwife because I want my baby to be saved.

Nantale: I would also tell her because I want to save my baby.

Nabawanuka: I would inform them because I want the treatment.

Jane: I wouldn't mind telling the midwife, because I would know that I was already sick.

Nabukeera: I would tell her because I want to save my baby.

Kyomugisha: I would not mind informing her, but after telling her, she may mistreat you thinking that you may infect her also.

Ndawula: I would tell her. It is not a shame [to be HIV-positive] as it is becoming increasingly common. What I want is to save my baby.

Nagawa: I would also let her know so as to save my baby.

Nagawa: I do not mind if I am already aware of the infection. What matters then is to save my baby.

Facilitator: Would you mind Madam Kyomugisha?

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Kyomugisha: I would not mind because AIDS is very common these days, and you never know, that midwife might be infected herself.

However, shame at disclosure and fatalism were also mentioned:

Nakayiki: AIDS is a very shameful disease as we get it through shameful activities, so it is very difficult to tell any other person about it, even though it saves the baby. Women can't disclose it.

Nalongo: But then it would be advisable to alert these medical people who are helping you deliver. Maybe when the midwife alone knows about it she will never disclose it.

Barbara: Once I know about it, I can't keep quiet if it will save my baby.

Betty: But you're already sick. Why do you bother yourself with informing them? There's nothing you can save.

Generally most women said they would be willing to inform maternity staff of their status if this improved the chances of their infant surviving.

In various discussions the women distinguished between possible treatment received from biomedical staff and that received from traditional birth attendants (TBAs). They claimed that it was easier to confide their serostatus to biomedical staff than to TBAs because the former are more likely to be trained in counselling, aware of the importance of confidentiality and equipped with proper necessary protection against infection from seropositive patients.

Confidentiality

The problem was not so much the fact of informing maternity staff, as what maternity staff might do with that information, and what effect it would have on their behaviour toward the women when the time came to deliver:

Grace: I would be afraid to inform her [the nurse] because when she meets her friends she will tell them: 'You know, Mrs so-and-so told me that she is HIV-positive, she has slim disease.' So because of that, I fear telling anybody that I have AIDS. That is the only problem.

Facilitator: Do you think the midwife will keep it to herself or spread it around?

Margaret: She will keep it, because they normally don't tell others such things.

Juliana: I wouldn't tell her, and I wouldn't go there [to the maternity clinic] to deliver because she will be spreading it around: if the baby is to die, let it die.

Nazziwa: I don't mind about the spreading of the news that I have AIDS, because my aim is to save my baby. And anyway, that midwife may not be the one spreading it, but your neighbours, perhaps after knowing that your husband died.

Facilitator: Do you think the midwife will keep it a secret, or she will spread it around?

Nagawa: This depends on that particular person. If that midwife is good, she will not say it out, but if she is not, she will spread it.

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Grace: I do not think she can spread it because most of the midwives do not reveal such things.

Facilitator: But there is always a chance that the rumour might spread. Given that risk, would you still tell the midwife?

Grace: I would still tell her because there is no alternative.

Afisa: When you give birth in the hospital those ones can keep it a secret. But traditional birth attendants gossip. Hospital staff don't attend only to you, so they have no time for such gossip.

Nabossa: Even when you go there a few days later, they no longer remember your status.

All of the opinions expressed by participants in the FGDs are present in these quotations. Some women were worried that maternity staff would gossip and reveal their status to other members of the community, others thought they would be professionally responsible and not tell anyone; some women would deliver at the maternity clinic because they trusted the staff, some because they did not but had no choice, whereas yet others would take their chances and not deliver at the clinic.

Women made a distinction between local rural maternity clinics and hospitals (which are only found in the towns), saying that hospitals would be more confidential because staff do not live in the same community and patients are anonymous. Village health centres were, generally, thought to be more confidential than TBAs, though, as the former were said to be trained in such matters and to have a code of professional ethics.

Discrimination by maternity staff

Many of the women expressed strong sentiments about maternity clinic staff purposely refusing to assist them when the time came to deliver, if staff knew them to be infected with HIV:

Facilitator: How do you think the midwife will treat you after knowing that you are infected?

Doreen: Some nurses fear to assist these ladies once they know about it because they might also get infected.

Teopista: Yes, some midwives will refuse to attend to you, afraid they will also become infected.

Nagawa: There are those still on training. If you happen to have one of those, you will suffer. She will give you a hard time, thinking that you will infect her also.

Jane: It is difficult [to inform the nurse].

Facilitator: Why is it difficult?

Jane: Because we deliver at our local midwives, who do not have gloves, so if you tell her that you are sick, that you have the virus, she may refuse to attend to you [laughter] …so you don't tell her. In the hospital I can tell her because there are gloves, but in the village you cannot, because she will refuse to attend to you when you are in serious problems.

Nanyonga: I can only tell the one in hospital.

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A few women thought that the maternity clinic staff would be more careful when delivering the baby so as to protect it and themselves from catching HIV from an infected mother who revealed her status to them.

> Betty: She [the nurse] may treat you well, since you have told her the truth which may also help her to get ways of protecting herself from acquiring it from you.
>
> Madelena: I think that she might be very careful when delivering the baby not to be infected also. And, on the other hand, she might fear getting in contact with your blood as it may infect her also.
>
> Jane: I think she will treat me well, because I know that they get even more serious cases, but they keep everything to themselves, they deal with it as professionals.

At the other extreme, a few women feared revealing their positive HIV status because of rumours that medical staff intentionally kill people who are seropositive in an attempt to reduce the spread of infection:

> Mary: It would be good to know my status in order to get that medicine you are talking about, but we hear that when you are tested and the nurses get to know that you have HIV, they will give you a drug that will kill you soon because they want to reduce the number of infected people.
>
> Afisa: My worry is that if you inform the maternity staff they might decide that in order to prevent you from killing others they will kill you first.

Informing husbands

A more serious concern for the women was their husbands' possible reactions. Some of the women were worried that their husbands would find out about their status, either directly because they would have to inform them before they heard the rumours themselves, or indirectly through rumours. The consensus was that men would universally condemn their wives for 'bringing the disease into the home', even if the woman was faithful and the husband knew himself to be promiscuous. They were worried that such disclosure could lead to separation, which in practical terms means the wife being thrown out of the home and having her source of livelihood cut off, given that most rural Ugandan women are entirely financially dependent on their husbands. Because men have control over household cash, they are generally responsible for paying for general medical treatment for their wives and children. They would also be responsible for paying for antiretroviral treatment if this were made available but was not free:

> Teopista: Informing the maternity staff is the same as telling my husband, because the maternity staff can't treat me without informing my husband, and my husband is going to say that I was the one who brought the disease.
>
> Florence: No madam, the maternity staff can't inform your husband. Those doctors know many secrets about us, especially when giving birth, but they don't inform other people about them.
>
> Sarah: And I think that she can first ask you whether you want your husband to know about your secret and if you say you don't, then she can't inform him, because she knows that it can cause separation.

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Teopista: If they [maternity staff] know, then sooner or later he [husband] will also know.

Betty: If they have informed me of my status, then I must tell my husband.

Facilitator: What do others say?

Nalongo: Can you tell him that you are infected? Once you tell him that, he will say: 'It is you who caused the infection.'

Grace: I would say nothing, and wait for it to come from him [i.e. that he goes for a test himself and reports his results first].

Facilitator: But what if he isn't tested, only you?

Jane: I wouldn't tell him because he would say I am the one who brought it, and he can send me away as well.

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Discussion

The women in this study were generally aware that HIV can be transmitted from mother to child during delivery. In principle, most were willing to be counselled and tested if they thought that this would increase the chance of their infant avoiding HIV infection. There was, however, much ambivalence, relating mostly to confidentiality. Women did not seem to be particularly averse to informing maternity staff of their serostatus per se, but they were concerned as to what staff might do with that knowledge. First, women were concerned that this knowledge might become known in the community, leading to stigmatisation. Second, they were worried that maternity staff might withhold treatment out of fear of infection, or might even mistreat them if they were known to be HIV-positive. This was particularly the case regarding rural health centres and maternity clinics, which were said to have a shortage of protective clothing and gloves. There were also rumours of health staff deliberately killing HIV-infected patients to 'prevent the epidemic spreading'. Third, women were concerned that their husbands would find out about their status and condemn them for 'bringing disease into the home'. These were, however, opinions and attitudes expressed with regard to hypothetical situations, and actual decisions may be different if the women were confronted with the same choices in real life (see, for example, Boyd *et al.*, 1999; Simpson *et al.*, 1998).

Due to the cost of counselling and testing, the universal provision of nevirapine to all pregnant women might be cost effective in contexts in which the seroprevalence of HIV is above 3% (Marseille *et al.*, 1999). There are, however, various reasons why, in developing countries, it would be better to target seropositive women who have been identified through testing and who have been counselled. VCT has benefits other than those directly relating to vertical transmission. Women could be targeted with specific interventions or information depending on their HIV status. For example, HIV-negative women could be given information on how to stay negative, and HIV-positive women could be informed about access to treatment, the importance of not infecting others, the risks of pregnancy, etc. Because the major mode of HIV transmission in Africa is heterosexual intercourse and pregnant women constitute a substantial proportion of the population (at any given time 20% of Ugandan women are pregnant), VCT of all pregnant women would expose a large section of the at-risk population to information on how to avoid infection, thus contributing to sexual behaviour change. Various studies have now shown that VCT is effective as a behaviour change intervention (Allen *et al.*, 1992; Campbell *et al.*, 1997; Kamenga *et al.*, 1991; Van der Straten *et al.*, 1995; Voluntary HIV-1 Counselling and Testing Efficacy Study Group, 2000).

A comparison of 13 studies in urban areas, mainly in Africa, showed that VCT is acceptable to pregnant women who want to reduce the risk of transmitting HIV to their children. However, return rates varied widely between sites. Acceptability of HIV testing in pregnant women was high in sites where particular effort in implementing VCT programmes had been made (Cartoux *et al.*, 1998). However, it has been pointed out that in many developing countries VCT is inadequate (Cartoux *et al.*, 1998; Coovadia, 1999), and the data presented in this paper suggest that much needs to be done to ensure not only that adequate VCT is provided but that the knowledge gained is treated confidentially and does not influence how patients are treated by maternity staff. Even if VCT is up to standard and confidentiality is respected, women will have to be convinced of this. As long as there is general suspicion regarding lack of confidentiality and concomitant perceived risk of inadequate treatment, social stigma and domestic conflict, general VCT of pregnant women will remain unfeasible. Women in general will need to be convinced before going for VCT that it is useful and safe. Indeed, the community in general is going to have to be sensitised before any such scheme is implemented. And attention will also need to focus on gender relations. It is all very well talking about the importance of 'shared confidentiality', but in practice, in much of sub-Saharan Africa, patriarchal structures dominate and relationships are characterised by gender inequality: men have the final say in deciding numbers of children, whether or not condoms are used and whether or not household members receive medical treatment, and this dominance is underlined by their control over the domestic purse strings. Ideally, VCT should also involve the participation of both partners (Van der Straten *et al.*, 1995), but men will have to be sensitised to accept that an HIV-positive wife does not necessarily imply that she was unfaithful and that 'disease in the home' might conceivably have been brought there by themselves. Women, on the other hand, will need to be sure that if they are to share their HIV status with their partners, this will not lead to marital break up or domestic violence.

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Notes

[1] These are not the women's real names.

[2] After the data had been analysed we provided the health centres with feedback on such inaccurate beliefs and gave suggestions as to how to improve women's knowledge of HIV-related issues.

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